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The transcript of the 1985 House of Representatives hearings on reauthorization of the Rehabilitation Act of 1973 contains verbatim testimony and committee questions, prepared statements; letters; and supplemental material. Or anizations providing testimony or statements include the following: Council of State Administrators of Vocational Rehabilitation; individual state rehabilitation offices; Easter Seal/Goodwill Foundation; Gallaudet College, National Rehabilitation Counseling Association; National Council for the Handicapped; National Head Injury Foundation, Office of Special Education and Rehabilitation Services Office of Technology Assessment; Rehabilitation Research and Training Center, American Association of Community and Technical Colleges, and Protection and Advocacy Agency. (DB)

## OVERSIGHT HEARINGS ON THE REHABILITATION ACT

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# HEARING

SUBCOMMITTEE ON SELECT EDUCATION

## COMMITTEE ON EDUCATION AND LABOR HOUSE OF REPRESENTATIVES

## NINETY-NINTH CONGRESS

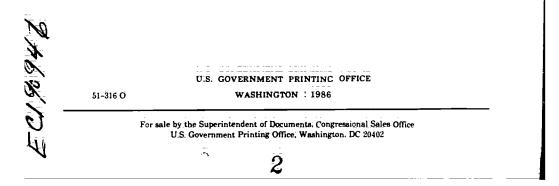
FIRST SESSION

HEARINGS HELD IN WASHINGTON. DC. ON JUNE 11, JUNE 25, AND JULY 17; BOZEMAN, MT, AUGUST 27; AND HONOLULU, HI, NOVEMBER 26, 1985

## Serial No. 99-85

Printed for the use of the Committee on Education and Labor







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## REAUTHORIZATION OF THE REHABILITATION ACT OF 1973

## TUESDAY, JUNE 11, 1985

HOUSE OF REPRESENTATIVES, SUBCOMMITTEE ON SELECT EDUC...TION, COMMITTEE ON EDUCATION AND LABOR, Washington, DC.

The subcommittee met, pursuant to call, at 9:40 a.m., in room 2257, Rayburn House Office Building, Hon. Pat Williams (chairman of the subcommittee) presiding.

Members present: Representatives Williams, Martinez, Bartlett, and Jeffords (ex-officio).

Staft present: Gray Garwood, staff director, Celinda Lake, legislative associate; Colleen Thompson, clerk; and Pat Morrissey, minority counsel.

Mr. WILLIAMS. Welcome, everyone, to the first in a series of hearings that the Subcommittee on Select Education will be holding on the reauthorization of the Rehabilitation Act of 1973.

Throughout the summer and fall we will be holding hearings in Washington, DC, and across the Nation to hear from disability groups, Federal and State administrators, private providers to the rehabilitation system, scientists developing new technologies, consumers and others who have concerns about the Rehabilitation Program, the effectiveness of current service delivery, and the future challenges the system must meet. Our goal is to draft a comprehensive proposal for the reauthorization of the Rehabilitation Act and to begin to hold hearings on that proposal some time this fall or early winter.

Vocational rehabilitation is the major Federal jobs related program serving persons with disabilities and providing support services to allow them to work. The vocational rehabilitation effort is of critical importance, making a major contribution to leeping people self-sufficient and independent.

This appears to be a tremendously cost-effective program. In 1980, the Rehabilitation Services Administration informed us that for every dollar spent on vocational rehabilitation, \$10.80 was returned to the Treasury in taxes. Despite its cost effectiveness, in fiscal year 1983 this Federal and State program served only 938,923 people. Many others in need were unserved. The 1978 census has identified 20 million people who work with disabilities.

Consequently, despite our successes, we have a long way to go in developing the most comprehensive and effective program. For example, people with disabilities suffer on the average 50 to 80 per-





cent unemployment. Disability has even a more depressing effect on the employment of women and minorities. We are poised at a critical threshold in determining Federal policy in this area. Our society is in the midst of a series of changes to which the rehab system must respond. The technological revolution has the potential to completely redefine what is possible in terms of rehabilitation. Technology and improvements in health care are also changing the characteristics of the population of persons with disabilities in ways which provide new challenges for rehabilitation services.

We have already recognized in previous amendments to the Rehabilitation Act the need to provide more comprehensive services and the need to serve the more severely disabled. Rehabilitation is embedded in a general work force whose contours are dramatically shifting with the increase of women in the work force, the aging of the work force, and the shift to high tech jobs

Finally, Federal policy itself has reshaped the task facing the Rehabilitation Administration. We are now passing out the first generation of students who have benefited from the full Education of the Handicapped Act. However, while we provide individualized comprehensive services for children, we have not yet come to terms with what will-be needed after high school for further education and job training. As we design such services, we must also consider what is best provided by the unique focus of rehabilitation services, what is better provided by other programs, and how those services should be coordinated.

In today's hearing we will be exploring issues relative to Federal and State administration of the programs created by the Rehabilitation Act. We have asked the witnesses to focus on how well the Rehabilitation Act is working, what direction Congress should give about future programs and what changes we should make.

Because of the press of business today and the number of issues that we must cover, I want to set a few ground rules for the hearing process. This is going to be a busy morning, not only because of our witnesses but because of other work which many of the members of the committee have to do. We most likely will be interrupted by votes this morning. Therefore, I am going to ask that each witness contain themselves to about 7 minutes. At the end of 5 minutes you will hear me tapping with the end of the gavel and you will know you have a couple of minutes left to sum up, but at the end of the 7 minutes I will become more impatient and hopefully you will be able to close what you are testifying toward.

Of course, the full statement of each of the witnesses will be placed in the hearing record.

I am also going to hold the members of the committee to the 5 minute rule.

Again, I want to thank each of you for joining us. I will ask the first panel representing the Council of State Administrators of Vocational Rehabilitation to come forward. That is Vernon Arrell, David Mentasti, Robert Rabe, Susan Suter, and Richard Switzer. Mr. Arrell is the president of the Council of State Administrators of Vocational Rehabilitation and a member of the Texas Rehabilitation Commission. Mr. Mentasti is director of the Verment Division of Services for the Blind and Visually Handicapped. Mr. Rabe is the administrator of the Ohio Rehabilitation Services Commis-



sion. Ms. Suter is director of the Illinois Department of Rehabilitation Services, and Mr. Switzer is the deputy commissioner of the New York Office of Vocational Rehabilitation.

Mr. Arrell, if you will begin, please.

STATEMENT OF VERNON M. ARRELL, PRESIDENT, COUNCIL OF STATE ADMINISTRATORS OF OCATIONAL REHABILITATION, AND COMMISSIONER, TEXAS REHABILITATION, COMMISSION; DAVID M. MENTASTI, DIRECTOR, VERMONT DIVISION OF SERV-ICES FOR THE BLIND AND VISUALLY HANDICAPPED; ROBERT RABE, ADMINISTRATOR, OHIO REHABILITATION SERVICES COMMISSION; SUSAN S. SUTER, DIRECTOR, ILLINOIS DEPART-MENT OF REHABILITATION SERVICES; AND RICHARD SWITZER, DEPUTY, COMMISSIONER, NEW YORK OFFICE OF VOCATIONAL REHABILITATION, & PANEL

Mr. ARRELL. Thank you, Mr. Chairman.

I am Max Arrell, commissioner of the Texas Rehabilitation Commission and president of the Council of State Administrators of Vocational Rehabilitation. You have already introduced my colleagues so I will not repeat their names:

We do have written testimony, Mr. Chairman, and in deference to time I will not read that but would ask your indulgence and ask you to please submit that for the written record, if you would. Each of the panel members would like to make a few remarks and thei, of course, respond to any questions you might have.

I will lead off by indicating that the Council of State Administrators for Vocational Rehabilitation represents some 84 State agencies, general rehabilitation agencies, and Commission of State Agencies for the Blind. We continue to feel that the Rehabilitation Act of 1973, as amended, continues to be the most complete and well-balanced legislation in the human services field. For that reason, we would like to recommend to you for consideration an extension of this act for a 5-year period.

I would like to give you some information from my own State of Texas as to why I feel this is important: In our State, since 1979, our level of appropriations and resources for our program really has not kept pace at the Federal level. It has become very necessary, and more necessary all the time, for us to do better planning with our State, our legislature and our State leaders. It is a let easier for us to sit down and work with them on a day-to-day basis if they know there is consistency in our program and the fact that the program is going to be around.

For example, in 1981 the State legislature recognizing the fact that we did not get Federal appropriations that kept up with the inflation rate, enhanced our program with State appropriations to make up for the loss of Federal funds. In 1983, because we had lost \$6 million due to amendments to the Social Security Act, and also for the loss of buying power in the rehab appropriations, the State of Texas enhanced the Vocational Rehabilitation Program by 71 percent State appropriations. That was in a year when we had a billion dollar surplus in our State.

In 1985, our legislature came in with a billion dollar deficit. We went from a billion dollar surplus in 1983 to a billion dollar deficit

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in 1985. As a result, we had to take a little bit over an 8-percent decrease in State funds this year.

In the next session of the legislation in 1987, and then the next session in 1989, obviously there are going to be some very hard decisions made in my State. Taxes are going to have to be raised and it would enhance my program and my opportunities tremendously if this act could be extended for a 5-year period.

I would like to give you a little background of where we are, where we have come from in our State, and where I think we need to go. I have to give you a little bit of history, if you will bear with me.

In 1975, the Texas Rehabilitation Commission had 575 vocational rehabilitation counselors. At that time we were working with 38 percent severely disabled. In 1985, we have had to cut that number down to 349, and we are now working with 68 percent severely disabled. In 1975 we had one counselor for every 28,000 population in our State. At the present time, we have one counselor for every 48,000 population:

Right now we feel we are serving about 1 out of every 20 individuals needing our services. At the same time we are being asked by the Assistant Secretary to work with the more severely disabled, to work with the developmentally disabled, with no cutback in services to the present population that we're working with and no increase in Federal funds.

In my State at the present time there is a big need for increased services to the severely physically disabled, primarily the spinal cord injured, and the newest and fastest growing severe disability, those individuals with head injuries.

We are also being asked to work with the severely involved, multiple handicapped, developmentally disabled. Most of these individuals at the present time are being housed in either State institutions, nursing homes, or some other restricted environment. We feel, and the consumers feel—and I think the Assistant Secretary feels—that most of these individuals, with proper resources, could be moved into the community and become productive citizens. We are also being asked to work with the more severely involved, mentally restored individuals, most of whom are now being housed in State and private institutions.

Our State legislature this year, even with the shortfall that we have, gave us the appropriations to begin a program for the deafblind in our State. I feel very strongly that the potential of working with the deaf-blind population can be enhanced tremendously if we can just get the resources.

One other ingredient that I feel is very important, and that is, we have been a State-Federal program for over 60 years. The relationship between the State and the Federal partnership, by and large, over the years has been one that we have been very proud of. Over the last 18 months we have been trying to build a better relationship with our Federal partner. I feel personally that at the Office of the Assistant Secretary level we have made considerable progress. We do have some philosophical differences with the Assistant Secretary, but we also feel that there are things that we can work out that would be in the best interest of the disabled of this country. I am sorry to say that we feel we might not have



made as much progress with the Rehabilitation Services Administration level.

It is very important that this program continue to be a full State-Federal partnership. We would encourage your enhancement and encouragement of that partnership.

I will now turn it over to Mr. Mentasti.

Mr. MENTASTI. Mr. Chairman, I thank you for the invitation to appear before this committee and for the opportunity to present this testimony.

I would like to begin by expressing, on behalf of Vermont's 66,000 disabled persons, our appreciation for the bipartisan support that rehabilitation has traditionally enjoyed. Many disabled Vermonters are leading active, productive, and self-directed-lives because of the assistance which they have received from programs sponsored under the authority of the Rehabilitation Act.

My area of specialty is blindness and visual impairment, and I represent the State agency which provides rehabilitation services to this population. However, before I talk specifically about services in Vermont, I would like to present a brief national overview.

Blindness and visual disability impose an enormous social and economic burden on those afflicted in all of society. Nearly 11.5 million people in the United States suffer from some degree of vision impairment. Twelve percent of these are unable to see well enough to read ordinary newsprint, even with the aid of glasses. Another 4 percent are classified as legally blind, which means that their visual acuity, even with best correction, is no better than 20 over 200.

Each year, an estimated 47,000 people become blind. That is one person every 11 minutes. The leading causes of blindness are glaucoma, muscular degeneration, and diabetic retinopathy. As people live longer, the prevalence of blindness increases markedly. Fiftythree percent of all blind persons are over the age of 65. The economic costs of visual disorder are estimated to be in excess of \$5 billion annually. This includes the cost of professional care for eye diseases and injuries, the cost of special treatment, rehabilitation, and benefit programs. It is estimated that 70 percent of working age blind people are unemployed and, of those employed, 70 percent are underemployed.

For preschoolers and teenage children, it is access to developmental and compensatory skills training that will keep them at home and out of more expensive, more restrictive educational institutions. For the adult blind, it is access to adequate rehabilitation services that will enable them to become productive taxpayers instead of tax consumers. For the increasing number of elderly blind, it is access to independent living services that will allow them to remain self-reliant.

This then, in brief, is the nature and scope of the issues in the field of blindness and visual impairment from a national perspective.

In Vermont there are an estimated 4,400 people with severe visual dysfunction, and each year there are approximately 400 new cases in the State. For over 40 years, the Division for the Blind and Visually Impaired has provided services to this population. Last



year, the Division served a total of 510 clients who ranged in age from 5 months to 92 years.

Services are organized into three major program areas: vocational rehabilitation, social rehabilitation, and a vending facilities program. The vocational rehabilitation program is the Federal-State program funded under the Rehab Act. The Social Rehabilitation Program is a 100 percent State-funded program which provides rehabilitation services to those individuals who do not have a vocational objective but are in need of services to advance and promote independent functioning. Clients in this program are primarily school aged and elderly. The vending facility program provides employment and food service operations for blind vendors under the authority of the Randolph-Shepherd Act. Last year we successfully rehabilitated 97 people in our combined programs and our per client cost was slightly under \$1,000.

Client case service dollars which are for the direct purchase of service to clients were spent in the following ways: 26 percent on vocational evaluation and training, 20 percent on medical and medical-related services, 17 percent on adaptive equipment, 15 percent on tuition for postsecondary education, 6 percent on glasses and optical aids, and the remaining 16 percent in a variety of other service categories such as mobility, communications skills, self-care, and low vision training.

The Division has four regional offices, and since Vermont is one of the most rural States in the Nation, counseling services are provided primarily on an itinerant basis. According to Census Bureau information, Vermont has a greater proportion of its people living in communities of 2,500 or less than any other State. This population dispersal, coupled with the relatively low incidence of blindness, presents problems and unique challenges with respect to resource development, employment, transportation, and housing.

In Vermont there is an independent living center for blind and visually impaired which is funded through title VII, part B, and is operated by a community-based, nonprofit organization. This independent living center provides peer counseling, mobility, reha. teaching, and low vision services. During its 3-year history, the center has demonstrated the value of comprehensive independent living services, but the available resources are not adequate to do all that needs to be done.

At this point I would urge the committee to support realistic funding levels for title VII, part A. I would also urge the committee to consider funding title VII, part C, services to older blind individuals. As I indicated earlier, the majority of blind and visually impaired are elderly. There is a definite need, not only for specific compensatory skills training and physical restoration, but for outreach and public education as well. The number of elderly in our caseloads is growing rapidly. From 1980 to 1984, there has been a 131-percent increase in the number served in our social rehabilitation program, with the vast majority being 65 years or older.

At this point I would echo what Max said. With adequate funding I believe we can solve the issues which are before us in rehabilitation within the context of the present Rehabilitation Act.

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I thank you for your attention.

Mr: WILLIAMS: Thank you very much.

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Mr. Rabe.

Mr. RABE. Mr. Chairman and members of the subcommittee, I, too, appreciate the invitation to testify before you today.

I would like to take a few minutes to talk about rehabilitation in the State of Ohio. Currently, the Vocational Rehabilitation Program is housed in a commission which is made up of seven members appointed by the Governor, who appoints the administrator and executive staff. In the current year, the Rehabilitation Services Commission, through the State-Federal program, has rehabilitated 7,000 individuals, and approximately 57 percent of those individuals are severely disabled. Approximately 72 percent were closed in competitive employment and approximately 40 percent of the competitive employment individuals were severely disabled.

- Rehabilitation in Ohio is reaching into groups of persons with disabilities who, in the past, would not have been thought likely to find a job in the competitive sector of the economy. The current Rehabilitation Act provides the flexibility and the coordination that is necessary to work with other State agencies as well as local and State government in the rehabilitation of individuals.

In the State of Ohio, we have three types of programs that I would like to discuss with the committee this morning. The first program is a contract with the Ohio Department of Mental Health in which we are reaching out to severely mentally ill individuals who have been institutionalized and are currently coming out of institutions. Those individuals are referred to the vocational rehabilitation agency and become joint clients with the Ohio Department of Mental Health, as well as with local mental health agencies. In this way we are able to meet the two tracks of needs for these individuals. One, we are able to provide the mental health services that are necessary, and two, we are able to provide the vocational rehabilitation services that are necessary for these individuals to return to the labor market.

The second program that we have worked on in the State of Ohio is in the area of mental retardation. We have been able to use our grant programs utilizing the Federal, State, and local funds to create programs within our local agencies for the mentally retarded who are able then to look into competitive jobs and provide the training that is necessary for those individuals to reach a level of employment that goes beyond the sheltered workshop concept.

The third area has to do with the Ohio Industries for the Handicapped. This program was started several years ago, but only in the last 2 years have we been able to reach into substantial employment in this particular program. This program was started using vocational rehabilitation grant funds, and it also utilizes State and local funds to carry the program on.

What happens is, individuals with severe disabilities are placed into this program, earning above minimum wage, primarily in service jobs, that include cleaning roadside rests along the Interstate System, janiorial contracts in State and county buildings, and other programs related to the service industry. What this allows is ind: "iduals with disabilities to get work experience that previously they have been unable to have.

As you know, when an individual goes and applies for a job, one of the things that is requested of that individual is their prior expe-



rience. This program provides real-life job experience that can be used as the basis for placement into the competitive labor market. This program currently is self-sufficient. There are no Federal funds, no State funds, being utilized. What comes from the program are contracts that are utilized to provide the wages as well as the payment to the supervisors within that program.

Currently, the State of Ohio has managed to place several hundred individuals in this program and then to have the individuals come out and enter program into the competitive labor market. We think this particular program is a long step in providing the kinds of services that are necessary for individuals with disabilities.

The Rehabilitation Act has allowed the State agency in Ohio to provide these specific kinds of services, and at the same time has

I certainly echo the statement in seeing that the current Rehabilitation Act be extended for 5 years, and certainly for the reasons relating to budgeting within the State of Chio. Under this Act, in a period of time of 5 years, it is much easier to discuss with the State legislature the amount of matching funds necessary to bring in the Federal funds to the State of Ohio.

Currently, the State legislature has appropriated the funding not only for the Vocational Rehabilitation Program but is also appropriating, within the current biennium, additional moneys for independent living centers within the State of Ohio. These would be solely State-funded independent living centers. The State legislature and Governor Celeste see this as an important priority for the State of Ohio, that independent living is part of a continuum of services that goes both before and after vocational rehabilitation is completed.

There are two other programs that are solely State funded that the State of Ohio is currently involved in. One is community centers for the deaf, in which we provide services to individuals who are deaf and with hearing impairment, that go beyond just vocational rehabilitation. In order to be fully integrated into the community, these individuals must have access to interpreters, and agencies within local and State government need to be able to have a place to call for interpreter services.

The last program is the Personal Care Assistance Program that provides partial reimbursement for attending care within the State of Ohio for those individuals currently employed.

I wish to thank again the chairman and members of the committee for this opportunity to adress them. Thank you very much.

Mr. WILLIAMS. Thank you very much.

Ms. Suter.

Ms: SUTER. Mr: Chairman and members of the committee, it is a pleasure to be here today and to have the opportunity to tell you about some of the things the Rehabilitaton Act has made possible in Illinois:

Opportunity is what the Act is all about, 'o see that people with disabilities have the opportunity to get an education, the opportunity to get a job, the opportunity to contribute to society, the oppor-

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permitted and directed the State agencies to serve more severely disabled individuals. We feel this has been accomplished under the current Rehabilitation Act.

tunity to support themselves and their families, and the opportunity to live with pride as respected members of the community.

The old saying in America is to be ready when opportunity knocks, but people with disabilities have to be ready to knock on opportunity and the Rehabilitation Act helps make sure someone answers that knock. As an advocate for people with disabilities in Illinois, our mission isn't to help people adjust to or learn to live with their disabilities. Our mission is to help people overcome the handicap that society places on us and rise above them to realize the dreams and achieve goals that some thought were out of their reach. That is the mission that Governor Thompson gave us when he made the Department a Cabinet-level agency, and the importance the Governor has placed on our services is opening doors in business and industry throughout the State:

The State also funds four schools, independent living centers, a home services program, and community services for the visually impaired program. Our Vocational Rehabilitation Program begins by helping people achieve the highest possible level of physical or mental ability. If surgery or an artificial appliance or work adjustment training can improve their condition and their ability to live independently, then we provide it.

We follow those services up with training designed to help individuals make the best of the cools that are available. Then we help them to prepare to enter the job market with education or training for a specific type of job. Some people have the skills and talent to be entrepreneurs and start their own businesses, and we help them get set up and get going and off the public rolls.

For instance, a man in Danville is now operating a successful health club for other people with disabilities. We helped another man, who was an expert machinist before he became disabled, set up his own machine shop. Now he has more business than he can handle. In Illinois we provide some type of rehabilitation services for nearly 50,000 people a year and we place more than 10,000 individuals directly into jobs. Every one of those people would have been unable to get those jobs without the services we provided them mandated by the Rehabilitation Act.

We are having good success with programs that we operate in cooperation with private industry. At Archer Daniels Midland, the giant food processing plant in Decatur, several people with disabilities are working in the hydrophonics plant, and at the NSC Corp., people with disabilities are operating one of the assembly lines. They work together with a specially trained supervisor and eventually they should become skilled enough to join the company's regular work forces and leave us behind.

We have contracts with Holiday Inn and the Marriott Hotels to provide a job coach to train people with disabilities on the job. They are working in housekeeping, food service, and in janitorial services.

Cooperation with private industry is one of the keys to all our efforts. It wouldn't do us much good to train people for jobs that aren't there. So our nearly 50 local DOR's offices are developing close ties with local industries to find out exactly what type of employees they need and we tailor our programs to meet these needs.



Through our Illinois Jobs Committee for the Handicapped, we are examining State contracts to find products and services that can be supplied by people with disabilities. So far we have identified 50 contracts worth more than \$3 million and that are all well within our reach. There are 84 rehabilitation facilities in Illinois that have the equipment and the expertise to qualify for State contracts, and we are working with others to get them qualified. Recently, our Secretary of State signed a \$10 million contract with a county rehabilitation facility to produce all of the State's automobile license plates.

We also realize that some people need more assistance than others, and for them centers for independent living called for in the Rehabilitation Act provide important support for people fighting to be as independent as possible. These centers provide a continuum of services for someone who might not yet be ready for the VR 110 Program. We now have five centers. Plans are to open between three and six State-funded centers over the next year, de pending on our funding and the quality of our proposals.

When people with disabilities are the ones running the centers and providing the assistance and advice, you know what they are providing is right on target. Our centers provide advocacy training so people with disabilities know their rights and how to exercise them. They provide peer counseling to help with personal problems that get in the way of rehabilitation or work opportunities, and they teach independent living skills like cooking and grooming and personal care. They teach people how to be employers, how to handle any personal attendance they need to live at home.

We think that waiting lists for independent living centers over a 3-month period are unacceptable and that we need to quadruple the number of independent living centers and to begin to handle the demand for assistance. But when you compare the money the centers save, it is easy to see what a good investment they are. It costs a lot more to put people in an institution than it does to help them stand on their own. It is a mistake to put limitations on the potential of people with disabilities, and there are people out there proving it every day.

I believe the Rehabilitation Act is the key to the door of opportunity for thousands of people with disabilities and we should keep pushing that door open wider and wider to let more people through.

Thank you.

Mr. WILLIAMS. Thank you very much.

Mr. Switzer.

Mr. SWITZER. I am Dick Switzer. I am the State director for vocational rehabilitation for New York. Vocational rehabilitation is under the Department of Education in New York. Commissioner Gordon Umbach is my boss and I answer to him. That's why I'm known as the deputy commissioner.

I am optimistic about what is happening with the disabled in this country. Having grown up literally in the vocational rehab movement since I was born, almost, with my disability, I have seen it grow. I have seen it change, and I am excited.

Now, why am I excited? I feel the Vocational Rehabilitation Act is the catalyst. The catalyst for the employment of the thousands



and thousands of disabled people of this nation. We talk about a partnership, the partnership between the Federal, the State I think the partnership is more than that. In New York State we have been able to develop the partnership not only between the State and Federal Government but the partnership with business and industry, the partnership with the not-for-profit agencies— United Cerebral Palsy, the Epilepsy Association and so on—the partnership now with the schools and with the aging out problems that we are now facing.

Gentlemen, thousands and thousands of students are graduating each year from special ed programs. This is thanks to Public-Law 94-142. But what is going to happen to them without vocational rehabilitation? It is extremely important that there be early interventions and a linkage program developed. Last year—and I will share this document with you—New York

Last year—and I will share this document with you—New York State developed a comprehensive plan for services for the disabled. The comprehensive plan talks about the partnership between business, industry, the not-for-profit agencies, parents, students and the disabled adults.

Vocational rehabilitation is the train Let's never forget that. In your opening ment, Mr. Williams, you mentioned that it is cost effective. This is one of the reasons vocational rehabilitation survived all of the human services programs. I happen to believe it is an important part of our nation and of our country. It shows what a minority group, disabled people, can do. It shows that they can do a day's work for a day's pay.

In New York State we have developed many, many linkages with business and industry. We have seven PWI programs: This enables us to work closely with independent business, industry and labor to change their attitudes about hiring disabled people. They are ready. The business community knows that this is cost effective. Every time they hire a person who happens to have a disability, they know they are saving dollars.

So often we get people up here testifying who work with disabled people. You listen to the disabled themselves. You listen to coalition groups. Gentlemen, get business and industry up here: Let them talk about the paraplegic, the quadriplegic, that they hire for a day's work for a day's pay.

As part of the Vocational Rehabilitation Act we have independent living centers. New York State is excited about this. Through the small amount of funding we received, we developed seven independent living centers. Our legislature was so excited about it that they wanted an independent living center in every community. We new have 19, 12 of which are funded by the State of New York. We have on the legislative docket this year three more that we're developing. How did all this happen? It happened through the Vocational Rehabilitation Act.

I  $\cap$ m requesting a 5-year extension of this Vocational Rehabilitation Act. I would like to see a lifetime extension of it. It is a partnership that proves that disabled people can do a day's work for a day's pay.

The other catalyst is the counselor program. New York State employs 450 rehabilitation counselors. This is another ingredient of



the Rehabilitation Act that makes it unique, a 1-to-1 relationship, one individual working with a disabled person to prove what he can do, never mind what he or she can't do.

I would like to see this catalyst continue, this Rehabilitation Act continue. Therefore, I am recommending approval of it.

My colleagues and I would be very happy now to answer any questions that you may have.

[The rrepared statement of the Council of State Administrators of Vocational Rehabilitation follows:]

## PREPARED STATEMENT OF THE COUNCIL OF STATE ADMINISTRATORS OF VOCATIONAL REHABILITATION

The individual State Rehabilitation\_Agency Directors appearing before the Subcommittee today are members of the Council of State Administrators of Vocational Rehabilitation.

The Council is an association comprised of the chief administrators of the public rehabilitation agencies for persons with physical and/or mental disabilities in all the states, the District of Columbia, and our Nation's territories.

These Agencies constitute the state partners in the State-Federal Program of Rehabilitation Services for persons with disabilities as provided by the Rehabilitation. Act of 1973, recently reauthorized in February, 1984, hy Public Law 98-221. Since its inception in 1940, the Council has enjoyed a quasi-official status as an

Since its inception in 1940, the Council has enjoyed a quasi-official status as an active advisor to the Federal administrators in the formulation of national policy and program decisions and has been an active force in strengthening the effective ness of service programs for disabled Americans. The Council serves as a forum for State Rehabilitation Administrators to study, deliberate, and act upon matters bearing upon the successful rehabilitation of persons with disabilities.

As Administrators of State Rehabilitation Agencies, we appreciate this opportunity to provide Members of the Subcommittee information on the Rehabilitation Program, and compliment you for starting the process of Reauthorizing the Rehabilitation Act early, in order that critical decisions affecting the lives of our Nation's citizens with disabilities can be made in a deliberate, informed manner.

We are pleased to be a part of this effort today and look forward to appearing before the Subcommittee again, in the months ahead, to provide more in-depth views relative to these issues.

The core of America's reliabilitation effort is the 65 year-old State-Federal program devoted to providing a combination of Rehabilitation Services to physically and/or mentally disabled adults. At the center of this Program is the State Rehabilitation Agency which provides for and/or coordinates a wide range of services for eligible, disabled persons.

These services are provided with the cooperation of, and/or through, private, nonprofit service providers.

The primary purpose of the provision of Vocational Renabilitation Services is to render "employable" those persons with mental and physical disabilities who, because of the severity of their handicapping condition, are unable to secure and/cr hold employment.

The Rehabilitation Act, as currently authorized, is the most complete and wellbalanced legislation in the human services field.

In one Act, provisions are included for a (1) comprehensive and individually-tailored program of vocational rehabilitation services to individuals with physical and/ or mental disabilities; (2) a training Pi ogram; (3) a research program; (4) a program providing comprehensive services in independent living; (5) a rehabilitation facilities program; (6) a community services employment program, and (7) a special projects program.

For the Rehabilitation Program to be effective, there must be trained personnel to work with persons who are disabled; research to reveal new knowledge and techniques; a comprehensive program for the provision of independent living services to persons who are so severely disabled that they cannot benefit from traditional rehabilitation services; facilities in which severely disabled individuals may be served with optimum care and expertise; and special demonstration projects to test new knowledge in practical settings. Agencies must also be encouraged to initiate new programs and expand existing ones to apply new knowledge to new groups of individuals with disabilities.



This balanced emphasis embodies the elements necessary for a successful rehabilitation program to be provided through a nationwide network of public and private, community-based, service providers.

It is this balanced approach which has enabled millions of persons with disabilities to be rehabilitated from dependency to employment and productivity, during the 65-year history of this Program.

#### EXTENSION OF THE ACT

The Rehabilitation Act of 1973; as amended, is a model of what can be done in the human services field.

We are of the strong contention that to amend or rescind portions of this law might severely unsettle the balance that makes this program one of the most—if not the most—balanced and effective programs in the human services area, as well as one of the most cost-efficient.

We urge the extension of the Rehabilitation Act of 1973, as amended, for five years. This will provide authorization levels through Fiscal Year 1991. This extension is needed to insure Program stability in the State-Federal Rehabilitation Program and to insure the continuation of the provision of quality services to the millions of disabled Americans who are in desperate need of rehabilitation.

It is imperative that the States be given a clear indication from the Congress of the future Federal commitment to the Rehabilitation Program and the persons eligible for services.

State legislatures, many of which will be session for short, specified periods of time, require advance knowledge of Federal Authorization levels for future years in order to provide the state financial contributions necessary for matching. Extension by the Congress for five years will have a significant, favorable impact on state appropriations and programmatic decisions affecting rehabilitation for future years.

The need for the extension of the Rehabilitation Act is but one of three main needs of the Vocational Rehabilitation Program, for any program must have at least three main pillars to support its effective operation.

It needs wise enabling legislation, effective leadership, and adequate appropriations, based on need.

The State-Federal Rehabilitation Program—in fact, any Program—vitally needs strong, committed, and knowledgable National leadership. We look to the current Administration, as we have looked to past Administrations; to provide this. It is an irreplacable element.

It is also vitally important that the U.S. Congress authorize and appropriate adequate monies to enable the State-Federal Rehabilitation Program to serve as many individuals who are eligible for rehabilitation services, as is possible.

Basic State Grants, authorized by Section 110, are the lifeblood of the Vocational Rehabilitation Service Program. It is this Section of the Act which finances the provision of Vocational Rehabilitation Services to eligible individuals with mental and/ or physical disabilities, whose disability constitutes a substantial handicap to employment.

The Federal dollars authorized by this Section—matched with state money at a ratio of, at most, four Federal dollars to one state dollar—permit State Rehabilitation Agencies to provide, as well as to contract with private organizations to provide, individualized, comprehensive services to persons with mental and/or physical disabilities, for the purpose of rendering these individuals employed and independent.

From 1979 through today, the Rehabilitation Program has been faced with escalating medical and other costs which have far outpaced inflation. It has faced a sharp decline in the purchasing power of the "rehabilitation service dollar." It has contended with an annual loss of over \$122 million in funds previously used to provide Rehabilitation Services to SSDI Beneficiaries and SSI Recipients.

\_\_In times of scarce resources, State Agencies must, by law, focus those resources on the provision of services o the most severely disabled persons.

Eue to the increased costs of serving the more severely disabled, and the deterioration of the strength of the "rehabilitation dollar" as described above, there has occured since 1979, a marked decline in the numbers of persons served annually by State Agencies-from a 1979 level of 1.1 million to under 940,000 last year.

To rectily this dilemma, the Congress, following the bill initially sponsored by this Subcommittee, passed the Rehabilitation Act Amendments of 1984. The extension based future authorization levels for State Vocational Rehabilitation Services on amounts deemed necessary to reverse the erosion in the purchasing power of the "rehabilitation Dollar," and to stop the commensurate decline in the number of per-



sons receiving services. It was the intent of Congress to restore, by FY 1987, the purchasing power to its FY 1979 equivalent.

Last year, FY 1984, for the first time in nearly a decade, the number of persons with disabilities served did not significantly decline. In fact, the Program served the highest percentage of persons with severe disabilities in its 65-year history, and the actual number of severely disabled persons served increased for the first time since 1979.

These positive signs exist because of the continued support of this Subcommittee and the Congress.

Bi-partisan recommendations endorsed over two years ago by this Subcommittee and approved overwhelmingly in February, 1984, by both houses of Congress, have worked to end a debilitating decline in the ability of the Rehabilitation Field to provide quality services to eligible persons with disabilities.

But sucess is not achieved just because the patient has stopped bleeding.

For America's Rehabilitation Effort to be broadened and strenghtened, resources must be made available to allow for an increase in the provision of quality services to more and more persons with disabilities.

to more and more persons with disabilities. Unfortunately, ther <u>lare not sufficient funds to serve all those eligible</u>, disabled people who have the potential and desire to work and who need Rehabilitation Services to obtain employment and self-sufficiency.

tion Services to obtain employment and self-sufficiency. Our best estimate is that State Rehabilitation Agencies are able to serve only one

out of every twenty people who are eligible for such services. There is no greater frustration to Advocates than to know that individuals are not being served because there are not sufficient resources avaitable for services.

There is no greater waste of resources than the waste of I aman potential.

We strongly recommend that the Congress provide legisliticn which contains authorization levels for the Basic State Vocational Rehabilita ion Program which will allow for the provision of Rehabilitation Services to an ever-increasing number of eligible individuals with mental and physical disabilities.

Whatever the cost, there is no other human service p ogram whose funds are spent in such a cost-effective manner to help people li ... more self-sufficient and productive lives.

## COMPREHENSIVE SERVICES FOR INDEPENDENT LIVING

Part A, of fitle VII of the Rehabilitation Act, establishes a state grant program to meet the current and future needs of individuals with disabilities so severe that they do not presently have the potential for employment, but who may benefit from establishing order to live and function more independently.

rehabilitation services in order to live and function more independently. In 1978, when this law was enacted, a substantial new service program was envisioned with, as the Senate Report declared, "sufficient funds" available to develop "effective long-range plans and services." Such funds have never been made available.

Last year, \$5 million was appropriated by the Congress to allow states to plan for the implementation of services under Part A. These monies have yet to be released to Store Agencies

to State Agencies. The time to fully implement a new Comprehensive Services Program is now. The existing Independent Living Centers across the country have proven—and continue to prove on a daily basis—the effectiveness of, and the need for, the foll implementation of the independent living concept. We need desperately to supplement the services provided by the existing Centers.

We need desperately to supplement the services provided by the existing Centers. This can be done by providing meaningful authorizations and appropriations for the statewide service delivery system in independent living for the severely disabled, under Title VII, Part A, and adequate monies to begin the Older Blind Individuals Program in Part C.

Funds are needed to devise an equitable state distribution procedure for Part A Service Grants; allowing a continued adequate funding base for the Centers for Independent Living as authorized under Part B; and funding for the first time an Older Blind Individuals Independent Living Program as authorized by Part C.

### REHABILITATION TRAINING

While all provisions of the Rehabilitation Act are necessary for a balanced service delivery system, the training of personnel to work with persons with mental and physical disabilities is one of the most important for the assurance of quality and relevant service delivery.

The Rehabilitation Training Program provides resources for the training of professional, dedicated men and women in the latest techniques in service delivery, ad-



vances in technology, and in information on improved job placement and development.

Inservice training and continuing education for persons currently providing Rehabilitation Services assists in insuring that they are aware and knowledgeable of the latest service delivery techniques, information on employment, job placement, and technology. This Section of the Act is one of the most valuable. It should be continued with authorizations commensurate with the need.

The Members of this panel are prepared to address the exciting new advances in Rehabilitation being made in their various states, as well as to discuss with the Subcommittee any problem which they are encountering in the delivery of services to persons with mental and physical disabilities.

Mr. WILLIAMS. Our thanks to you and each of the panel members for your testimony.

Mr. Bartlett.

Mr. BARTLETT. Thank you, Mr. Chairman

Mr. Chairman, I do apologize for coming in late. I heard most of the testimony. Of course, I hear testimony from Max Arrell almost on a weekly basis.

One thing you never learn up here is how to be in two places at one time. We had a surprise, an unannounced witness this morning in a markup that I'm currently engaged in, and in which I have several amendments up. It was the Chairman of the Federal Home Loan Bank Board, and since he was giving informal testimony on my first amendment, I thought I probably ought to stay and give him some support.

Mr. Chairman, if I might say a few preliminary comments and then go to my 5 minutes of questions——

Mr. WILLIAMS. Please.

Mr. BARTLETT. I have looked forward to this hearing and this series of hearings for a long time. I am very appreciative of Chairman Williams for beginning early, setting a rather ambitious schedule of a comprehensive set of hearings over the next year where we can look at the changing and improving world of rehaoilitation and disabilities in this country.

The Rehabilitation Act itself has been, without a doubt, one of the most successful Federal statutes ever written. It au rizes a wide variety of programs that contribute directly to the independence, to the employment, and to the well-being of persons with disabilities. During its 65-year history, it has demonstrated a cortain power and value in investing human potential.

It has become a complex statute—some would say too complex with the State Grant Program and Discretionary Program. So I think, in that light, it is helpful to have this series of hearings, of which today is the first, to see if there are ways to improve the Rehabilitation Act, to build on the strength that we have now and to build for the future.

I would also hope during the course of the hearings, at least during the hearings, perhaps included in the Rehabilitation Act, perhaps not, that we address and think about that whole array of Federal legislation that is responsive, and sometimes not responsive, to the needs of the disabled. I have seen one estimate which estimates some 16 percent of disabled persons in this country are employed. Now, it would be substantially less than that if it weren't for the work that was done by the rehabilitation agencies around this country. But the fact of a 16 percent employment rate



tells us that we need to consider the Rehabilitation Act and to link it with the world of employment, of technology, of community living, housing, incentives and disincentives, health insurance, attendant care and transportation on an array of issues.

So I enter with an open mind but with a few preconceptions. First, in terms of preconceptions, I would like to see the Rehabilitation Act more closely complement the intent of Section 1619 in the Social Security Act to give that full array of employment opportunties to those persons who are presently on SSI and SSDI. Second, I would hope that we can find ways that the independent living segment could be expanded to be more truly comprehensive: Third, I would seek ways to capitalize on the interest of the private sector.

Now, one comment about the private sector and that will lead me to my first question. That is, as I heard the witnesses—and I think you are essentially correct—and as I see the direction of these he irings, the goal of the Rehabilitation Act and this subcommittee should not be to harness the benevolence of the private sector—there is plenty of that—bu' to harness the profit motive. The fact of the matter is, that's a much greater motivator, and the fact of the matter is, as insurance companies and private employers will tell us, it is far more profitable and far less expensive to retrain and readapt the workplace for a disabled employee, to put that employee back to work; than it is to provide for a lifetime of care for that potential employee.

So my first question then becomes, could you cite for us either changes in the act or changes as you can see over the next 5 years that could harness the private sector. What changes in either the law or in actual practice need to be made in the workplace to provide for that kind of access to employment opportunities? If you had a perfect world, a blank blackboard, how would you improve the 16 percent employment rate among the Nation's disabled?

Mr. ARRELL. Mr. Bartlett, I think that under the broad auspices of the present Rehabilitation Act we have that. I think if we obtain the resources to use the technology we already have, along with the resources in the private sector, I think we have that possibility. I don't know of anything in the act that keeps us from doing that except resources.

Mr. BARTLETT. Then let me address funding, in terms of resources

Right now in the rehabilitation agencies it is your mission, loosely stated, to rehabilitate persons and to help them seek private employment. Obviously, you don't touch but a tip of the iceberg in terms of disabled persons just take the ones that are on SSI and SSDI.

What mechanisms are in place that you know of in the Federal law that give employment placement services or attendent care for SSI and SSDI and is that a function that rehabilitation agencies could adopt?

Mr. ARRELL. Of course, you and I have discussed this in section 1619 and the SSI and SSDI. Obviously, we do need to take care of the disincentives. We have a large number of severely disabled individuals who would be working today if it was prefitable for them to work, and if they would not lose benefits, especially medical ben-



efits. I mean, obviously, that needs to be addressed and needs to be corrected.--

As far as actually placing these people in the work force and having the technology to do it, and having the counselor and staff do it, we have that now. But we're talking money. We're really talking money. We're really talking individuals who can sit down on a one-to one basis and work with industry, giving us enough personnel and counselors to go out and sit down and talk to people in industry. Right now our counselors only have time to do very little counseling and very, very much less than that contact with the general public because their caseload is so heavy.

Mr. BARTLETT. You're saying your agencies have the infrastructure----

Mr. ARRELL. We have the structure.

Mr. BARTLETT [continuing]. To place SSI and SSDI persons in private employment?

Mr. ARRELL. Absolutely.

Mr. BARTLETT. But not the resources.

Mr. ARRELL. Absolutely. The first job I ever had in rehabilitation was purely in Social Security caseload. That's all I had. I will guarantee you, those individuals can and will go to work and can be placed into employment.

Mr. BARTLETT. So who is doing it now? -

Mr. ARRELL. We're doing some of it, and the rest of them are not being done. These people are staying on benefits.

Mr. BARTLETT. Does SSI or SSDI have a placement or counseling or employment service?

Mr. ARRELL. Not effective, that I know of.

Mr. BARTLETT. One last question, Mr. Chairman.

Who would save the money? I mean, if rehabilitation agencies were to take on that task, there would be a tremendous savings, I assume. Who would save the money and how could we link the cost savings to the cost of----

Mr. ARRELL. Obviously, the savings would be in lesser payments to SSI and SSDI, Federal appropriations in that area. That's obvious

Mr. BARTLETT. Mr. Switzer.

Mr. SWITZER. I think that we have only scratched the surface of dealing with business and industry. I am all for projects with industry and the expansion of projects with industry. Because what it did, you see, it got business involved with what disabled people can do, that we had a product to sell, to do work for the business community.

I think what is lacking in the budget—there are many things lacking probably in the budget, and yes, we could use more money, but in particular, that which was taken out a few years ago—is innovation and expansion. We're dealing with new populations in New York State, the head injury, the learning disabled, the spinal cord injury and the aged disabled. We have no moneys that we can use to give to anyone to innovate new ideas, new techniques in teaching the disabled how to work and how to get a job. Innovation and expansion is extremely important in the act; and that money must be put back in so that we can do the necessary programmatic type of research, to give moneys to nonprofit facilities, to United



Cerebral Palsy, to experiment with us and work and solve some of these problems of, for example, the head injury.

Mr. BARTLETT. Thank you, Mr. Chairman. Mr. Williams. Mr. Jeffords.

Mr. JEFFORDS. Thank you, Mr. Chairman.

Dave, it is good to see you here and I commend you on the excellent job you're doing.

I have three questions that I would like anyone to comment on. First, with the Job Training Partnership Act, could you tell me what kind of coordination and assistance you have had from your State and local agencies regarding the area of assisting the handicapped:

Second, there is a tremendous capacity in our-modern-technology to design various techniques for training the handicapped. Do you find there is sufficient resources being dedicated to that area, or is that some place where we should to place more special attention?

Third, regarding independent living, especially that which Mr. Mentasti described, give me an idea of the percentage being served compared to those that ought to be served. Also address special attention to part C of title VII; which apparently has no funding. Should we push for more funding there or would it be better to push for more funding in the other parts of that Title. Is there a problem with respect to special needs for the blind?

Mr. SWITZER. Your first question on JTPA, in New York State we have approximately-and I will send you the number of projects we have with JTPA funding. We have been able to link very nicely with vocational education private facilities and voc rehab dollars. We have two programs in training computer pro-grammers, one on Long Island and one in Queens, New York City, and we are developing one in Rochester as well. Here we have joint funding of JTPA dollars for training, voc ed dollars, and OVR dollars, and money is coming in from private business to develop it. I think it's a very worthwhile project.

In New York I have 16 district offices. All of my managers serve on advisory councils to the JTPA funding, so that we make sure that percentage of dollars goes for the disabled.

Mr. JEFFORDS. Thank you.

Ms. SUTER. We have 23 service delivery areas, JTPAs, in Illinois. We have the same thing. We have representatives in each of those areas. We do joint training awareness programs and work jointly with the employers. It has been a very helpful program.

Mr. RABE. I can echo in Ohio, that the same type of coordination goes on with JTPA.

I would like to comment on the training aspect. I do feel that it is necessary to have additional training funds within the States, especially when we're talking about national issues. Other States, including Ohio, require training in how to serve disabilities such as head injuries when counselors don't have the training or need to be brought up-to-date with the new advances in technology. So I think that training is very important, especially as technology changes.

Ohio continues to spend money on training in order to bring our counselors up to date in the areas of technological advances as well as information on different disabilities and new disabilities.

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Mr. MENTASTI. Congressman Jeffords, with respect to the Job Training Partnership Act, although it got cff to a slow start in Vermont, in the trenches there is certainly cooperation with the Job Service in implementing and we have found it a very effective relationship, a very effective program, for our clients.

In terms of part C, I think it's important that we fund part C, services to older blind, to highlight the need for specialized services to this segment of the population. This segment of the population is growing rapidly. I believe there are special needs, particularly in the areas of social recreational activities.

In a rural State like Vermont, isolation is a critical factor in terms of remaining independent and being able to take care of oneself. If we are to keep the elderly out of more expensive, more restrictive environments, I would strongly encourage funding of part C.

I would also encouraging funding of part A. I think what happens, if you say "let's do it all with one", you tend to dillute. Again, I think the elderly blind are an issue which I think we have neglected for long enough and now it's reaching a critical mass.

Thank you.

Mr. ARRELL. I would like to make one comment about the independent living program. I think this is probably the most innovative and best thing that has come along in rehabilitation in the last 25 or 30 years. I think this is going to be the one thing, if you're going to enhance the employability and the liveability, to allow the multiple handicapped and serverely disabled individual to live a productive life in a community setting, than any other one thing.

If you ask me today, if I had to say today where could I have an increase in funding in one program in the Rehabilitation Act, what would it be, I would have to say in the independent living program.

Mr. JEFFORDS. Do the others on the panel agree?

[Panel nods affirmatively.]

Mr. JEFFORDS [continuing]. Would each of you quickly run down the percentage of the population presently being served that should be living independently. Can you give us at least a ballpark figure?

Mr. ARRELL. That would be hard for me to do off the top of my head, yes.

Ms. SUTER. The only figure that I have in Illinois right now—and I could provide that for you—J know we have anywhere from 12,000 to 20,000 individuals that are living in nursing homes right that with some kind of independent living services could live in their communities.

Mr. JEFFORDS. Without pushing you, if you could provide us with that information, I would appreciate knowing that. Mr. MENTASTI. The only comment I might make, Congressman, is

Mr. MENTASTI. The only comment I might make, Congressman, is that, since the independent living center for blind and visually impaired was established 3 years ago, clients in our social rehabilitation caseload, which is essentially an independent living services program, increased by over 100 percent. That was due mainly to the outreach efforts of the independent living program.

Mr. ARPELL. I can tell you, Congressman, that in our State we have a State-funded program we call the Extended Rehabilitation Services Program. It has been in operation now about 5 years and was funded for those individuals who, at the time, we thought prob-



ably would never be able to work in the community. We are finding that is not true.

We have 19 projects at this time serving over a thousand individuals. I have a consumer consultation committee that works on the ERS Program and they are encouraging us to quadruple our program. We could quadruple it and still not meet the needs of the people that are out there right now. But I can give you hard figures on that.

Mr. JEFFORDS: Thank you very much.

Mr. Chairman, I apologize to everyone. I am supposed to be in four places at the same time. I was trying to get two out of the four. So I appreciate very much your testimony and thank you, Mr. Chairman, for allowing my participation.

Mr. WILLIAMS: Thank you, Mr. Jeffords.

Before we proceed, apparently there are people in the room around the corner who can't see and can't get much closer because of the way we are seated. I can't tell from here whether anyone in the back can move their chairs in such a way that come of the people around the corner may be able to come closer and at least enter the body of the room. But there are some seats up front. Maybe we could move a back row of chairs in a way that we could allow people in the chairs around the corner to come closer.

Are we all in now? Thank you.

Again I want to thank the panel for their testimony and the precise and appropriately brief answers that you have given to my colleagues' questions.

Although this is the first of a series of hearings on the reauthorization, and it may perhaps be too soon to expect specific recommendations for changes in this Act. Nonetheless, let me note I didn't hear any specific recommendations for changes in this act coming from those of you representing the Council of State Administrators. Each of you said the act should continue; some had indications that one title or section or another of the act should perhaps be somewhat improved and particularly, better funded. But no one made any recommendations as to specific or certainly significant changes in the body of the act.

Let me just quickly go down the table, starting with you, Mr. Arrell, and ask if that's an oversight, if time simply didn't allow it, or if, in fact, there are specific changes which you would like to see in the act. If so can you provide those suggestions to the committee in writing at a later time.

Mr. ARRELL It's not an oversight, Mr. Chairman, on my part. I genuinely believe that the Rehabilitation Act ought to be left intact as it is for a period of time to continue to give us some consistency in the program. I think we have the authority to do what we need to do.

Mr. WILLIAMS: Thank you:

Mr. Mentasti.

Mr. MENTASTI. I would agree with that, Mr. Chairman.

Mr. RABE. I would, as well. I believe the current act provides that flexibility that is necessary, as well as the detail, to serve the population that needs services.

Ms. SUTER. I agree.

Mr. Switzer. I ägree, but I would like it for 5 years:



Mr. WILLIAMS. You would like it reauthorized for 5 years.

Ms. Suter, do you agree with the 5 years?

Ms. SUTER: Yes.

<u>Mr. Williams.</u> How about the rest of you? Is there any disagreement on the 5 years?

Mr. Arrell. No.

Mr. Williams. Let me assure you, just in the way of devil's advocate—let me ask you a question this way. It seems to me there is almost unnoticed today in America a great political debate. That debate centers around whether or not, if I may put it in its simplest terms, federalism as we have known it for 50 years is to continue, or whether the Nation is going to go more to a system of a combination of volunteerism and the user pays, the early toll road mentality, which really was accepted in this country for many, many years.

I think there is no question but that it's in the best interest of all Americans that each American be able to live independently and have an ample opportunity to secure a good-paying, safe job at a good wage. The Vocational Rehabilitation Act establishes those two goals in its title.

The question before the Congress and before you is, given today's debate, and what is apparently a new mood in America, of turning away from federalism. Should we maintain the Federal requirement for independent living as a national goal, and for a job for each of our citizens as a national goal, but place the cost c<sup>r</sup> that more with the private sector and with the user themselves?

Let's start with you, Mr. Switzer.

Mr. SWITZER. I answer the question this way. Without federalism, would we have integration with minority groups in this country, without the laws of the land?

Mr. WILLIAMS. The answer to that is no.

--Mr. SWITZER. Right. The same thing would be true with rehabilitation. I think if we left it up to the States, it just wouldn't happen. We need the Federal law and we need that, as I said in my testimony, as the catalyst, as the direction which you're going in to provide services to disabled people. It must be a Federal movement, in niy opinion.

Mr. WILLIAMS. Ms. Suter?

Ms. SUTER. I believe that a partnership is beneficial, but I believe there absolutely has to be the Federal mandate to carry out these programs or they wouldn't get done. I believe t...at we need the Federal mandate to see that the programs are carried out and that people do get the rights, as you mentioned. to employment, to education, that they're entitled to: I think it absolutely has to come from the Federal Government.

Mr. WILLIAMS: Let me ask you, along with the mandate—and my question presupposed that the need for the mandate for independent living and work for all Americans is now clear in this country. My question presupposed that that mandate continue, but it went to the heart of who should administer that mandate, number one, and second, who should pay for it.

Ms. SUTER. I believe that there should be funding from the Federal level also to see that those programs are paid for and that the funding has to come from the Federal level and that there has to



be flexible and there has to be steady and consistent leadership on the Federal level as well.

Mr. WILLIAMS. Mr. Rabe?

Mr. RABE. I feel that the framework that exists at the Federal level is sufficient but that the States have to be part of the overall program and have to show that they, too, can support programs such as independent living. I think without the Federal framework you will have a patchwork of independent living programs that may not all reach a certain level. I think the State of Ohio and other States have shown that they are willing to put up monies for independent living. But I think again it needs to be a joint effort to reach all of the populations that are in need.

Mr. WILLIAMS. Mr. Mentasti?

Mr. MENTASTI. I believe we're dealing with a national issue that needs a national voice and national leadership.

Mr. WILLIAMS: Mr. Arrell:

Mr. ARRELL. The user fee mentality has just been demonstrated in our State very highly. In the past session of the legislature they increased college tuition by three times, increased all user fees in our State by 50 percent. I think that mentality certainly, at least in our part of the country, is very prevalent.

But I would also indicate to you that I think a Federal presence in this area is mandatory, for this reason. To give you an example of what I expect in my State in the next session of the legislature in 2 years, it is very obvious there is going to have to be an increase in taxes. We held to no tax this time by increasing user fees. There is going to have to be a rather large increase in taxes. The constituency that we represent, without a Federal mandate, without Federal laws requiring it and being involved in this, we cannot compete in our State with the University of Texas, the University of Texas system, we cannot compete with the Highway Department and other such agencies for the State dollar. In order to be able to compete with those individuals, we just do not have the lobbyists. All we have are disabled people who are willing to work 24 hours a day, and that's very effective. But when you're-up against large lobbies trying to get State funds, when there is going to be an increase in taxes, we need some Federai leverage.

Mr. WILLIAMS. Well, each of your statements on this in response to my question I think is very important. Each statement, because you have weighed in primarily on one side of what really is a raging national debate, even though it seems to be centered inside of the Washington beltway. There are many of us who believe that the economic and social magic which America has experienced these past 50-plus years is, in fairly significant measure, due to the application of this unique brand of federalism which started following the Great Depression.

When I say the debate goes largely unnoticed, let me put it in this framework for you. Along with being a member of the Education and Labor Committee, I am also a member of the House Budget Committee. Americans, it seems to me, seem somewhat mystified about the budget debate. Not so much because they don't understand it, but rather, because they have noticed that the Democratically-controlled House has cut the deficit by the same amount as the Republican-controlled Senate. So the question is,



what's all the brouha about if you have kept the deficit almost exactly the same amount?

Well, the debate is about just that of which we speak. Those who would cut the budget one way would cut it to begin to move those programs that need federalism to properly survive, as perhaps yours does, to cut those programs and move them into the localities for both management, administration and funding. Others of us who believe more strongly in a Federal role have found other ways to cut the deficit. So that is what the Budget Committee spent all of its time debating, not whether or not we ought to cut the deficit—almost everybody in this country agrees with that. The question is how do we do it.

As citizens of this country, who have a deep and abiding stake in the outcome of this debate, I encourage you to continue to not only pay close attention to it, but to try to swing the national compass in the direction which you believe is the proper course for America.

Again we thank this panel for your assistance.

- Mr. WILLIAMS. We will now go to panel two, representing the rehabilitation coalition. I will ask Mr. Charlson, Ms. Presson, Ms. Mendelsohn, and Ms. Spivack to take the witness table. I also encourage this panel to try and stay within our 7 or so minutes in your testimony.

Ms. Spivack, we will begin with you.

## STATEMENT OF MARILYN PRICE SPIVACK, FOUNDER AND EXEC-UTIVE DIRECTOR, NATIONAL HEAD INJURY FOUNDATION, INC.; NANCY PRESSON; BRIAN CHARLSON; AND HELEN MENDEL-SOHN, A PANEL

Mrs. SPIVACK. Mr. Chairman and members of the subcommittee, on behalf of the National Head Injury Foundation I want to thank you for this opportunity to speak before you today. My name is Marilyn Price Spivack and today I wear two hats: first, as a mother, and second, as the founder and executive director of the National Head Injury Foundation.

My daughter, Deborah, was severely head injured in an automobile accident in 1975. That tragedy caused us such stress, frustration and anger that my husband and I. Dr. Martin Spivack, founded the foundation in 1980. Since then, the NHIF has represented a newly identified disabled population that has been long ignored. I was very pleased to hear that it was mentioned a number of times this morning.

This population is rapidly multiplying as the result of major advances in neurosurgical acute medical care techniques, diagnostic methods, and the establishment of trauma centers. Yet still, in 1985, extended rehabilitation programs, human services and public policies have not caught up to the needs of these survivors. Our submitted testimony covers statistics and facts regarding the impact of the Rehab Act upon the victims of traumatic brain injury in detail, but because of time constraints, I will review just some of the numbers.

Five-hundred thousand yearly are admitted to hospitals with traumatic brain injury, leaving 50,000 to 70,000 with physical, psychological, and intellectual disabilities, precluding their return to a



normal life. We are talking about our most precious resource, our young people. Two-thirds of the victims are under 30, and approximately 20,000 are under 18. It is important to recognize that the vast majority of survivors will have a very normal life expectancy which then creates an overwhelming, unrelenting emotional and financial burden on the family and on society. Today, I am representing these young people to enthusiastically support the Rehabilitation Act of 1973, as amended.

It is for us, the families and the survivors, the most meaningful and critical legislation that ensures a possible future of productivity and dignity for our sons and daughters. Without this act, the lives saved at tremendous expense are doomed to an empty wasteland, thereby creating a greater drain on our welfare and economic systems. The indirect costs of traumatic brain injury are staggering.

ing. Switching hats and speaking as a mother, I will tell you why the Rehab Act is so important to me. I was fortunate to be blessed with three bright, healthy, and beautiful children. They had everything we could afford to give them so that their future would be productive and promising. Like all parents, we had many dreams for them. We had made no plans for catastrophic trauma. But then, head injuries happen without warning.

- My family was touched twice. Fifteen months after Debbie's accident, my son, then 20, was killed in a motorcycle accident. He was a passenger on a motorcycle, as Debbie was a passenger in a van. It was a dreaded telephone call that was our only warning and preparation.

It is the same for all of us. Immediately the family is dropped into a pit of fear, disbelief, anger, guilt and dispair. If our loved one survives, we quickly learn the meaning of what multiple disabilities are. We are still unaware of traumatic brain injuries and its horrendous consequences.

What is traumatic brain injury? It's a mosaic of complicated disabilities affecting the body, the senses, the mind and the personality, leaving lifelong disability and long-term impairments. In severe cases, the traditional prognosis after severe head injury was hopeless, as it was for my daughter. Now we know that more often it is not. Return of function is not a miracle. It is hard work, dedication, and appropriate therapeutic intervention. In the milder cases, it is often ignored and treated quite casually, leaving impairments to worsen and psychological problems to mount. What could then be an excellent rehabilitative outcome turns into a failure because appropriate extended education, rehab programs and funding mechanisms are nonexistent.

Like all other families, Debbie's accident left us with a deep anguish and bewilderment to her future. We had no training or support systems to help us cope at the time. I had never had to access any State service or agency before. I was totally unfamiliar in the world of disability.

From 1975 to 1977 we found the best medical management and early rehab treatment that was available in Massachusetts. Upon hospital discharge, the systems of rehabilitation began to break down and our world began to crumble again. It was most evident that the professionals in all areas of rehabilitation and extended



services were not prepared to treat this population, whether they were mildly impaired or severely disabled. At that point, even my husband, a physican, was at a loss as to where to turn. Meanwhile, the Rehabilitation Act was alive and well in the late seventies. I didn't realize then how the Rehab Act benefited my daughter.

- We had from almost the onset of medical rehabilitation the support of our special ed department. They gave us whatever help they could. They shared our frustration and then funded Debbie when the time came. We all learned about head injury rehabilitation by trial and error. During that time I was told by the special ed department to contact the Massachusetts Rehabilitation Department. They had funds at the time for prevocational training programs. At my request, that agency joined our planning team and Debbie's next placement was in New Hampshire. It was jointly planned and jointly funded.

I personally know how important prevocational training programs are for the survivors of traumatic brain injury. The facility happened to be unique and they tried to amend the program for her. But when it was no longer appropriate, our options again became quite limited—to keep Debbie at home—because the programs to provide her what she needed did not exist:

Through the advocacy effort, we have brought traumatic brain injury to the attention of Congress and Federal agencies. Special language was incorporated last year in House bill 6028, which directed the Department of Education and related agencies to review all programs and services and to report back to Congress this spring. As a direct result of that mandate, we took the most important step in our history. On May 14, the National Head Injury Foundation entered into a cooperative agreement with OSERS and related agencies. The goals that are stated in that agreement—and that must also be carried out at the State and Federal level depend upon the Rehabilitation Act.

What are our priorities? To review, training is a major one, case managers, vocational counselers and special educators. The second priority is special demonstration projects to fund innovative and prevocational programs to bridge the gap in services providing necessary cognitive remediation, behavior modification, and social and community integration skills.

Rehabilitation research must continue. Head injury rehabilitation is still in its infancy and we need to refine the techniques and technology. Research is needed to document the long-term outcome after a continuum of services. The Rehab Act allows us to move forward and we do not have to start from scratch because the stateof-the-art in head injury rehabilitation is being developed in the private sector. Visiting these programs, I see the positive results and improvement in function, even when the individual's prognosis was that of a hopeless future.

I would like to mention that where our States are active, so have become the State rehabilitation commissioners and the commissions. Fifteen States are now working with our State associations in planning needs assessments, training programs, and service delivery.

I would just like to close and say that our loved ones were bright and articulate young people, at the verge of becoming productive;



and vital citizens. Many of them had started families and careers. They were productive and successful. Now this devastating tragedy, causing a spectrum of disabilities, leaves many without hope or dignity and without a means toward achieving independence for their maximum potential of function. They are isolated, angry, depressed, and sometimes suicidal, without friends and without lovers, and often without an extended family in a world that does not understand them.

Gentlemen, the Rehabilitation Act which will authorize the goals of our agreement within each agency mandate is critical to us

To sum up my testimony, as a mother I will say that we think rehabilitation is cost effective in dollars and in the return of dignity. As founder of the National Head Injury Foundation, I urge you to continue to recognize that the future of all survivors of traumatic brain injury, as well as all disabled people, depend upon the programs within the Rehabilitation Act.

Thank you very much.

## [The prepared statement of Marilyn Spivack follows:]

#### PREPARED STATEMENT OF THE NATIONAL HEAD INJURY FOUNDATION

Thank you, Mr. Chairman, for allowing this additional written testimony by the National Head Injury Foundation (NHIF) to be entered into the record of these hearings. We do so in order to expand on and document the epidemic nature of traumatic head injury in this country and to detail the needs of this too long neglected population. The NHIF is an organization of 30 state associations, 315 chapters and 10,000 members providing support, information, education and advocacy for individuals suffering brain damage after head injuries. We have served over 60,000 families and professionals since the Foundation began. We have brought the problem of head injury before the House Subcommittee on Labor, Health and Human Services and Education in 1983, 1984 and in 1985.

### INCIDENCE AND PREVALENCE OF HEAD INJURY IN THE UNITED STATES

Brain damage from traumatic head injury is the number one cause of death and neurological disability in persons under age 35.

Two major studies document the extent of this epidemic: The National Head & Spinal Cord Injury Survey (NHSCIS) of 1980 and the San Diego Head Injury Study which was published in 1984. The NHSCIS studied all persons surviving long enough to be admitted to hospitals in 1974 with either head injuries or spinal cord injuries. As shown in Table 1, 422,000 people were admitted with head injuries compared to 10,000 with spinal cord injury. Ir addition the vast majority of those with head injuries, 262,000, were under age 24—young people at the beginning of their most productive years. Similar data was obtained by Kraus et al. who looked at all people suffering brain damage from traumatic head injury in San-Diego County during 1981. The incidence rates reported in this study are shown in Table II where we also present rates for the entire United States population based on these data. The study found that 21/100,000 people died of head injuries at the scene of the accident, and an additional 9/100,000 died after hospitalization. Thus, the number of people dying from traumatic head injuries prevar in the U.S. would be 30/100,000 or almost 70,000 per year. One can calculate from these data that 13,500 people in this country will survive after severe traumatic brain damage, 31,500 after moderate brain damage and 294,750 after sustaining minor brain damage. Those 44,000 people surviving moderate to severe brain damage each year will be left with disabilities which may seriously limit their return to previous employment or even fully independent living. Dr. Joyce Brink of the Rancho Los Amigos Hospital in Downey, California, estimates that 18,000 children under the age of 18 will suffer such disabilities and be limited in their return to school. As shown in Table III, this annual incidence of persons suffering moderate to severe head injury exceeds the combined total of individuals with Spinal Cord Injury, Multiple Sclerosis, Cerebral Palsy and Muscular Dystrophy!

What of the 294,750 people a year who are admitted to hospitals with "minor" head injuries? No head injury resulting in unconsciousness is truly minor. Indeed,



many neurologists feel that any bief loss of consciousness (concussion) reflects some brain damage, and we are all aware of the result when prize-fighters sustain repeated minor head injuries. A study at the U. of Virginia hospitals by Rimel et al. clearly documents the fact that in a group of people unconscious less than twenty minutes, fully one third were still out of work because of their head injury 3 months later. The economic costs to Workmen's Compensation Insurance and unemployment benefits are enormous when one considers the numbers of people involved.

It is much more difficult to find reliable data on the prevalence of various neurologic disabilities. The data of Kurtzke shown in Table III estimates that 1,800,000 people (800/100,000) in this country suffer neurologic disability from traumatic head injury. This number is remarkably close to NHIF estimates. We know that life expectancy after having survived traumatic head injury is close to normal and that the mean age of all head injured people is about 22 years. Thus, if each of the 44,000 persons sustaining moderate to severe brain damage lives 40 years, one might expect 1,760,000 people with brain damage from head injury to be living in this country. In any case, there is little question that there is a very large population of traumatically brain damaged people who have not been recognized as a unique disability group but who ere in dire need of specialized rehabilitation services.

#### ECONOMIC COSTS OF HEAD INJURY.

The direct costs of traumatic head injury are estimated by the NHSCIS at close to 5 billion dollars a year in 1980 dollars. This is a gross under estimation of total costs as it does not include lifelong care or income lost from work. Direct lifetime costs for one person seriously brain damaged by head injury can range from \$500,000 to over a million and a half dollars. Lost income and productivity can only be guessed at. When one considers that we are talking about a population disabled in the prime of productive years, this amount must be staggering.

## UNMET NEEDS OF THE HEAD INJURED POPULATION: RECOMMENDATIONS FOR COMMITTEE

I have spent most of my time this morning recounting in detail the difficulties faced by head injured people and their families when trying to obtain services as well as the limited resources allocated to this problem for research, training and service delivery by the various agencies. These will not be reviewed here. Suffice to say that head injury has not received the attention it deserves considering the epidemic nature of the problem because until 1980 there has been no consumer group voicing its concern. The NHIF now respectfully asks this committee to address itself to the problem. In 1984, both the House and Senate Appropriations Committee inserted special language in their reports requesting the Departments of Education and Health and Human Services (HHS) and the Rehabilitation Services Administration (RSA) to report back to Congress this year as to: (1) the current research and service delivery activities related to head injury being carried out by federal agencies, (2) the unmet needs in research and service delivery, (3) the most current techniques in acute care and rehabilitation of head injured persons and (4) plans for future directions of head injury research and service delivery.

In addition. Congress requested that the report address the issue of a specific category of disability for head injury and the utilization of that category by the relevant federal and state agencies. We are anxious to hear the report of those specified agencies and we hope there is not much further delay in those reports.

It is the purpose of my testimony to comment on some of the issues outlined above and the importance of the Rehabilitation Act upon the Traumatically Brain Injured survivors. In addition, as an active member of a number of coalitions representing disabled people—the Consortium for Citizens for Developmental Disabilities (CCDD), the National Committee for Research (NCR), the National Rehabilitation Coalition (NRC) and the National Alliance for Rehabilitation Research (NARR)—I wish to add my voice to those representing all disabled people in asking that our country's disabled not be without the needed research, training programs and service delivery provided by the Rehabilitation Act.

## REHABILITATION AFTER HEAD INJURY

"There is broad agreement among studies that maladaptive behavior is a frequent effect of Closed Head Injury (CHI) which is related to the severity of the brain injury and is particularly distressing to families. "The deterioration of social functioning is evidenced by decline and eventual loss

of friends, recreational opportunities and inability to be integrated in a work setting



with fellow employees. Investigators have shown that residual effects of brain injury contribute to the social maladjustment of these individuals. Inability to process information in an overstimulating environment with a number of individuals, speech and/or hearing problems, added to self monitoring of behavior, all contribute to social maladjustment."<sup>1</sup> \_\_\_\_\_The advances in emergency evaluation, trauma units and neurosurgical manage-

"The advances in emergency evaluation, trauma units and neurosurgical management of the past two decades have increased survival while producing an increasing number of post traumatic patients with marked cognitive and behavioral deficits who require rehabilitation to attain full potential for recovery. There is a growing recognition that rehabilitation of young head injured patients/clients must be designed to accommodate severe impairment of attention, memory and behavioral disturbances."<sup>2</sup>

The availability of "early" rehabilitation services after traumatic head injury has improved greatly over the past five years. The Committee on Accreditation for Rehabilitation Facilities (CARF), working with the NHIF, has developed and now placed into the field, guidelines for accreditation of head injury rehabilitation facilities which will improve those programs even further. The problem begins when the head injured person is discharged from the rehabilitation hospital to a community ill prepared to provide the long term services required for each individual to reach his or her full functional potential. The private sector has begun to develop such programs, but in general, they are expensive and available only to those with workman's compensation or other insurance coverages. At the present time, there are no states with fully implemented programs providing a continuum of care leading to maximal independence. Such programs might include:

(1) Extended rehabilitation—residential for the more seriously injured—day programs for the less severe cases with emphasis on cognitive retraining, behavioral adjustment, reorientation of psychosocial skills and pre-vocational training.

(2) Vocational rehabilitation-programs specifically structured for persons with traumatic brain injury.

(3) Independent living programs—capable of managing traumatically brain injured clients with or without physical disability.

(4) Behavior management-facilities for those with aggressive or self-abusive behavior.

(5) Special Education Programs-for scheel-age children staffed by specially trained educators.

- (6) Innovative Blended Funding-mechanisms including DVR's, Mental Health, Special Education, etc.

(7) Designated Head Injury Disability and Rehabilitation Planning Office 3 to:

a. Serve as case manager and coordinator of services and funding.

b. Interact with the family and provide counseling.

Although such a comprehensive system does not exist, there are hopeful signs that the situation is changing. Through the efforts of the NHIF and its state associations, and because of the expression of concern from both the House and Senate Subcommittees in 1984, there is an awareness of the problem which did not exist two years ago.

On May 14, 1985 a most significant cooperative agreement between the NHIF, RSA, Department of Education, NIHR and the Council of State Administrators of Vocational Rehabilitation (CSAVR) and the National Association of State Department of Special Education (NASDSE) was signed. This agreement signifies the recognition of the magnitude of the head injury problem and the commitment of the agencies to do everything they can within the mandates of their agencies and limits of their funding to provide effective programs at all levels (Cooperative Agreement attached). A number of states have begun to move on their own either through independent agency action or through legislation to address the needs of head injured people. For example, in Massachusetts, the Massachusetts Rehabilitation Commission, with the support of the Executive Office of Human Services, the Massachusetts Chapter of the NHIF and with special funding provided by the Legislature, has developed a plan for a comprehensive regional program of services for the severely head injured person. In Virginia, a head injury registry was established in 1984 and the Virginia Head Injury Foundation was funded by the Virginia Rehabilitation commission to conduct a survey of need and to function as an information and referral center for head injured persons.



<sup>&</sup>lt;sup>1</sup> Levin, Harvey-General Considerations and Neurobehavioral Recovery Part II p. 29697-Central Nervous System Trauma-Status Report-1985-Becker, D. and Poulishock, Jonn. <sup>2</sup> Ibid.

<sup>&</sup>lt;sup>3</sup> The NHIF State Association working with a specific, appointed state agency.

These states and agencies have taken it on themselves to provide funding, but it is abundantly clear that most states will be unable to implement new programs, and those just started will be in jeopardy if the Rehabilitation Act is threatened by the budget and the Vocational Rehabilitation State Grunts is frozen at \$1.1 billion for FY 86 as the Administration proposes. We join with the CCDD in requesting \$1.2 billion for this program.

### SPECIAL DEMONSTRATION PROGRAMS

Since rehabilitation of head injured individuals is a relatively new field. Special Demonstration Programs under Section 311 of the Rehabilitation Act are essential to "expand and improve" rehabilitation services for this population. Under NHIF urging in 1984, head injury was included as a category under this program and two proposals were funded This year, the NHIF is urging the development of preventative programs focusing on cognitive remediation, behavior modification and social and community skills retraining that is critical if our population is to have the opportunity to participate in higher levels of rehabilitation services and independent living.

The NHIF has requested of the House and Senate Subcommittee on Appropriations that 5 million dollars be allocated for this important area of rehabilitation and prevocational services.

#### REHABILITATION TRAINING

In all rehabilitation, training of personnel is the most critical element in providing effective services to disabled people. Nowhere is this more true than in the rehabilitation of head injured people whose special programmatic needs are only beginning to be appreciated. We were most pleased to see this recognized by the RSA of Region 3 and George Washington University Research & Training Center who devoted the entire three-day conference organized by Region 3 to head injury, the problems encountered in rehabilitation and the types of services required. This conference was attended by D.V.R. staff and case workers, service providers and program administrators. We must develop a skilled cadre of rehabilitationists who understand head injury. By reducing the FY 86 congressional authorization for rehabilitation training from \$31 million to \$15 million, the Administration will make it impossible for RSA to institute any new initiatives in this area. We urge the Committee to recommend full funding of \$31 million and, if achieved; request that RSA set aside specific funds for training of personnel in head injury rehabilitation.

### EDUCATION OF HEAD INJURED CHILDREN-PUBLIC LAW 94-142

P.L. 94-142 is the backbone of special education programs for handicapped children. It is estimated that each year 18,000 children of school age suffer head injuries with moderate to severe disability characterized by cognitive dysfunction, memory impairment and psychosoci al and behavioral disorders. Clearly, most of these children will t quire special programs funded under P.L. 94-142. Many times, trained personnel are not available within the local school district and the child must be transported to other programs or be placed in specialized residential schools. Even at present levels of funding, many states cannot meet the needs. Freezing the funding level at \$1,135.1 million will have the effect of a decrease and will stop any progress in this area. We agree with CCDD that an appropriation of \$1,347.2 million is necessary to allow Departments of Special Education to meet their responsibilities towards disabled children.

### SPECIAL EDUCATION PERSONNEL DEVELOPMENT

As with rehabilitation programs, special education programs require trained personnel. This is particularly true when teaching a head injured child whose disabilities do not fit neatly into the categories most educators are accustomed to. Because there are very few special education teachers knowledgeable about head injury, the NHIF has had a Special Education Task Force meeting for the past year to define the needs of head injured youngsters and effective techniques in teaching them. The results of that effort will be published and a series of teaching conferences are planned. We urge the Department of Education to set aside specific funds to train educators about head injured children. Clearly, that will not be possible if this budget is cut from \$61 million to \$50 million as the Administration proposes. We



### INDEPENDENT LIVING SERVICES

Independent living centers established in 1978 and reauthorized by Congress in 1984 (P.L. 98-21; under part B of the program) have allowed 30,000 individuals with severe disability to achieve some level of independent living. Unfo-tunately, the programs have been specifically directed towards individuals with physical disability and thus most head injured people with cognitive and behavioral dysfunction have not been served. In 1985, part B centers were encouraged to expand their services to additional groups of disabled persons. The NHIF urges RSA to enjourage the development of I.L.C.'s for head injured people with or without physical disability as eligible for the Independent Living Services programs. To do this will require, at the very least, the full 23 million dollars authorized. We also as a in full support of the CCDD in urging the appropriation of 30 million actients to continue the activation of Part A of Title VII of the Rehabilitation Act to provide for a comprehensive program of servic - for those individuals too severely handicapped to be eligible for current vocational rehabilitation services.

## RESEARCH-NATIONAL INSTITUTE OF HANDICAPPED RESEARCH (NIHR)

If progress is to be made in rehabilitating head injured individuals back to productive lives, it is essential that new and innovative approaches be developed. We are particularly interested in studies on cognitive retraining, use of computerneuropsychological evaluation and most importantly, innovative approaches to vocational retraining. Millions of dollars are being spent to fund programs utilizing techniques which have not been subjected to scientific evaluation. In the long run, dollars spent in careful research will be returned many fold. NIHR has funded four Research and Training Centers for head injury since 1983, but three of these are combined stroke units. Much more needs to be done. Because of limited funding, the investigator/initiated research program was able to fund only 15 percent of applications. Level funding at \$39 million will not allow this low number in FY 86. We advocate full funding to the FY 56 authorization level of \$44 million.

### SUMMARY

1 Since the problems experienced by persons with traumatic brain injury impact so many agencies, the NHIF requests an interagency committee be established to delineate the needs and outline agency responsibility in the areas of research, training and service delivery and to coordinate a system to deliver appropriate cervices to the consumer

Create a multidisciplinary task force or special working committee composed of agency representatives, experts in the field of head injury and consumers for the purpose of:

A. Investigating all the current research and service delivery activities relative to the problem of head injury now being carried out by the various federal agencies in the Department of Education and Health an ! Human Services.

B. Documenting the unmet needs found in recearch, training and service delivery

currently existing within each agency; C. Reviewing the "state-of-the art" as it exists anywhere in the acute care of head injured people and early and late techniques in rehabilitation leading to return to maximal function, and

D. Developing a coordinated plan of action to be undertaken by the federal government over the next decade in head injury research and service delivery

2. The NHIF respectfully requests this committee use its influence to direct the agencies under Health and Human Services and the Department of Education to institute a specific disability category, "brain damage secondary to head injury," within their agencies, in order to establish clearly the nature of this disability and the appropriate services required.

On behalf of the National Head Injury Foundation. I want to express my appreciation for the interest and concern this subcommittee has expressed for the needs of those who have sustained traumatic brain injury. We are available to you for any further information that you may require.



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Age	Head injury 1	Spinal cord
0 to 24	262	4
25 to .44	76	3
Total	2 422	10

<sup>1</sup> × 1.000---<sup>2</sup> Rātē = 200/100,000

Source, Journal of Neurosurgery, November, 1980

TABLE II.—BRAIN INJURY IN PERSONS SUFFERING TRAUMA, SAN DIEGO COUNTY—1981

Seventy	Number 01 cases 1	Ir Lidence/ 100 000/yr	Fatality rate (percent)	Survivars/ 100,000/ýr	Brain injured survivors U S
Immediate death	385	21	100	ل	
Severe injury	265	14	58	6	13,500
Moderate injury.	2/1	15	7	. 14	31,500
Milt Injury	2:435	131	0:1	131	294,750
Total cases .	3.258	181	17	151	343,750

LGünshöt wöündis nöt änölügen Source Kraus et al., Ame: U soudemioli, 1984

TABLE III.-COMPARATIVE INCIDENCE AND PREVALENCE OF BRAIN DAMAGE FROM TRAUMA AND OTHER NEUROLOGIC DISABILITIES 1

Disorder	Incidence per year	Prevalence
Traumatic brain Damage, moderate to severe	2 44.000	1,000,000-
Spinal cord injury	6,750	1,800,000 112,500
Multiple scierosis	6,750	135 000
Cerebral pasy	20,000	560,000
Muscular dystrophies (herefiliery)	2,700	45,000

Data from Kurtzke, J. Neurology 32:1207, 1982 3 Data from Kraus et al. Amer. J. Epidemiol., 1984. Addendums—Coop agreement; Resolution of Head Injury Awarchess Month—House Joint Pesolution 200; and Senate Joint Resolution 132 Mr: WILLIAMS: Thank you.

Miss Presson.

Ms. PRESSON. Good morning. My name is Nancy Presson. I happen to have epilepsy. I have had it for the last 5 years. I am also the mother of a mentally retarded epileptic and cerebral palsy little girl. I am especially pleased to nave this opportunity to express the concerns of organizations about how vocational rehabilitation assistance serves individuals who are developmentally disabled.

There is a collective opinion that the Federal/State operated vocational rehabilitation system is notoriously difficult to access for people developmentally disabled. If an individual is deemed eligible, there are many inadequacies and often negligence surrounding the services provided which then result in grossly inappropriate placements when and if placements occur at all.

These are the areas I would like to address—the issues of eligibility, services and placements.

Vocational counselors often look upon people who are developmentally disabled as too difficult to work with. This fact, in our opinion, remains the primary factor in the overall ineffectiveness of services. Epilepsy, for example, is a very complex disorder and presents a number of obstacles to gainful employment. Counselors who do not work intensively with epilepsy generally are unaware of these conditions and misunderstand their vocational significance.

In my own experience, the emotional trauma of having epilepsy diagnosed and witnessing certain loss of coordination was totally overlooked by my counselors. As a result, my first jobs were disastrous. All my problems on the job were attributed to my epilepsy, not to the emotional rollercoaster I was riding. I had no help in understanding this myself or helping my employer to understand the situation. Hence, the myths of epilepsy prevailed with my employer and I lost my job.

This kind of misconception is rampant among VR counselors, not just with epilepsy but regarding cerebral palsy, mental retardation, psychological disabilities, autism, learning disorders, and other severe handicaps.

For a person even to be eligible for services, the counselor must determine that the disability constitutes a vocational handicap and then must judge that the service that he or she provides will result eventually in the person finding employment. This judgment is left totally to the discretion of the counselors. They often will determine that the services most readily available to counselors, such as physical restoration services and training, will probably not assist a developmentally disabled person secure gainful activity.

In some States, a rehab for which the counselor can get credit is dependent upon persons engaging in full-time employment. For the chronic ily mentally ill, as well as many others being represented here today, part-time employment may be the highest level of functioning feasible.

Counselors also find themselves with the RSA mandate to provide short-term help to those most severely handicapped clients toward substantial gainful activity. Most are reluctant to take on clients with autism, or moderate or severe mental retardation. It is not uncommon for an individual with cerebral palsy to be told by the vocational rehabilitation counselors that they are unemployable, only to complete college degrees and become very highly successful professionals.

People with autism are typically rejected automatically as being too serverely disabled to benefit from any services. Those who are considered, are subjected to vocational evaluations using assessment tools to accurately assess their assets and limitations.

The person with epilepsy is commonly found to be ineligible for services because he or she has controlled seizures and therefore is determined not to be vocationally handicapped. Tragically, just as often the reverse will happen. A person who is actively having seizures will also be found ineligible because they are too severely handicapped.



The services provided to the people who are developmentally disabled tend to be inadequate, inappropriate, and often nonexistent. Most developmental disabilities fall pitifully low on the lists of priorities in most States. The only services for which he or she may be eligible are counseling, guidance, placement and follow-up. There seems to be a pattern in vocational rehabilitation that counselors tend to provide only those services which they can pay, such as medical treatment, physical therapy, or other equipment needed. The problem is that they frequently cannot pay outside organizations to provide job preparation and placement services, even though these art the services needed and VR counselors do not possess the expertise to provide them.

Another serious concern is that the vocational rehabilitation system is painfully slow to pick up on, endorse, or purchase new program concepts which have and are being proven effective with people with developmental disabilities.

Another critical missing link is the application of rehabilitation engineering to enable persons with cerebral palsy and other more severe handicaps to become more productive and independent. While much research in technology is being done, the benefits of this technology is not reaching the consumer.

Developmentally disabled adults are most typically placed by VR in sheltered employment or as homemakers. Even among the competitive jobs into which a developmentally disabled client may be placed, they are traditionally low-paying menial jobs with little or no opportunity for advancements, insurance, or retirement. I should also add that the followup services are virtually nonexist-

We are encouraged by some of the more recent developments. The concept of the Client Assistance Programs has a valuable role to play in ensuring that adequate and consistent services are being provided. We strongly believe that these programs should be established independently of the vocational rehabilitation system.

Though CAPS provide a reasonable mechanism for remedy, their existence in no way relieve RSA of its commitment to improving the quality of their services. If we reach a point at which services are adequate for our population, remedies, as available though CAPS, should not be needed. We think RSA should not lose sight of that. Band aids cannot replace the need for services.

Other changes also need to be made. Better preparation of counselors to work with caseloads, including specializations in these disabilities, needs to be encouraged through the institutions receiving RSA grants for masters level rehabilitation programs and through systematic inservice programs.

Additionally, the disabilities represented in this testimony must be categorized at a higher level of priority to facilitate eligibility and to encourage purchase of appropriate services from available resources.

By better educating counselors relative to the disorders presented here and encouraging counselors to develop more specific expertise in the specified areas, we will ensure that people who are developmentally disabled can access the system.

It is vital that the vocational rehabilitation system recognize its responsibility to the millions of developmentally disabled adults they are mandated to serve. The vocational rehabilitation system is the only federally supported system with a broad enough mandate to make substantial contributions to the lives of people with developmental disabilities in this country by helping them overcome the one limitation cited at the beginning of my remarks-we want selfsufficiency.

Isn't it amazing, the time spent and the budget spent on defense and other mechanisms of this country. I strongly believe that part of that money could certainly come to this action. However, I would like to thank the Department of Defense, the Armed Forces Radiobiological Research Institute, Major Mann and Captain Rand, because without them I would not be employed.

Thank you.

[The prepared statement of Nancy Presson follows:]

# PREPARED STATEMENT OF NANCY PRESSON

Good morning, my name is Nancy Presson and I am appearing here this morning on behalf of the following 10 national organizations: American Association on Mental Deficiency; Association for Children and Adults with Learning Disabilities; Association for Retarded Citizens; Epilepsy Foundation of America; National Alli-ance for the Mentally III; National Association of Protection and Advocacy Systems; National Martin Hardth Association, National Association for Children and Advite with National Mental Health Association; National Society for Children and Adults with Autism; The Association for Persons with Severe Handicaps; and United Cerebral Palsy Associations, Inc.

As an individual with epilepsy and the mother of a child developmentally disabled by epilepsy and cerebral palsy, I am especially pleased to have this opportunity to talk with you about my experiences with the vocational rehabilitation system and to express the concerns of these organizations about how the vocational rehabilitation system serves individuals who are developmentally disabled. We would like to acknowledge at the outset that each of the disabilities represented here present their own unique challenges in placement, some of which may be complex, and that there are many dedicated vocational rehabilitation counselors who accomplish impressive results with too few dollars and bulging caseloads. There is collective opinica-hat the Federal/State operated vocational rehabilitation system is notoriously difficult to access for people developmentally disabled. Wren an individual who is develop-mentally disabled is deemed eligible, there are many inadequacies and often negligence surrounding the services provided which then result in grossly inappropriate placements when, and if, placements occur at all.

These are the areas I would like to address—the issues of eligibility, services and placements. Before describing further these difficulties, I would like to tell you a little about developmental disabilities and to explain that many people who are developmentally disabled, if not most, can work competitively.

Developmental Disabilities are chronic disabilities which are attributed to mental and/or physical impairments which are apparent before the age of twenty-two. They tend to be life-long and can result in limitations of such major life activities as self care, mobility, self-direction and the capacity for independent living and economic

self-sufficiency. Vocational counselors, however, often look upon people who are developmentally disabled as too difficult to work with. This fact, in our opinion, remains the primary factor in the overall ineffectiveness of services. Epilepsy, for example, though episodic in nature, is also a complex disorder and presents a number of impediments to gainful employment such as the severity, nature and frequency of the seizure activity, medication side effects (double vision, nausea or drowsiness) and associated neuropsychological or emotional difficulties. Counselors who do not work intensively with epilepsy generally are unaware of these conditions or misunderstand their vocational significance. In my own experience the emotional trauma of having epilepsy diagnosed and witnessing certain loss of coordination was totally overlooked by my counselors. As a result my first jobs were disasterous-all my problems on the job were attributed to my epilercy-not to the emotional rollercoaster I was riding. And I had no help in understanding this myself or helping my employer to under stand the situation. Hence, the myths of epilepsy prevailed with my employer and I lost my job.



This kind of misperception is rampant among VR counselors- not just with epilepsy but regarding Cerebral Palsy, Mental Retardation, Psychological Disabilities, Autism, Learning Disorders and other severe handicaps. It weighs heavily on the counselor's decision to approve the eligibility of the person and is carried through all the way to employment.

For a person to be eligible for services from the vocational rehabilitation agency they must have a mental or physical disability which presents a handicap to employment and also must be expected to achieve gainful activity with the provision of vocational rehabilitation services. This means the counselor must determine that the disability, which is confirmed by a medical or psychological examination, constitutes a vocational handicap and then must judge that the service he or size provides will result eventually in the person finding employment. This judgement is left totally to the discretion of the counselors, who are tragically ill informed about the complexities of developmental disabilities and will often fail to appreciate the very real vocational barriers presented. Further, they often will determine that the services most readily available to counselors such as physical restoration services and training will probably not assist a developmentally disabled person secure gainful activity.

In some states, the likelihood of a rehabilitation for which the counselor can get credit is dependent upon persons engaging in full-time employment. For the chronically mentally ill, as well as many others being represented here, part-time employment may be the highest level of functioning feasible.

ment may be the highest level of functioning feasible. Counselors also find themselves with the RSA mandate to provide short-term help to the most severely handicapped clients toward substantial gainful activity (SGA). Most are reluctent to take on clients with autism, moderate or severe mental retardiction or other developmental disabilities recognizing that they are severely impaired but fearing that the client will not achieve SGA and will not be counted as a successful rehabilitation. Most of that fear is generated from lack of knowledge about the disability. Most vocational rehabilitation counselors possess antiquated views on the employment potential of developmentally disabled persons or may nave no knowledge at all. It is not uncommon for an individual with cerebral palsy to be told by vocational rehabilitation counselors that they are "unemployable" only to complete college degrees and become highly successful professionals.

People with autism are typically rejected automatically as being too severly disabled to benefit from services. Those who are considered are subjected to vocational evaluations using assessment tools that term to be biased against people with autism, not having been modified to accurately assess their assets and limitations.

The person with epilepsy is commonly found to be ineligible for services because he or she has controlled seizures and therefore is determined not to be vocationally handicapped. This may happen even though the individual may be heavily medicated to maintain seizure control or be suffering from a mix of psychosocial/behavioral problems associated with the long-term condition.

problems associated with the long-term condition. Tragically, just as often the reverse will happen. A person who is having active seizures will also be found ineligible because they are "too severely handicapped" to benefit from VR services.

The services provided to people who are developmentally disabled tend to be inadequate, inappropriate and often nonexistent. To begin with, clients in the VR system must vie for available funds hased upon the priority rating given to their disability. Most developmental disabilities fall pitfully low on the lists of priorities in most states. So, though a person meets the eligibility requirements and may be accepted, often the only services for which he as she may be eligible are counseling, guidance, placement and follow-up. These in many cases are precisely the services required to rehabilitate a person developmentally disabled and are the least costly to provide but oddly enough are the least likely to actually be provided. There seems to be a pattern in vocational rehabilitation that counselors tend to provide only those services for which they can pay such as medical treatment, physical therapy or prosthetic equipment. The problem is they frequently cannot pay organizations like Goodwill Industries. The Association of Retarded Citizens. The Epilepsy Foundation of Americs, United Cerebral Patsy Association and others to provide job preparation and placement services even though these are the services needed and VR counselors do not possess the expertise to provide them. The reasons for this is that the counselors are required to provide such services to clients themselves and are not allowed to utilize funds for clients in this criegory. The fact is most of these services are inadequately provided, if provided at all.

Another serious concern is that the Vocational Rehabilitation system is painfully slow to pick-up on endorse and/or purchase new program concepts which have and are being proved effective with people with developmental disabilities. The use of



"job coaches," people who accompany clients throughout the vocational process, is a much more effective mechanism for helping people with autism to achieve successful independent employment. Supported-work or transitional models are successfully being perfected through programs funded by the Office of Special Education and the Administration on Developmental Disabilities involving people with mental retardation, epilepsy, and mental illnesses. The VR system not only does not utilize these avenues with any regularity, but is reluctant to purchase the services.

Another critical missing link is the application of rehabilitation engineering to enable persons with cerebral palsy and other more severe handicaps to become more productive and independent. While much research in technology is being done, the benefits of the technology is not reaching the consume. For example, some persons with cerebral palsy and edequate speech, but lack the manual dexterity to dial and hold a phone. There are simple devices that can enable these persons to dial a phone and can also "hold" the phone for them. Such an accommodation for some persons may be the key to achieving a self-fulfilling career and independence.

As indicated there is a fairly consistent pattern of not utilizing available services, techniques and technological advances to facilitate successful rehabilitation of people with developmental disabilities. Yet team approaches to working with this population are believed to especially be effective and more likely to produce favorable results.

In a 1984 study of specialized vs. generalized rehabilitation conducted by the University of Washington Epilepsy Center in Seattle, Washington, it was shown that "simply providing vocational services to a large number of people with epilepsy does not result in a high proportion of these people being successfully rehabilitated" and that serving people with epilepsy can require specialized intervention. Additionally, the Commission for the Control of Epilepsy and Its Consequences noted in its 1977 report to Congress that factors contributing to the lack of success of vocational rehabilitation counselors in working with people who have epilepsy include a lack of understanding about the problems and a failure to match training with either interest or available jobs. This leads to my next point, the case closure system that discourages that of placement or follow-up.

A special work group convened by the Rehabilitation Services Administration in August 1984 to recommend changes to the VR Service to improve services for chronically mentally ill adults observed that: State VR agencies frequently utilize traditional community based rehabilitation facilities, particularly sheltered workshops, for provision of services to those with chronic mental illness, even though most of these facilities are geared to work with persons with mental deficiences or physical disabilities.<sup>1</sup>

I should point out that of the recommendations which resulted from this work group, none have been implemented to date.

As a result of these problems, people with developmental disabilities will often languish in the system until one of several things happens. 1) they find their own job with no help from VR, 2) they tire of the non-service services and stop trying, or 3) their counselor places them. This brings me to my next point which is the inadequacy of placement and follow-up services.

The fact that counselors know little about developmental disabilities, the lack of effort to utilize new techniques, technology or available expertise in conjunction with the general lack of attention given to the whole point of VR—p .cement—contribute to the abysmal placement record for people with devlopmental disabilities. Developmentally disabled adults are most typically placed by VR in sheltered employment or as homemakers. Even among the competitive jobs into which a developmentally disabled client might be placed, they are traditionally low paying, menial jobs with little or no opportunity for advancement and are substantially below the individual's capability.

I should also add that follow-up services are virtually nonexistent. Once a client is placed on a job, he or she enters a status 22. In order to move from status 22 to a status 26, successfully rehabilitated, a client must remain on the job. Most often, the only time a client hears from his or her counselor after placement is at the two month period—the purpose of the contact being to verify continued employment. This is true despite the fact that most jobs are lost in the first week or two and irrespective of the significant issues which arise for people who may not have

<sup>&</sup>lt;sup>1</sup>Traditional rehabilitation practices and intervention mechanisms, proven to be successful in working with persons with less severe and stable disabilities, often are not appropriate rehabilitation modalities for persons with chronic mental illness, yet State vocational rehabilitation agencies continue to utilize them in working with this disability population.

worked outside the nome for a long time, if at all. The fact that there are inadequacies in the system is well documented and needs to be addressed.

We would like to note, however, that we are encouraged by some more secent developments. The concept of the Client Assistance Programs (CAP) has a valuable role to play in ensuring that adequate and consistent services are being provided. Though we strongly believe that these programs should be established independently of the Vocational Rehabilitation System and that the 21 in-house CAPS are subject to conflicts of interest, the concept in its infancy is a positive move which we would like to encourage. We also urge restoration of the requirement that the VR agency. This provision was dropped during the 1983 reauthorization process.

Though CAPS provide a reasonable mechanism for remedy, their existence should in no way relieve RSA of its commitment to improving the quality of their services to people with developmental disabilities. If we reach a point at which services are adequate for our population, remedies, as available through CAPS, should not be needed. We think RSA should not lose sight of that. Remedies will not replace the need for services.

Another positive development in recent years has been increased cooperation, at least at the administrative levels between vocational rehabilitation services and organizations representing people with epilepsy. Cooperative agreements currently exist between RSA and United Cerebral Palsy and between RSA and The National Institute of Mental Health. Area and regional agreements also exist between rehabilitation agencies and the Epilepsy Foundation of America's Training and Placement Service sites. Again, these agreements are a start but need more emphasis and clear objectives. Additionally, they should begin at the administrative level and be actively encouraged all the way through the system to the service delivery level

actively encouraged all the way through the system to the service delivery level. Other changes also need to be made. Better preparation of counselors to work with cuseloads, including specializations in these disabilities, needs to be encouraged through the institutions receiving RSA grants for Masters level rehabilitation programs and through systematic in-service programs for existing counseling staff. This will facilitate eligibility, more appropriate services and better placements.

Additionally, the disabilities represented in this testimony must be categorized at a higher level of priority to facilitate eligibility and to encourage purchase of appropriate services from available resources. Currently, the priority structure and spending restrictions preclude even a well informed counselor from acting in the best interest of a client with a developmental disability.

By better educating counselors relative to the disorders presented here and encouraging counselors to develop special expertise in the specified areas, we will better ensure that people who are developmentally disabled can access the system, obtain more appropriate and timely services and achieve job placement more consistent with their talents and potential.

We are not here to say that placing people with developmental disabilities is not challenging. We have, in fact, tried to identify some of those challenges in our earlier comments. But it is vital that the Federal Vocational Rehabilitation system recognize its responsibility to the millions of developmentally disabled adults they are mandated to serve. The Vocational Rehabilitation system is the only Federally supported system with a broad enough mandate to make substantial contributions to the lives of people with developmental disabilities in this country by helping them overcome the one limitation cited at the beginning of my remarks which is not endemic to the conditions—that is economic self sufficiency!

Thank you!

Mr. WILLIAMS. Thank you very much.

Mr: Charlson:

Mr. CHARLSON. Mr. Chairman and members of the committee, I want to precede my remarks by telling you exactly how proud I am to be sitting at the table with consumers, the people, those people on the first panel, who are charged to assist and to help toward a life of both gainful employment, and I think one of dignity as well.

I want to tell you a little bit about my life and how it has been affected by the rehabilitation process, and in some cases how it wasn't affected by the rehabilitation process.

I was blinded at the age of 11 in a household accident. I did not go through special education in an instituation but, rather, was



mainstreamed my entire life through public-schools. At the age of 17, between my junior and senior years in high school, the Commission for the Blind in the State of Oregon, my home State, had me in for a review, wherein they were going to test my abilities, what actually had I learned during my time in the public school system; was I ready to go on to rehabilitation and what kind of form should that rehabilitation take.

I was found to be adequately trained, to go on to higher education when the time came, and they then offered me an opportunity to work a little bit and get some summer work experience.

After my graduation from high school I went on to community college: The Commission for the Blind in Oregon provided me with readers funds to assist in in reading those textbooks not available in other media. I paid for the rest of my education at community college through work and scholarships.

After 2 years at a community college, I continued on to a 4-year liberal arts college in Salem, OR, Willamette University, where I eventually obtained my bachelor's in political science, I worked throughout my college years in order to attempt to offset as much as possible the expense of my education.

During the time when I first became a client of the Commission for the Blind, I told the counselors that what I was really interested in doing is a job similar to yours, Mr. Chairman. I wanted to enter into public life. I wanted to become an elected official, to have some impact on the society around me. I saw some needs that I believed my special background might help me in meeting.

The counselors agreed with that assessment and decided that yes, in fact, what I needed to do was go on and get my degree in political science and become a politician. That's a filthy word, I guess, but I liked the name of it.

I went on and got my degree, only to find out after graduating that, in fact, there are very few professional politicians in my home State. Oregon has a legislature that meets every other year, and every member of the State legislature had another career that paid for their maintenance between sessions. Sessions only last about 6 months, every 2 years. That was a bit of a surprise to me that, in fact, there was not enough pay from the job itself to maintain them.

I was left in a position where I had a political science degree and no real way of entering straight into political life with that. So I obtained part-time employment, or full time, during sessions at the State legislature. I didn't let that keep me away from public life, and I worked there for each of the next three sessions. Between sessions I was unemployed, at least with State government, so I went on. One year I worked for the city of Salem as a human rights specialist. Between the 1981 and 1983 sessions I entered into the business enterprise program as a vendor, thinking that maybe here was the answer to my problems—that is, a career that would allow me to earn enough income that would allow me to leave, when necessary, to engage in statesmanship with the State government.

Unfortunately, that program did not provide that kind of an income or anything near it. So I went back to the legislature and eventually moved up in the system until I was assistant sergeant



at arms. I know that sounds like a high position, but in the State of Oregon that position pays \$860 a month, and although it is a political patronage job, it only lasts for about 6 months every 2 years.

In the 1983 session, I worked for 8 months. The session went on a little bit longer than normal. We know how that is around here on the Hill, things lasting a little bit longer than expected. At that time I went to 8 months. I found out 6 months is a magical number in Oregon. When you have been employed for 6 months full time, you are rehabilitated. So my case was closed and the commission, knowing that the job was only going to last for a short period of time longer, and knowing at that time I would be unemployed, said "Don't worry about it. There is a thing called post-employment services. We'll just reopen your case when this job is over under postemployment services."

I fought it at the time because ! had heard bad rumors about that phrase, but I really had no course of action that I could take at that point. I was closed. My job ended. I went to the commission and said, "All right, now let's see what you can do for me in postemployment services." The State of Oregon has an unemployment right around the 10 percent figure, so employment is a very difficult thing for blind people to obtain.

At that point they told me that post-employment services consisted of one program called "job club". This is where blind people got together once every other week in order to discuss interview techniques or to discuss where they hadn't gotten jobs, and then they would trade on one another's paranoia and dispair. I did not get anything from that program nor did it assist me in any way, shape or form in obtaining other employment.

I kept myself busy doing volunteer work. I continued to look for a job in the public sector. I was asked back again to the legislature that was supposed to begin January 1 of this year. But after 18 months of unemployment in Oregon, my wife was offered a job in the State of Massachusetts as the assistant director of the Library for the Blind in that State. She hadn't been unemployed, although she is blind also. We moved to Massachusetts.

Bingo. Suddenly I am no longer successfully rehabilitated. Because I moved from State to State, I now can be reopened as an unrehabilitated individual, in which I called up and said I would like to be put on the agency's rolls in order to receive services. They said, "fine, when do you want to start looking for work?" I said immediately. "Fine, we'll be out to see you in about 10 weeks." I said, "Ten weeks? Wait a minute. There's a 4 percent unemployment rate in Massachusetts. I think I should be able to do something within the next 2 ½ months of my life rather than wait for you to come out."

"Fine, you can do that. But it's going to be about 10 weeks. We might be able to stretch that and come out in about 6 weeks."

"So why don't I just come down to your office?"

"No, you can't do that. You see, we believe that in order to bring you into the service we need to come out and do a home visit." I live in Watertown. That's about a 25-minute commute on public transit into the Commission for the Blind offices.

I was disappointed at that and decided that I wasn't going to let that hold me back. I was going to look for work. They told me also



about a couple of projects with industries programs, both of whom worked with services in which I did not have training. One offered me an opportunity to take some training and become a telephone operator for an emergency medical system. You push the button and it automatically calls them and you, in turn, send out the emergency medical services. I thought that that wasn't quite what I wanted out of a college education, for which I am still paying loans, and, in fact, I wanted something that took advantage of my education. So I declined that and went out looking.

I eventually found myself a job. Right now I am a computer instructor in microcomputers at the Carroll Center for the Blind in Newton, MA. I am delighted and proud of the fact that I am employed. Yes, it is not in the public sector, but then again, I have only lived in Massachusetts for 6 or 7 months. I suggest to the Massachusetts House, "Watch-out, here I come."

I am fairly pleased with some of the services that i got over the course of my time with the rehabilitation program. I am not ignorant of it. I did serve for 5 years as a member of the Commission for the Blind Board of Directors in the State of Oregon: I am actively involved with the American Council of Blind, a major consumer organization of blind people, and I am on their board of directors. So I know what I'm talking about, both as a consumer and as a person who had to work with and struggle with creating systems that will work.

A 16 percent employment rate among the handicapped community might sound like a wonderful number, but to me that translates as 84 perent unemployment, an inexcusable figure. We need help. I had difficulties, as I described here today, being young and educated. Imagine the troubles for those who are multiply-handicapped; imagine the difficulties for those who are elderly. Sometimes the only way that they can get services is kind of an under-the-table situation. Ask our professional rehabilitators how many people have been closed under homemakers because they couldn't be served any other way.

I urge the committee, Mr. Chairman, and each member, to look carefully at rehabilitation. I would like to see a continuation of the act, naturally, but I also would like it to be looked at and the regulations which carry out the programs examined carefully. We need some more consideration for upward job mobility once you do obtain employment, for continuing employment service, if you need technology, and we need help for the elderly blind and the multiply-handicapped.

Thank you very much.

[The prepared statement of Brian Charlson follows:]

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### PREPARED STATEMENT OF BRIAN CHARLSON

Mr. Chairman: My name is Brian Charlson of Watertown, Massachusetts. I lost my sight at the age of eleven as a result of a household accident. I appreciate the opportunity to discuss with you today some of my experiences as a recipient of rehabilitation services, first in the state of Oregon where I grew up and went to college, then later in the state of Massachusetts to which my wife and I have recently relocated.

The good news is that I am presently employed as a computer training instructor at the Carroll Rehabilitation Center for the Blind in suburban Boston, Massachusetts. The bad news is that I obtained my present job despite the rehabilitation



system. In fact, I am still waiting for a counselor from the Massachusetts Commission for the Blind to make a home visit to open my case file. The Commission advised me that it would take about ten weeks before such a visit could be scheduled. Thus, I got my present job before my rehabilitation case file was even opened.

Please don't misunderstand me! I have found many rehabilitation professionals to be dedicated, committed people who try to serve their clients to the best of their ability, considering their training, experience, and the structures of the federal/ state system. Unfortunately, I have found most rehabilitation counselors to be more concerned with case facilitation (completing the necessary paper work required by the federal/state system), rather than emphasizing meaningful guidance, counseling, and placement services designed to assist a handicapped individual achieve his or her employment objective. Perhaps many counselors are ill equipped to provide such services. In Oregon, for example, the only educational requirement for a rehabilitation counselor or a job developer is a college degree—any kind of a college degree!

But allow me to get back to my own personal story. Prior to my final year of high school, I attended a vocational evaluation program at the Commission for the Blind headquarters in Salem, Oregon. I am sure, Mr. Chairman, that you will be able to identify with my career goal. I wanted to obtain a degree in political science to prepare me to enter public service. The Oregon Commission for the Blind agreed to provide me with reader services and I managed to pay my own tuition at a community college for the first two years of my higher education. I then transferred to Willamette University, a private school in Salem. It was the ideal classroom for me since the campus was located across the street from the state capitol building. I also worked to pay part of my expenses at Willamette. By the time I graduated from college in 1978, I discovered that I was ill prepared to achieve my vocational objective. The Oregon legislature is a part-time governing body and most members of the legislature by necessity have outside full-time employment. I was never advised of this fact when I first discussed my vocational objective with my rehabilitation counselor while still in high school and subsequently agreed to an individual written rehabilitation plan.

habilitation plan. Undaunted, however, I took part-time employment as a staffer with the Oregon legislature. I worked there during the 1979, 1981 and 1983 terms and progressed to the position of assistant sergeant-at-arms, a patronage position lasting six to eight months during each term at a salary of \$860 per month. In 1980 I also worked as a vending facility operator in Oregon's business enterprise program. I thought the vending job would give me the necessary financial base to allow m. to start my political career. It didn't and I returned to the legislature as a staffer during the 1981 term. I also worked between legislative sessions for the city of Salem as a human rights specialist. All of these jobs were obtained through my own efforts without any placement assistance from the Oregon Commission for the Blind.

In 1983 my rehabilitation case was closed. I fought the closure because I felt that In 1983 my rehabilitation case was closed. I fought the closure because I felt that perhaps an advanced degree such as a master's in public administration or public relations would help me to secure full-time employment commencurate with my abilities and interests. Unfortunately, as it turned out, I was employed during the '83 term of the legislature for a period of eight months, which under the Commission's policies, meant that my case file would have to be closed. Oregon closes cases after six months of successful employment. Fronically, both the Commission and I knew that I would be out of work at the end of the '83 term, only two short months later.

I was advised that I would be eligible for post-employment services. Post-employment services consisted of something called "job club," a periodic meeting of blind job seekers at which we could compare notes, feed each others paranoia, etc. It-was very definitely a low cost form of post-placement services—I doubt it cost the Commission for the Blind a dime. Unfortunately, post-employment services did not include such things as resume printing, assistance in developing job leads, or other useful personal marketing assistance. Needless to say, all of this was very discouraging. Although I had done well in school and working for the legislature, I still lacked full-time employment (and for that matter, even the tools to obtain full-time employment). Yet, as far as the Oregon Commission for the Blind was concerned, I was a successful rehabilitation case closure.

In 1984, my wife, who is also blind, was offered a position as assistant director of a library in Massachusetts. We decided to relocate to the East Coast and have resided in suburban Boston since the beginning of this year. I immediately started to look for a job in Boston. I thought that perhaps my

I immediately started to look for a job in Boston. I thought that perhaps my newly found interest in personal computing would help me secure full-time employment. I called the Massachusetts Commission for the Blind to ask their assistance in



updating and printing niy resume. I told them that I was anxious to find work; they told me that it would take ten weeks for a counselor to visit my home to fill out the Commission's applicati. n for service. Keep in mind that my medical records, eye test results, and the like were all part of my case records in Oregon. The Commission did suggest that I call two local Projects With Industry programs for possible job leads. One program offered me an opportunity to train as a telephone operator for an emergency medical response service. I declined the offer, because I felt that I vould be grossly underemployed in such a position; the job was more suitable for a high schoel graduate. Finally, I did find a job as a computer training instructor with the Carroll Rehabilitation Center for the Blind, certainly not a job in public life in line with my vocational objective, but I am working and proud of the fact. Although the Massachusetts Commission had nothing to do with my obtaining my present position, the rehabilitation system will undoubtedly be credited with another "successful" case closure. Remember, I secured the job before the application for rehabilitation service was even filled out. I could have easily gone to the Commission's office in Boston to complete the paper work, but no. They told me to wait; a home visit was mandatory under the Commission's policies.

Mr. Chairman and members of the Subcommittee, I do not think that my frustrating experience with the rehabilitation system is atypical. I have been in a position to see how the system works (and often doesn't work) for many people. I was a member of the board of directors of the Oregon Commission for the Blind from 1979 to 1984. I fully understand many of the problems which I have identified do not have simple solutions. Likewise, as a member of the board of directors of the American Council of the Blind and as state affiliate president in Oregon, I know others have been denied adequate post-placement services or have experienced other difficulties similarto or more egregious than my own. I was lucky because I am young, aggressive, and bright (at least that's what my mother says). Can you imagine, Mr. Chairman, my difficulties with the rehabilitation system if I were old, meek, or just scared. We need to re-think how best to deliver rehabilitation services in this country. The goal has always been employment-but what kind of employment? An entry level job? The system is presently geared to such placements or worse still favors the less expensive homemaker closure. Obviously, the rehabilitation system should not be expected to maintain a handicapped individual throughout his working life. It seems to me, however, to be a matter of degree. An employer may need continuing advice from a rehabilitation agency as a blind employee moves up the career ladder. An agency ought to be expected to provide such assistance and should also be able to participate in creative financing plans where necessary to allow an employee who has inadequate resources to obtain a piece of technology needed for advancement on the job.

How can we solve some of these challenging problems? I think it is more than just a matter of money. The rehabilitation system as well as the consumers it serves should re-examine what we want out of the rehabilitation system. If employment is the goal of rehabilitation—which I think it is—we must decide exactly what that means. We also must train our counselors with an emphasis on the employment objective. I believe that New York University has a rehabilitation training program which offers to its students an internship in business. Such programs should be encouraged and replicated so that rehabilitation counselors will have a better understanding of the needs of business and can thus better advise and place their clients. We must explore better ways for the rehabilitation system to reach out to business so that the rehabilitation counselor can better sell the abilities of his or her clients. Better criteria for provision of post-placement services should be established, more specific than the program guidance presently contained in the RSA manual, in order to insure the uniformity and adequacy of such services. Finally, we need to establish interstate cooperation in the rehabilitation program in order to avoid wasted duplication of time and effort.

Mr. Chairman, we don't have a national rehabilitation program in this country. Rather we have what seems to me to be 53 separate state programs with very little meaningful coordination from the federal government.

Mr. Chairman, I once heard about a T-shirt v hich reads "It's more fun to raise Hell, than to work with the administration." I am a member and director of the American Council of the Blind because that organization believes in solving problems through cooperative effort. I do understand the difficulty faced by the rehabilitation system as it tries to respond to what is perhaps one of the most complex problems facing society today: rehabilitating handicapped persons who themselves are as diverse as humanity itself. We must make the rehabilitation system work better through creativity and innovation. Money is only part of the solution.



Of course this is a challenging task, but I am happy to tell vou, Mr. Chairman, that there are many dedicated people, professionals and consumers alike, who are willing to meet this challenge today so that handicapped Americans can have a better rehabilitation system tomorrow. We look forward to Congress' support and involvement in this endeavor. I will be happy to take questions at this time.

Mr. WILLIAMS. Thank you.

Mrs. Mendelsohn.

Mrs. MENDELSOHN. My name is Helen Mendelsohn and I am from Ellicott City, MD. With me today is my husband, Paul, and my interpreter, Linda Casserly. I appreciate the opportunity to speak with you this morning and relate my experiences with rehabilitation programs.

I recognize that you would like a summary, but because of my handicap, it may take me a little longer. I would appreciate your consideration of allowing me to complete my statement.

I first became aware that I had neurofibromatosis 9 years ago. NF is a genetic disorder of the nervous system in which tumors can form on the nerves anywhere in the bcdy. There is no known cure, and the only treatment is the surgical removal of the tumors; which can reoccur. The nature of this disorder in individuals is variable, with some people only being mildly affected, while others such as myself, develop far more serious conditions.

Until 1976, I was healthy and pursuing a normal lifestyle. I had graduated from the University of Moryland in 1970. I went to work as a bank teller and later as a supervisor of the loan department of a large credit union.

Between 1976 and 198? I had 13 major surgical procedures. Throughout this period, I continued to work and receive excellent job performance evaluations. However, as my condition deteriorated, I was subjected to increasing prejudice and lack of support from my employer. Eventually, after an extended sick leave, my employer denied me job reinstatement.

In 1983, I first came to the Maryland Rehabilitation Center, MRC. I was admitted directly from the acute care hospital after the second brain tumor had been removed. I was now totally deaf and also had difficulties in speech and movement. Congenital cataracts were worsening and my vision was diminishing. For the first time in life, at the age of 32, I found myself unable to walk, talk, or hear. I found myself unable to communicate and physically isolated from the world I had known.

Over the next 9 months I received multidisciplinary services from MRC in a timely and well-coordinated manner. I received services from rehabilitation nursing, occupational therapy, physical therapy, speech pathology, audiology, recreational therapy, the blind unit and driver's education.

When I returned home with the assistance c? Maryland vocational rehabilitation, my husband and I together studied sign language. Today, though neither of us are proficient; we can now communicate without writing notes back and forth.

In the spring of 1983 I returned to MRC-for vocational evaluation. I am now again back at MRC taking a 9-month intensive training program in computer programming. Class is particularly difficult for me. You see, computer technology is a foreign language by itself and I must learn this foreign language through sign lan-



guage. Because I don't get all the information being presented in the class, I must study especially hard each evening and on the weekends. I review not only my reading material but also rely on notes taken by fellow classmates.

Because I felt I was missing much material, I requested a tutor. Because I am serious in my pursuit of success, MRC has attempted to accommodate me in every way possible.

We, the handicapped, are part of this world and we should not be ignored or pushed aside. We can do almost everything given some consideration and opportunities.

I am very fortunate to be a resident of Maryland. It is only 1 of 10 States with a rehabilitation center. I can't imagine where I would be today if I had not had the fortune to come to the rehab center.

My experience with the vocational field office was far less satisfactory. It wasn't a lack of desire to assist that created problems. Rather, unreasonable caseloads and ill-trained counselors frustrated reasonable attempts to provide services. Equipment purchases to help a person accommodate their homes to meet the needs of their handicap are often delayed by burdensome red tape. Furthermore, ignorance of the nature and needs of different handicaps often creates more problems than assistance for the clients.

In my particular situation, a deafened young adult has far different problems than those persons who have been deaf their entire lives. Such people need communication assistance, social and psychological support, and special equipment to make their homes functional. A deafened adult comes from a hearing world and not from the typical deaf community. All too often this fact is not recognized.

Also, rehabilitation programs often are constrained by laws and regulations which defeat their intention. The nature of disability benefits, including Medicare and Social Security disability insurance, SSDI, often discourage clients from seeking rehabilitation for two major reasons.

First, handicapped people with SSDI and Medicare are frequently afraid to enter a job market where they may not have adequate health insurance or make incomes which are adequate to support their increased expenses.

Second, we are afraid to try to return to work in the event that if we do not succeed we will have difficulty returning to the SSDI rolls. Unfortunately, we can no longer trust the Government to make appropriate determinations.

Those people such as myself who have the opportunity to take advantage of facilities such as MRC build upon their own self-respect and self-worth. We also develop from our experiences working together and gain a real admiration for what handicapped people really can be—warm, caring, funloving and hard-working individuals who offer to their community a valuable resource.

Because of MRC, I am like a newborn baby. I have learned to walk and talk and, again, be myself.

I strongly encourage this committee to continue its work to promote and maintain rehabilitation services throughout the country. I request that you also seek to expand and promote the rehabilitation system so that the clients will seek such services.



# Thank you again for this opportunity to address you. [The prepared statement of Helen Mendelsohn follows:]

## PREPARED STATEMENT OF HELEN MENDELSOHN

My name is Helen Mendelsohn and I am from Ellicott City, Maryland. With me today is my husband. Paul, and my interpreter, Linda Casserly. I appreciate the opportunity to speak with you this morning and relate my experiences with rehabilitation programs.

I first became aware that I had Neurofibromatosis (NF) nine years ago. NF is a genetic disorder of the nervous system in which tumors can form on the nerves anywhere in the body. There is no known cure and the only treatment is the surgical removal of the tumors which can reoccur. The nature of the disorder in individuals is variable, with some people only being mildly affected while others such as myself develop far more serious conditions. Furthermore, the course of the disorder over a lifetime, and the prognosis for individuals with NF is progressive though unpredictable.

Until 1976, I was bealthy and pursuing a normal lifestyle. I had graduated from the University of Maryland with a degree in secondary education but, because at that time the market for teachers was saturated in my area, I went to work in the banking industry, first as a teller and later as the Supervisor of the Loan Department of a large credit union.

In 1976, I discovered I had no hearing in my left ear. Subsequent medical tests demonstrated tumors on both acoustic nerves in my brain. I was told that one tumor was to be removed immediately and that the second tumor would need to be removed in the near future. I was told that when the second tumor was removed I would be totally deaf.

Over the next six years, I had 13 major surgical procedures removing tumors on my arms, spine and other areas of my body. Throughout this period I continued to work and receive excellent job performance evaluations. However, as my condition deteriorated, I was subjected to increasing prejudice and lack of support from my employer. Eventually, after an extended sick leave, my employerdenied me job reinstatement.

In 1983, I first came to the Maryland Rehabilitation Center (MRC). I was admitted directly from the acute care hospital after the second brain tumor had been removed. In addition to being totally deaf now, I also had other complications as a result of surgeries. I had difficulties in speech and in movement. Furthermore, probably because of medications I had received, congenital cataracts were worsening and my vision was diminishing. Every sensory and motor area of my body was damaged. For the first time in my life, at the age of 32, I found myself unable to walk, talk, or hear. I found myself unable to communicate and physically isolated from the world I had known.

I received multidisciplinary services from MRC in a timely and well-coordinated manner. I spent nine months at MRC at that time and received services from rehabilitation nursing, occupational therapy, physical therapy, speech pathology, audiology, recreational therapy, the blind unit and driver's education.

ogy, recreational therapy, the blind unit and driver's education. With the support of my husband, I returned to manage our home and to plan for my future. With the assistance of Maryland vocational rehabilitation, my husband and I together studied sign language. Today, though neither of us is yet proficient, we can communicate without writing notes back and forth. In the Spring of 1984, I returned to MRC for Vocational Evaluation. I am now

In the Spring of 1984, I returned to MRC for Vocational Evaluation. I am now again back at MRC taking a nine month intensive training course in computer programming. In my class are 20 very intelligent and motivated people. We all are classified as severely disabled, but we are all dedicated to returning to society as productive individuals.

Class is particularly difficult for me. Computer terminology is a foreign language by itself, and I must learn this foreign language through sign language. Because I don't get all the information being presented in the class, I must study especially hard each evening and on the weekends. I review not only my reading material, but also rely on notes taken by fellow classmates.

Because I felt I was missing much material, I requested a tutor who now spends two hours with me three evenings each week. Because I am serious in my pursuit of success, MRC has attempted to accommodate me in every way possible.

I realize that because of this special attention, I am a "more expensive" client. But when I finish this course, I intend to return to work and again be a contributing taxpayer. And with my success, I would hope that other clients will be given similar opportunities. I believe that too often clients such as myself are denied access because of short-term economic considerations.

We, the handicapped, are a part of this world, and we should not be ignored or pushed aside. We can do almost anything if we are afforded some consideration and appropriate opportunities.

I am very fortunate to be a resident of Mary'and, since few states offer the kind of comprehensive vocational rehabilitation services available at MRC. I can't imagine what I would be today if I had not had the fortune to come to the Maryland Rehabilitation Center.

But there is another side of the story and that is the field operations area. My experience with the vocational field offices was far less satisfactory. It wasn't a lack of desire on the part of rehabilitation personnel to assist that created problems. Rather, unreasonable caseloads and ill-trained counselors frustrated reasonable attempts to provide adequate and appropriate services. Equipment purchases to help individuals accommodate their homes to meet the needs of their disabilities are often delayed by burdensome red tape. Furthermore, ignorance of the nature and needs of different handicapping conditions often creates more problems and hinders adult has far different problems than those of a person who has been deafened young abut has far different problems than those of a person who has been deaf for his or her entire life. Such people need communication assistance, social and psychological support, and special equipment to make their homes functional. Often, family sup-port services are required. It does little good to teach sign language to an individual without providing similar training to that person's family. A deafened adult comes from a hearing culture and not from the typical deaf community. All too often this fact is not recognized.

Also, rehabilitation programs often are constrained by laws and regulations which defeat their purposes. The nature of disability benefits, including Medicare and Social Security Disability Insurance (SSFI), often discourage clients from seeking rehabilitation for two major reasons:

First, handicapped people with SSDI and Medicare are frequently afraid to enter a job market where they may not get adequate health insurance or make incomes which are adequate to support their increased expenses. Secondly, and particularly in the recent climate, we are afraid to try to return to

work in the event that if we do not succeed in the workplace we will have difficulty returning to the SSDI roles. Unfortunately, we can no longer trust the Government to make efficient and appropriate determinations.

We hear few advertisements or promotions for vocational rehabilitation. Because it costs States money for every new client, very few governments seek out clients. Also, because of overwhelming caseloads and quotas for closing cases, many difficult cases are dissuaded or "closed-out" without due attention and consideration.

Those people such as myself who have the opportunity to take advantage of facilities such as the Maryland Rehabilitation Center build upon their own self-respect and self-worth. We also develop from our experiences working together and gain a real admiration for what handicapped people really can be—warm, caring, fun-loving and hard-working individuals who offer to their community a valuable resource.

Like a newborn baby, the Maryland Rehabilitation Center has taught me to walk and talk and, again, be myself.

I strongly encourage this Committee to continue its work to promote and main-tain rehabilitation services throughout the nation. I request that you also work to expand and promote the rehabilitation system so that more individuals will be en-couraged to seek the services they need and so that appropriate services will be available to them.

Thank you again for this opportunity to address you.

## HONORING HELEN FOR WORK AND SERVICE

## (By Nancy Robinson)

"Helen Mendelsohn has some Gandhi in her, a lot of Helen Keller, some Lou Gehrig, some Sister Theresa, a whole lot of John Merrick and a little or a lot of any of your own personal heroes and heroines who demonstrate the courage and will to overcome adversity," said Fred Neil of the Maryland Rehabilitation Center (MRC). Mendelsoh:, a 35-year-old Ellicott City woman with several disabilities, recently received the William W. Lamprell Award as MRC's Alumnus of the Year. Neil's abapted the William W. Lamprell Award as MRC's Alumnus of the Year. Neil's

characterization of Mendelsohn refers to John Merrick, who is better known as the



"Elephant Man," because the local woman has the same condition from which he suffered. Called neurofibromatosis (NF), the genetically inherited disorder causes tumors to form on nerves in the body. The tumors, which may reoccur, can be removed only by surgery.

When she came to the rehabilitation center, Mendelsohn needed comprehensive services to resume an independent life. Since developing NF in her college years at the University of Maryland, she had undergone several operations to remove the tumors. The surgery on a tumor on the acoustic nerve cost Mendelsohn her hearing and resulted in other difficulties in coordinating speech and movement. She also had congenital cataracts.

However, the pluck woman set her goals—to take care of her home again and go back to work—and plunged into the MRC program. Day by day she worked hard to regain strength and coordination and adjust to deafness through occupational, physical and speech therapy.

"It is not that often that we at MRC actually get to follow through and watch the growth of our clients all the way through the rehabilitation process. Helen was the exception. We started her rehabilitation program and she showed us what she could do]" said another MiC spokesperson.

As she made progress on regaining skills, Mendelsohn has reached out to help others. In the late 1970s, she helped found the local VF chapter. Now, she attends meetings with an interpreter and, with her husband Paul, is trying to locate and counsel others with NF-caused deafness.

After returning home, Mendelsohn attended Gallaudet College last summer. She is an officer of the Baltimore based Council of Organizations of the Deaf and is a volunteer with deaf seniors at the Waxter Center in Baltimore. She is currently working on a book about practical ways to cope with deafness.

Mendelsohn is one of 10 graduates of this year's MRC program.

Mr. WILLIAMS: Thank you very much.

The first panel that we had, representing the Council of State Administrators, while in no way indicating that all was well within the rehabilitation community, did not have any specific recommendations for chai. In fact, when asked specifically if they had any, each of the members of that panel indicated no, they would prefer to see the act reauthorized virtually as is.

While we cannot expect that the consumers might have, at least at this hearing, specific recommendations for changes in the act, let me nonetheless ask that question, starting with you, Ms. Spivack. Do you have any specific recommendations for changes?

vack. Do you have any specific recommendations for change? Mrs. SPIVACK. Well, I don't know whether it would be specific recommendations for changes, but the very reason that we became involved and required a cooperative agreement was the fact that our population has very specific problems within the system. No. 1, the system—as I said, it's a new population and the needs are very specific. So we desperately need that training.

We have a problem in terms of the diagnosis of head trauma. Particularly mild head injury rehabilitation is not appropriate in a minimum length of time. All clients are not going to see 26 closures, so to speak. So we have a definite problem there.

Our constituents have the very same problem that Ms. Presson described in her testimony. Our people have been dead-ended, unfortunately, and we know through the establishment of programs in the private sector, indeed, these people can go back to work. I will say within the recognition of some of the States that have become involved with the head injury associations, we are beginning to see a difference in terms of at least a statement being made that yes, it is a new disability and we are going to try and address those needs. So we have a great deal of hope for the future. We have had too much dispair in the past.



Mr. WILLIAMS. Ms. Presson, you indicated significant concerns, and rather specific concerns, with the service. If you could make some a couple of changes in the act, what would they be?

Ms. PRESSON. Well, let me talk, number one, for epilepsy, because that's what I have. But my daughter is very handicapped. The biggest thing I would like people to know about epilepsy and montal retardation is that we are not mentally ill. We need some of the same benefits, but we can work and we can do well. The trouble is, we are ostracized because when you have a handicap that has the word "mental" in it—and that goes for those who are mentally ill also—right there you are stereotyped. I don't like it and I hope it will not continue. We need to educate every counselor there is in the various handicaps. A!though it would additional training, take it's absolutely worth it.

The other thing is that more funds are needed from the Federal Government. What better source. Let's take a look at our Constitution. We need money to go out and train these people. We also need the money for tax purposes, to give industry a tax break to hire us. If that is the only way we're going to get a job in private industry, I, for one, am going to take it. Every industry, whether it is General Motors or any other big ones, could be given a tax break to hire us—and some of them are. I know some of them are doing it. But it needs to be bigger and it needs to be better. I think that is an idea way to get some of us in. If for no other reason than to show people, "Hey, we're OK and we can do just as well as anybody else."

The Government, too, has a little problem in hiring us. If we can't quite live up to what a PD stands for in the Government, of course, we're fired. This makes it very difficult.

Also, not just educated along with the handicapped we have, whether we're in a wheelchair and they see us in our wheelchair, or whether we have a sign reader, please educate them psychologically. You don't know that when we lose a job, for me it causes more seizures. Emotionally, I know when I can't pay my bills and I can't take care of myself personally, then my seizures are rampant. Sure it is psychologically caused, but that's the nature of the beast. When I can't work I'm pretty upset. I think that goes for all the others as well. The disease becomes far worse when they don't understand psychologically.

Also, when counselors go out to look for a placement for us; they should fully realize the content of the job. If there is any probability that we might not fit, or that we are able to get education so we will fit. I think it's imperative. I saw one the other day come into our building to see about a person's job, and all they were interested in was seeing the building. Well, that's nice. I'm glad the building is standing. But look into it both psychologically, neurologically, every way that is needed for that person. Make that personeven though you have 50 or 80 clients—at that point make your client feel that they are the only person that matters to you and that you're going to do the best for them.

I'm not saying that all counselors are bad. I have had a great one. I put mine on a silver platter. But what I'm saying is, because they're so crowded, because there are not enough of them, that



they are so overloaded they can't (ake individual interests. So there has to be more money spent.

It looks like to me they get a report card, and they get to paint a gold star above their names if they get these people jobs. Well, I like to be patted on my back, too. But I don't want to feel that I need that patting on the back so badly that I'm going to destroy a person doing it. I think we have lost it somewhere along the line, when that gold star for rehab is better than getting that person a job that they're going to live with for the next 20 years.

Mr. WILLIAMS. You know, Ms. Presson, it is difficult for the Federal Government to eliminate biases, prejudices, practices of stereotyping among the American public. I personally believe that the Federal Government can be America's great teacher and can establish the model by which many Americans will set their goal. However, it is very difficult for the Federal Government to find a way to legislate against stereotyping and prejudices. So some of the very legitimate instances of difficulty that you express can only be dealt with in probably a limited way by the Federal Government.

With regard to the problem that you have seen with some of the counselors, some of that perhaps can be laid at the door of the legislation, and particularly the appropriation, which may not allow the local agencies to hire an appropriate number of counselors.

However, here at the Federal level we aren't involved in micro management. We aren't involved in training counselors. We aren't involved in the quality of counseling in these various agencies. We can't deal in that detail at this level, nor should we.

We tried to write the legislation in a way that might end stereotyping and might create quality counselors, but to absolutely guarantee you that we can rewrite the Vocational Rehabilitation Act in such a way as to eliminate those difficulties would be to mislead you.

Ms. PRESSON. I don't mean that, sir. But what I do mean is, if we have money for the U.S. Army, the U.S. Navy, the U.S. Air Force, to put ads on television 24 hours a day to show how great they are; we have money to show how great we are.

Mr. WILLIAMS. I agree with that. As I say, I think part of the problem that you're relaying to us can be resolved with adequate appropriation.

With regard to defense spending, one finds very quickly, when you go into service on the Budget Committee, that the wealth of this Nation, is not infinite, nor is the patience of the American taxpayer. But having said those two things, one of the things that becomes clear to all of us as members of the Budget Committee is that the breadth and depth of wealth in America—and I speak not just now of the Federal Treasury—is astonishing. The amount of money in the Federal Treasury is astonishing. What the Federal Treasury needs is not necessarily more money—although that's debatable in some quarters—what we need is a readjustment of the American will to decide where that money shall be placed.

Now, we are here today debating and pleading and poale cing around an amount of money that totals just slightly more than a billion dcllars. If we started the Pentagon spending clock ticking at dawn this morning, by the time we reach this time tomorrow the Pentagon will have spent all of the money that you are requesting for the coming year. So it really is a matter of the Nation's will as much as it is a matter of the Nation's wealth. So your remarks about the Pentagon spending are well taken, at least by this chairman.

Mr. Charlson, any specific recommendations for us, sir?

Mr. CHARLSON. Mr. Chairman, I have several that I would like the committee to consider. They may not, in fact, be part of the act itself. They may be a matter of how the act is interpreted by RSA. I know, for example, there is a manual which deals with what is actually meant by post-employment services. Yet, after taking a look at that, and taking a look at what I've seen in two States dealing with that subject—in fact, three States, because my wife—we laughingly referred to ourselves as 52's. I've been closed in Oregon and closed in Massachusetts. My wife has been closed in Oregon and closed in Texas. So we amount together to 104, which is wonderful a number for rehab.

But we are really concerned that every time we came to a postemployment question, the services as far as the job club kind of things were there, but when it came to a simple thing as getting a resume produced so that it looks professional, and duplicated and distributed in a way that would be helpful in getting employment, that was not forthcoming. My wife was able to receive a Brissa Braille machine. That runs about \$6,700. I wasn't able to get \$20 to duplicate my resume. I do not understand that rationale and I think it deals with the post-employment service.

As a young person, I am naturally interested in employment. But I am also interested in the dignity of human life, and that with an undoubted majority of the blind people in this country beyond employment age, they have earned the right to services from their Government, the Government that they paid into for those working years. So I think that is a very high priority and should be dealt with, not just in funding but in appropriate type programming for that.

Naturally I am also interested in whatever mechanism we can do and promote that will allow consumers such as myself to have an impact on the quality of these services in our States. If the Rehabilitation Act is not the place to touch base and make sure there is postemployment services that are appropriate, that make sure when you get counseling it's from a qualified counselor and not from a person who knows how to fill out the forms properly, then we need some way of getting the consumers into the system to make sure those individual systems do their job.

In my mind, the Client Assistance Program is the answer to that. But the client assistance project is such a spotty thing at this point, and the funding is so temporary in nature, that I'm not sure that without some changes in the Rehabilitation Act that that's possible.

For example, in the State of Massachusetts the client assistance project is paid for through State funds, 100 percent at this point. Also, I found during the course of my time in being an advocate for consumers, that client assistance project employees spend a great deal of their time working for the administrator of the agency in developing opinion papers and the like, rather than advocating for individual clients. Oftentimes in discussion with them I find they

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are promoting the opinion of the agency rather than trying to see about how the individual client can be served.

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So those are three areas that I think maybe this committee can

Mr. WILLIAMS. Thank you.

Finally, Miss Mendelsohn.

Mrs. MENDELSOHN. I would like to see some minimal qualifications for rehab counselors. That seems to be the root of the real problem. Their ignorance of various handicaps has created a lot of problems. So many people don't know about us and, really, the Government doesn't know what they're doing. There needs to be some guidelines, minimum guidelines, to be sure the States are doing what they're supposed to do.

Thank you:

Mr. WILLIAMS. My thanks to each of you. We very much appreciate your testimony.

We will move now to the Assistant Secretary for Special Education and Rehabilitative Services, representing the Department of Education, Ms. Madeleine Will.

Ms. Will, it is a pleasure to have you with us today. We have your prepared statement which, of course, will be entered into the record. You may proceed as you wish.

## STATEMENT OF MADELEINE C. WILL, ASSISTANT SECRETARY FOR SPECIAL EDUCATION AND REHABILITATIVE SERVICES, U.S. DEPARTMENT OF EDUCATION

Ms. WILL. It is a privilege to appear before the committee to present testimony regarding the reauthorization of the Rehabilitation Act of 1973. I think I will try to go through my testimony quickly.

The Federal/State Rehabilitation Program is one of the oldest Federal service programs in the United States. It had its beginnings with the Smith-Fess Act of 1920. During the past 65 years, the program has dramatically changed.

Changes in society's attitudes toward disabled persons have also brought changes in the Rehabilitation Program. As society accepted more assimilation of disabled persons into the community, disabled individuals returned to the workplace. Rehabilitation of disabled persons took on a new meaning. It was no longer a matter of doing something good on behalf of a handicapped person.

The Rehabilitation Act was last addressed by Congress in 1983-84 with the enactment of the 1984 amendments. A number of new provisions were introduced at that time. I have chosen to spend time this morning addressing those aspects of the program which were introduced for the first time in 1984.

The following is a list of the program items which were introduced in the 1984 amendments, or which were newly funded subsequent to that:

First, the changes in the Client Assistance Program to require it to operate outside of the VR general agency except in those instances where a CAP had previously been operated by a State agency.



Second, a requirement of a justification for the allocation of training funds.

Third, requirement for evaluation studies and the development of standards in the independent living and PWI programs.

Fourth, the authorization to include independent living and client assistance personnel in the RSA-Supported Training Program.

The requirement that information on section 504 of title V be included in the RSA training programs.

Authorization to continue research and training centers without competition, under certain circumstances.

Authorization of a new program of grants to test innovative ideas, to be administered by the National Institute of Handicapped Research.

Mandated continuation of all PWI and independent living projects through fiscal year 1986.

And, finally, specifications with regard to information in the data collection system for the annual report.

I would like to touch briefly on the operation of the State program before I get into the details of the 1984 amendments. The mission of the Rehab Services Administration is to assure that the basic statutory program of comprehensive and individualized rehabilitation services is properly administered by State agencies. State funds for these programs provide a 20-percent match against Federal funds.

The Vocational Rehabilitation Basic State Grant Program provides for a broad array of services to disabled persons. This Federal/State program constitutes the core of the public rehabilitation services delive y network in the United States. The Rehabilitation Services Administration in recent years has worked aggressively to improve the quality of services and program management in the national programs resulting from legislative amendments.

One requirement of the Rehabilitation Act is that a priority for services be given to severely disabled persons. Since 1973, the program has become increasingly responsive to the needs of severely disabled individuals. Approximately 32 percent of the persons rehabilitated in 1974 were considered severely disabled. In 1984, this figure has risen to nearly 60 percent.

The number of persons rehabilitated increased by 4.4 percent in 1984 over the previous year. The 1984 increase in rehabilitations of severely disabled persons increased during the same year by 6.8 percent. The percentage of successful case closures also rose from 61.7 percent in 1983 to 63.2 percent in 1984. The RSA emphasis on placement services is believed to be one of the factors leading to these improved statistics.

RSA continues to promote improved vocational outcomes for handicapped individuals by encouraging State VR agencies to enhance their job development efforts, job placement practices, and their efforts to work more directly with private businesses and industries.

Over the past several years, RSA has placed a high priority on activities that assist State agencies to improve their management operations to provide services more efficiently and effectively. Ini-



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tiatives taken by RSA have included the development and implementation of the management control project in various States.

Leadership conferences, inservice training and technical assistance have combined to assist the State to provide better services more efficiently. There is reason to be proud of our accomplishments and the people who make it happen.

I would like now to address the changes made by the 1984 amendments. In the Client Assistance Program, the administration of this program was placed in the State VR agency. The language of the act required that it be "funded, administered, and operated directly by and with the concurrence of the State agency" designated elsewhere in the act. This was considered a discretionary pilot program and not required for each State. The 1984 amendments require that this program exist in every State as a condition of receiving basic State grant funds and that it be conducted by an agency independent of the State rehabilitation agency; except in those States which have previously operated such programs in the State agency.

As a result of this change from a discretionary grant program to a formula grant program, grants totaling \$6 million were awarded to the 50 States, the District of Columbia, and the territories. Final regulations were published in March and plans are now underway to solicit applications for 1986 funds in advance of actual appropriations to facilitate program continuity. Eighty-five awards have been made this past month:

An evaluation of the Client Assistance Program was initiated in October 1984. Standards required by the act for this study have been developed and are available with the advice and guidance of the CAP Advisory Committee. A revised version of these standards will be forwarded to the Office of Management and Budget for review.

Two, training allocation. For many years RSA has been concerned about procedures used to allocate its training funds among various professional disciplines listed in the act. The 1984 amendments require that the Commissioner submit to Congress a report setting forth and justifying in detail how the training funds are allocated by professional discipline. RSA must take areas of personnel shortage into account.

A sound training allocation system should go beyond the issue of shortages. RSA is interested in the relevance of specific fields to the rehabilitation of disabled persons, the importance of specific services to the employability of disabled persons, and the need for Federal funds relative to the availability of alternative non-Federal funding sources for the same programs. We believe a priority system should point out areas where Federal funds are most needed to bring about the goal of returning disabled persons to full employment and enabling young school leavers to enter employment.

We have contracted with a private corporation to develop procedures which will be helpful in the development of an allocation system. The results of this study will be available to us early next year.

Three, independent living and PWI standards and evaluation. These programs were required by the 1984 amendments. We are to



have standards and to use these standards for a system-wide evaluation. In the meantime, all projects funded under these two programs were required to be continued through September 1986. I am pleased to report that standards have been developed for both programs. They have been reviewed and approved by the National Council on the Handicapped.

The evaluation of both programs is on schedule. As soon as the data forms are cleared, the data will be gathered.

Fcur, training of independent living center and client assistance personnel. The 1984 amendments authorized recipients under the RSA Training Program to include independent living center and client assistance personnel as eligible recipients for training under this act. In fiscal year 1985, RSA will support such training designed to upgrade the management skills and knowledge of administrators of independent living programs. In 1986, it is planned that RSA will support a project to train personnel to function effectively in client assistance programs.

Five, inclusion of training in section 504 in vocational counselor training programs. In 1985 the regulations for long-term training grants are being changed to require recipients of 1985 grants to include curriculum content covering the provisions of section 504 of the Rehabilitation Act. In addition, RSA has identified section 504 content as a priority for the continuing education programs supported by this agency.

Six, noncompetitive funding of the research and training centers. In accordance with statutory change, NIHR has regulations for standards and procedures for renewal without competition under certain limited circumstances.

Seven, new NIHR research program. A new authorization was provided to NIHR to make innovation grants up to \$50,000 in 1984. Final regulations for this program were published in April with applications accepted until July. Applications are on hand and are being reviewed.

Eight, continuation of independent living and PWI programs. One final change in the 1984 amendments required that all awards for Centers for Independent Living and Projects With Industry be continued through September, 1986, unless a recipient has substantially failed to comply with its approved application. This has been done. Each project under these two programs will be competing for funds starting with fiscal year 1987.

Nine, report data. A reporting system was developed to meet the reporting requirements under section 13 of the act. This is the Program Impact Reporting System, or the RSA-911, which contains all of the data elements listed in section 13, and a few others needed for purposes of case control, identification and management. The system was initially sent to the Office of Management and Budget on December 18, 1984.

Although not specifically referenced in the 1984 amendments, RSA did receive approval in the appropriations process to implement the new Supported Employment Program. This is one of the most important programs to be launched this year. Over the past 10 years, a few researchers were able to demonstrate that society has generally underestimated the abilities of severely disabled persons to work, earn substantial incomes, and to contribute to society



and their own independence. Previously, disabled workers had been assessed prior to providing them with training, and they were found to be too limited to be productive.

What these researchers demonstrated quite clearly was that training made a difference between employability and a life of welfare. They pointed out that many disabled individuals can work very effectively, but that they frequently need some kind of support system. Whether this be in a semi-sheltered environment or in a competitive job, they are likely to encounter problems without guidance, assistance, or just someone to trouble-shoot with an employer. Initial calculations by these researchers indicate that these programs were less expensive than full-time placement in a setting which encouraged dependency.

With this information so well documented by several independent researchers working in widely separated areas of the country, it is important to address the issue directly on an expanded basis. We have asked for and received the appropriations needed. We expect to have final regulations for this program and our first grant award competition announcement published in the Federal Register very, very soon.

I appreciate the opportunity to go over these changes with you and to summarize the operations of the basic State grant program. I would be pleased to answer questions.

## [The prepared statement of Madeleine C. Will follows:]

## PREPARED STATEMENT OF MADELEINE C. WILL, ASSISTANT SECRETARY FOR SPECIAL EDUCATION AND REHABILITATIVE SERVICES, U.S. DEPARTMENT OF EDUCATION

Mr. Chairman and Members of the Subcommittee: It is a privilege to appear before the committee to present testimony regarding the reauthorization of the Rehabilitation Act of 1973. The Federal/State rehabilitation program is one of the oldest Federal service programs in the United States. It had its beginnings with the Smith-Fess Act of 1920. During the past 65 years, the program has dramatically changed. Changes in medical and prosthetic technology, and pharmacology, have significantly modified the emphasis of this program to those with more severe disabilities from individuals with relatively minor disabilities. Changes in society's attitudes toward disabled persons have also brought signifi-

cant changes in society 5 attitudes toward disabled persons have also in ought organized more assimilation of disabled persons into the community, disabled individuals returned to the work-place. Rehabilitation of disabled persons took on new meaning. It was no longer a matter of doing something good on behalf of a handicapped person.

The Rehabilitation Act was last addressed by Congress in 1983-84 with the enactment of the 1984 amendments. A number of new provisions were introduced at that time. Although I could spend considerable time discussing the program as a whole, I have chosen to spend this morning addressing those aspects of the program which were introduced for the first time in 1984. I will also touch briefly on how well the State program is working.

The following is a list of the program items which were introduced in the 1984 amendments, or which were newly funded subsequent to that.

1. Changes in the Client Assistance Program to require it to operate outside of the VR general agency except in those instances where a CAP had previously been operated by a State agency.

2. A requirement of a justification for the allocation of training funds.

3. Requirement for evaluation studies and the development of standards in the programs for Independent Living and Projects With Industry. 4. Authorization to include independent living and client assistance personnel in

the RSA supported training program.

5. Requirement that information on Section 504 (of Title V of the Act) be included in RSA training programs.

6. Authorization to continue Research and Training (R&T) Centers without competition, under certain circumstances.



7. Authorized a new program of grants up to \$50,000 to test innovative ideas, to be administered by the National Institute of Handicapped Research.

8. Mandated continuation of all PWI and Independent Living projects through Fiscal Year 1986.

9. Specified the information to be included about each State program in the annual report.

#### THE FEDERAL/STATE PROGRAM

I would like to touch briefly on the operation of the State program before I get into the details of the 1984 amendments. The mission of the Rehabilitation Services Administration is to assure that the basic statutory program of comprehensive and individualized rehabilitation services is properly administered by State agencies. State funds for these programs provide a 20% match against Federal funds.

The Vocational Rehabilitation Basic State Grant Program provides for a broad array of services to disabled persons. This Federal/State program constitutes the core of the public rehabilitation services delivery network in the United States. The Rehabilitation Services Administration in recent years has worked aggressively to improve the quality of services and program management in the national programs resulting from legislative amendments in 1974, 1978, and again in 1984.

One requirement of the Rehabilitation Act of 1973 is that a priority for services be given to severely disabled persons. Since 1973, the program has become increasingly responsive to the needs of severely disabled individuals. Approximately 32% of the persons rehabilitated in 1974 were considered severely disabled; in 1984 this figure had risen to nearly 60%

The number of persons rehabilitated increased by 4.4% in 1984 over the previous year. The 1984 increase in rehabilitations of severely disabled persons increased during the same year by 6.8%. The percentage of successful case closures also rose from 61.7% in 1983 to 63.2% in 1984. The RSA emphasis on placement services is believed to be one of the factors leading to these improved statistics

RSA continues to promote improved vocational outcomes for handicapped individuals by encouraging State VR agencies to enhance their job development efforts, job placement practices, and to work more directly with private businesses and industries. As this continues, we expect our statistics to improve even more in the future.

Over the past several years, RSA has placed a high priority on activities that assist State Agencies to improve their management operations to provide services more efficiently and effectively. Initiatives taken by RSA have included the development and implementation of the Management Control Project in 12 States, the systematic use of a client Case Review Schedule in State operations and the approval and acquisition of data processing systems at the Federal, Regional and State level. Leadership conferences, in-service training, and technical assistance have com-

bined to assist the states to provide better services more efficiently. There is reason to be proud of our accomplishments, and the people who make it happen.

#### CHANGES FOLLOWING THE 1984 AMENDMEN'S

I will now address the various changes made by the 1984 Amendments. 1. Client Assistance Program. The 1984 Amendments significantly changed the management of the Client Assistance Program. Previously, the administration of this program was placed in the State VR agency. The language of the Act required that it be "funded, administered, and operated directly by and with the concurrence of the State agency" designated elsewhere in the Act. Furthermore, this was considered a discretionary pilot program, and not required for each state. The 1984 amendments required that this program exist in every State, as a condition of re-ceiving basic State grant funds and that it be conducted by an agency independent of the State Rehabilitation Agency, except in those states which have previously op-

erated such programs in the State agency. As a result of this change from a discretionary grant program to a formula grant program, grants totaling \$6,000,000 were awarded in August and September of 1984 to fifty States, the District of Columbia, and each of the Territories. Final regulations governing the new program were published on March 12, 1985. Plans are now underway to solicit applications for 1986 funds in advance of actual appropriations to facilitate program continuity into the next fiscal year

An evaluation of the Client Assistance Program was initiated in October of 1984. Standards required by the Act for this study have been developed with the advice and guidance of the CAP Advisory Committee. A revised version of these standards is under review and will be forwarded soon to the Office of Management and Budget for review of the survey instruments. The required study will be completed in De-



cember of 1985. At that time, it will be possible to assess the costs and benefits of this new program and describe the program's characteristics.

2. Training allocation. For many years RSA has been concerned about procedures used to allocate its training funds among various professional disciplines listed in the Act. The 1984 amendments required that the Commissioner submit to Congress "a report setting forth and justifying in detail how the training funds ....." are allo cated by professional discipline and other program areas. RSA must take areas of personnel shortage into account.

A sound training allocation system should go beyond the issue of shortages. RSA is interested in the relevance of specific fields to the rehabilitation of disabled persons, the importance of specific services to the employability of disabled persons, and the need for Federal funds relative to the availability of alternative non-federal funding sources for the same programs. We believe a priority system should point out areas where Federal funds are most needed to bring about the goal of returning disabled persons to full employment, and enabling young school leavers to enter employment.

We have contracted with a private corporation to develop procedures which will be helpful in the development of an allocation system. The results of this study will be available to us early next year.

3. Independent living and PWI standards and evaluation. These programs were required by the 1984 amendments to have standards developed for them, and to use these standards for a system-wide evaluation. In the meantime, all projects funded under these two programs were generally required to be continued through September 1986. I'm pleased to report that standards have been developed for both pro-grams. These were submitted to the National Council on the Handicapped, as required by law, and approved by that body. The evaluation of both programs is on schedule. As soon as the data forms are

cleared by the Office of Management and Budget, the data will be gathered

4. Training of independent living center and client assistance personnel. The 1984 amendments authorized recipients under the RSA training program to include Independent Living Center and client assistance personnel, as eligible recipients for training under this Act. In Fiscal Year 1985 RSA will support such training designed to upgrade the management skills and knowledge of administrators of CIL programs. In 1986, it is planned that RSA will support a project to train personnel to function effectively in client assistance programs. 5. Inclusion of training in section 504 in vocational counselor training programs.

In FY 1985, the regulations for long-term training grants are being changed to re-quire recipients of FY 85 grants to include curriculum content covering the provisions of Section 504 of the Rehabilitation Act. In addition, RSA has identified Section 504 content as a priority concern for the continuing education programs supported by this agency.

6. Non-computitive funding of R&T Centers. In accordance with statutory change, NIHR has regulations for standards and procedures for renewal without competition under certain limited circumstances.

7. New NIHR research program. A new authorization was provided to NIHR in 1984 to make innovation grants up to \$50,000. Final regulations for this program were published in April, with applications accepted until July. Applications on hand are being reviewed.

8. Required Continuation of CIL and PWI programs. One final change in the 1984 amendments required that all awards for Centers for Independent Living and Projects With Industry be continued through September 30, 1986, unless a recipient has substantially failed to comply with its approved application. This has been done. Each project under these two programs will be competing for funds starting with FY 87

9. Report data. A reporting system was developed to meet the reporting requirements under Section 13 of the Act. This is the Program Impact Reporting system (RSA11) which contains all of the data elements listed in Section 13, and a few others needed for purposes of case control, identification, and management. The RSA-911 system was initially sent to the Office of Management and Budget on December 18, 1984:

## SUPPORTED EMPLOYMENT

Although not specifically referenced in the 1984 amendments, RSA did receive approval in the appropriations process to implement a new Supported Employ.nent Program. This is one of the most important programs to be launched this year, and I want to take a few minutes to discuss it in more detail. Over the past ten year, a



few resarchers were able to demonstrate that society has generally underestimated the abilities of severely disabled persons to work, to earn substantial incomes, and to contribute to society and their own independence. Previously, disabled workers had been assessed prior to providing them with training, and they were found to be too limited to be productive.

What these researchers demonstrated quite clearly was that training made a difference between employability and a life of welfare. 'They pointed out that many disabled individuals can work very effectively, but that they frequently need some kind of support system. Whether this be in a semi-sheltered environment, or in a competitive job, they are likely to encounter problems without guidance; assistance; or just someone to trouble-shoot with an employer. Initial calculations by these researchers seem to indicate that these programs were less expensive than full-time placement in a setting which encouraged dependency and inhibited the individual's ability to work.

With this information so well documented by several independent researchers working in widely separated areas of the country, it is important to address the issue directly on an expanded basis. We asked for, and received, the appropriations needed. We expect to have final regulations for this program and our first grant award competition announcement published in the Federal Register in the near future.

I appreciate the opportunity to go over these changes with you and to summarize the operations of the basic State grant program. I'd be pleased to respond to any questions.

Mr. WILLIAMS. Thank you, Ms. Will.

On page 6 of your testimony you mention, with regard to the 1984 requirement mandating the report detailing how the training funds are allocated by discipline, that you have contracted with a private corporation to develop those procedures. This committee would find it helpful if you would share with us the proposed guidelines under which you have asked the private corporation to complete its work.

Ms. Will. We would be happy to submit that.

Mr. WILLIAMS. The RSA-911 System, looking at page 8, was sent to OMB apparently just before Christmas. Do you have any idea as to when that will be finalized?

Ms. WILL. We sent the system to OMB in December and received from them a rather lengthy critique. They asked for further justification with respect to some of the items in the data collection system and, in some cases, asked for changes. Discussions between RSA and OMB have ensued. This is not any different from the kinds of discussions that our staff engage in with OMB on a variety of programs and issues throughout OSERS. We expect to have many of the issues resolved and hope to get the system to the States in the fall so that they can begin collecting data.

As a matter of fact, many of the States are already collecting the data on a voluntary basis, so we expect that this system will not be a burden to the States.

Mr. WILLIAMS: As part of those 1984 hearings, this subcommittee, under a different chairman, stated that an updated cost-benefit analysis of the Federal Rehabilitation Program was needed. Such data has not been provided since the RSA annual report in 1981.

Is the assessment for a cost-benefit analysis ongoi g now? What is the status of that? Will you be able to provide this fairly impotant information to the committee any time soon?

Ms. WILL. There is a project funded to develop a cost benefit model, and there is, in addition, a project funded in the National Institute of Handicap Research on the economics disability,



which is also looking at some aspects of cost benefit. We hope to have preliminary information next year.

Mr. WILLIAMS. A memo was sent earlier this year by George Kahn to supervisors at the branch level, and above as well, as to special assistance to the commissioner. The memo requested that they change their work hours because of the 35 percent reduction in staff during the past 4 years at RSA. The memo also referred to continued workload increases on the staff who remain with the agency.

Give me your judgment as to how RSA is able to function efficiently and with expertise, given such reduction in staff.

Ms. WILL. I'm not familiar with the particular memo that you cite. I do recall having asked for an extensive review of the flexitime policy in RSA and the other components because we were concerned about the fact that flexitime allows people to leave early or to arrive late. Particularly in the case of RSA with regional offices across the country, it is important to be able to get to California in the late afternoon.

Since 1980, 1981, there has been a reduction in RSA staff from 279 to 216—or I think it's 218—in 1985, 16 person losses in the regions and 47 in the headquarters. Several years ago a human resources review was conducted of programs in the Department and reductions in RSA were recommended on the basis that there was excessive overhead personnel, that there was much layering in RSA. Since 1982, we believe that our staffing ratios have been reduced slightly but that this has had a positive effect on the program, and that our management effectiveness has not been damaged.

Mr. WILLIAMS. Do I understand correctly that there has been a 35 percent reduction in the staff during the past 4 years at RSA?

Ms. WILL Well, I'm not sure if 47, if that comes to a 35 percent reduction. It's 36 percent in headquarters and 16 percent in the regional offices.

Mr. WILLIAMS. We have heard today from some consumers of rehabilitation services who have indicated some lack of response to their needs, and further indicated that that may be due to a lack of appropriate numbers of staff as well as staff expertise. I know that that is a long-standing complaint with any agency that undergoes significant reductions. But this committee does express its concern that when we have a 35-percent reduction in staff and a travel budget reduced by 77 percent, we worry about the effect of that on the eventual providing of appropriate services to the consumer.

Ms. WILL I begin by saying that, as you know, RSA moved from Health and Human Services to the Department of Education relatively recently. That has required a good bit of coordination to absorb that program in the Department of Education which is not like the Department of Health and Human Services. I would point to the fact that one function was eliminated in RSA, therefore, staff assigned to that function were not required to spend time on that function. It has taken reorganization and coordination to adequately and appropriately integrate RSA into OSERS.

I would add also that if you look at the rehabilitation program and you evaluate the general health of the program, one would give it a very good rating. Now, we have an increase in the number



of rehabilitations, we have an increase in the number of severely handicapped individuals, and we have much better dissemination and use of technological devices. It is a program that is very alive and exciting right now. There's a focus on job placement and targeted training.

I think that, judging from the health of the system, that RSA is adequately carrying out its mission. But, in addition, one must remember that the program is largely conducted by the State agencies and it is a State/Federal cooperative venture. But the large share of the burden really falls to the States. They are doing a very good job.

If there is concern about staffing RSA, travel dollars\_and so forth, I would encourage people to contact me and my OSERS staff about those concerns.

Mr. WILLIAMS. There has been, at least in 1984, an increased placement. Perhaps that has to do with better management efficiencies, or perhaps it has to do with increased funding for rehabilitation, and also the turnaround in the economy. In any event, we do know that we are not serving anywhere near the number of people who need service in the United States. That doesn't necessarily mean that we need more administrators at the top to provide that service. But neither does it mean we can have a 35-percent cut in personnel at the top and still provide that service. So that's the dilemma that I know you deal with and this committee is expressing its concern about.

Along with creating those kinds of efficiencies, which I generally applaud, is RSA trying to find better ways or special initiatives to identify and serve handicapped individuals, particularly severely handicapped individuals, who live in rural areas and find services increasingly difficult to reach? It seems to me, being from Montana, that is a need that is virtually unmet.

I would like to see you and your people also spending time, along with creating greater management efficiencies, trying to find better ways to serve handicapped individuals in rural America.

Ms. WILL. We are concerned throughout OSERS with the problems that are faced by severely handicapped people in rural areas. We have begun some efforts, but I would not pretend we have resolved all those problems. We are thinking about special initiatives and we have worked with several States close and are very pleased with their attempts to solve the problems

In Wyoming, a State plan amendement was approved to provide a fast track approach to eligibility determinations and the provision of services. In Nebraska, a training program for selected staff of community based services was initiated to provide a constant VR presence in rural areas. In Kansas, a PWI grant was used as the basis for expanding the PWI concept on a comprehensive basis. This approach has been attempted in the area of independent living services as well.

The comprehensive statewide approach is the important factor here. So often in rural areas you will find adequate services but they are fragmented and they are not consistent throughout the State. That is the problem that we are trying to address. Transportation, of course, is always a unique problem in rural areas. We are cognizant of the problem.



66.

Mr. WILLIAMS. There is also another hurdle for adequate services in the more rural areas of America, and that hurdle can only be resolved with increased funding. The former U.S. Senator from Montana, Lee Metcalf, coined a phrase, "the high cost of space." There is, indeed, a high cost in servicing one severely handicapped individual living a hundred miles from the nearest urban or semiurban center. I think we always have to understand the need for additional expenditures in that area.

Ms. Will, I have other questions. I know your time is limited, and unfortunately, this afternoon so is mine. But with your permission, I would like to send you those questions and I would appreciate having your answers. I will leave the hearing record open for a couple of weeks so that we're able to include your answers in the hearing record.

Ms. WILL. Thank you.

[Additional material submitted for the record follows:]

Committee on Education and Labor, U.S. House of Representatives, Subcommittee on Select Education, Washington, DC, June 11, 1985.

#### Ms. MADELEINE WILL,

Assistant Secretary for Special Education and Rehabilitation Services, Department of Education, Washington, DC.

DEAR Ms. WILL: Pursuant to my guestion to you in the hearing this morning, I would appreciate your answering the following questions in writing for inclusion in the hearing record. As I noted, I will hold the record open for two weeks.

\_\_() You mentioned in your testimony the demand for training monies and the need for a prioritization as well as allocation system. How does this fit with the Administration's recommendation in the last budget to substantially cut training money? How does the Rehabilitation Services Administration (RSA) suggest implementing a priority system for training which would include importance for services and need for federal money?

(2) How does the suggested work initiative fit with the priority of the system for short-term job placement and closing cases?

(3) You mention the increase in 1984 in placement and persons served by the rehabilitation system—the first in several years. While you attribute it to increased efficiencies in the system, isn't it more accurately attributable to declining overall unemployment rates and increase? funding for rehab?

(4) The 1984 Amendments reinstated a requirement in Section 14 that the Secretary establish and use standards for evaluating the impact of all programs authorized by this Act. Please, tell me specifical'v. how the Department has interpreted this language and how you are implementing this requirement?

Have the State Vocational Rehabilitation agencies been included in this evaluation process and if so, how? What proportion of the evaluation funds has the Deparment used and what proportion has been given to RSA to use in evaluation?

(5) As part of the August 1, 1984, hearing held by this subcommittee, you provided information indicating that the RSA program data analysis had identified State vocational rehabilitation (VR) agencies "that serve largely clients with relatively minor as opposed to severe handicaps." These data also identified "problems such as high percentages of clients being rehabilitated into non-remunerative occupations, e.g., homemaking." Were States with these problems notified that they compared unfavorably with national averages? When were they notified? What steps have been taken to help correct these problems?

(6) What is the staus of grant awards to American Indians? If several awards have been made, as the Administration has planned, are any of the awards large enough to provide comprehensive vocational rehabilitation services to Indians living on reservations? Do you feel these awards should replace State R agency activities on these reservations?

(7) Please describe the involvement of the RSA and the State VR agencies in the transition services the Administration is initiating to improve services to handicapped youth completing education programs.



(8) What is the status of the information which states are required to collect projecting demand for transition services?

(9) The 1984 amendments require that rehabilitation training include preparation for the delivery of services in independent living centers and client assistance programs. The amendments also require that training provided to rehabilitation counselors include training in the applicability of Section 504. In what ways is the Administration implementing these requirements?

(10) The RSA has suffered a significant reduction in workforce in the last four years. Has this produced an increase in contracting out for various forms of evaluation and program monitoring? If so, what kind of savings have actually been effected with the more expensive services?

(11) The 1984 amendments require evaluation studies of the independent living centers: client assistance programs, and projects with industry. Results of these evaluations are to be submitted to the Congress by February 1. 1986, and are needed for the reauthorization process. Do you anticipate that these studies will be completed on time? Are the contractors doing the evaluations assessing the effects of these programs on the handicapped persons participating in the programs?

(12) The Department of Education budget request for FY 1986 states that evaluations are being done on the migrant worker and American Indian rehabilitation programs, the projects for the severely disabled, State VR programs, private sector reliabilitation programs, and the research and training centers of the National Institute of Handicapped Research. Would you please furnish the date that each of the evaluation studies is to be completed? Could you explain the methods to be used in these evaluation studies, including whether information from clients of the programs is being included in the evaluations?

(13) The 1984 amendments require that training funds be targeted to areas of personnel shortage shown in the annual budget request. This information was not provided in the Administration's FY 1986 budget request. When will the Congress be provided the report documenting rehabilitation manpower shortages?

(14) What is the status of implementation of Part A of Title VII, the State allotments for independent living? How are the States utilizing these funds? Are Part A programs being effectively coordinated with Part B centers for independent living?

(15) The Administration is initiating projects to demonstrate that very severely handicapped persons can work in the competitive labor market if sufficient support is provided to such persons. What part will the RSA play-in the supported employment initiative being developed by the Office of Special Education and Rehabilitative Services? Are State VR agencies to participate in this initiative at State and local levels?

(16) Referring to the supported work initiative which has been developed by the Office of Special Education and Rehabilitation Services—Does this not overlap with the Department of Health and Human Services' programs for the developmentally disabled on this initiative and if not, how is such overlap being avoided?

(17) The 1984 amendments to the Rehabilitation Act require that the client assistance program not be placed in a State VRagency unless a State had operated such a program in the State VR agency prior to enactment of the amendments. Please compare the effectiveness of client assistance programs operated independently of State VR agencies with those operated within State VR agencies.

(18) In FY84, there was a 4.4 percent increase over the previous year in the number of handicapped persons rehabilitated in the basis State grant program. This was the first increase in rehabilitations in six years. What were the major factors contributing to this increased productivity, and what initiatives has the Administration undertaken to help the States continue to rehabilitate more handicapped persons?

(19) The 4,000 persons who became dest-blind at a result of the Rubella epidemic of the mid-1960s are now using out of the education programs and are in need of independent living services and vocational training. Many of these persons may require life-long institutionalization if they are not provided services now. What special efforts is the Administration making to provide services to this population?

(20) The 1984 amendments to the Rehabilitation Act established a National Council as an independent agency within the Federal Government. Has this designation assisted the Council in moving forward with its work unimpeded by departmental procedures and political considerations?

The 1984 amendments to the Rehabilitation Act require the Council to assess Federal programs serving the handicapped and submit a report to Congress by February 1, 1986. The report is to include findings and recommendations regarding the extent to which Federal programs provide incentives or disincentives to the estab-



ishment of community-based services for handicapped persons. How is this assess-

curred in the health field, the aerospace industry and other areas not immediately affecting handicapped persons. How effective have the NIHR programs been in developing innovations for handicapped persons based on medical and technological advances in these other fields?

The 1984 amendments to the Rehabilitation Act authorized the Director of the NIHR to use 5 percent of research funds to test new concepts and innovative ideas in rehabilitation research. For which special purposes are these funds being used?

What efforts are being made to broadly disseminate research results of NIHR projects to agencies and individuals in the rehabilitation field? How much funding is used for this purpose?

The 1984 amendments to the Rehabilitation Act required the Director of the NIHR to establish a research and training cruter in the Pacific Basin. In addition to providing assistance to rehabilitation personnel and handicapped persons in Hawaii where the center is located, is this center assisting rehabilitation personnel andhandicapped persons from the more remote areas of the Pacific Basin?

Thank you for your help in this matter. I look forward to receiving your response. Best regards.

Sincerely,

PAT WILLIAMS.

U.S. DEPARTMENT OF EDUCATION, OFFICE OF THE ASSISTANT SECRETARY FOR LEGISLATION AND PUBLIC AFFAIRS, Washington, DC, August 2, 1985.

Memorandum to: Gray Garwood, Subcommittee on Select Education. From: Doris Dixon, Office of Legislation and Public Affairs. Subject: June 11, 1985, Hearing Questions and Answers.

Attached are the responses to questions submitted by Mr. Williams following the June 11, 1985 hearing on the Reauthorization of the Rehabilitation Act of 1973. Please let me know if you have any questions or comments.

#### TRAINING FUNDS

Question. You mentioned in your testimony the demand for training monies and the need for a prioritization as well as allocation system. How does this fit with the Administratica's recommendation in the last budget to substantially cut training money? How does the Rehabilitation Services Administration (RSA) suggest implementing a priority system for training which would include importance for services and need for Federal money?

Answer. Regardless of the level of funds available, there is a need for a rational system to establish funding priorities. The recommendation to reduce the level of funds available for the support of new projects was a direct result of the Department's concerns about priorities establishment and the need for an objective allocation system. It is reasonable to support vo new projects until the Department can be certain that funds are being used to meet existing and high priority rehabilitation personnel needs.

A priority system for allocating training unds must start with an understanding of the goals and purposes of the State/Federal rehabilitation service delivery system in this country and an understanding of the training programs which contribute to this system. The system must take into account the importance of specific services in the rehabilitation service delivery process and the need for Federal assistance to ensure the availability of those services. It is not enough to know there is a shortage of personnel in a specific rehabilitation professional field or program area; one must also know the role played by such personnel in meeting the objectives of the State/ Federal rehabilitation service delivery system and the extent to which Federal funds are necessary or critical to generate or continue a supply of such personnel.

Results from ongoing contractor work will enable the Rehabilitation Services Administration to implement a rational process for rehabilitation personnel needs data collection, priorities determination, and training funds allocation.

#### THE SUPPORTED WORK INITIATIVE

Question. How does the supported work initiative fit with the priority of the system for short-term job placement and closing cases?

Answer. There is no priority in the rehabitiation service system "for short-term job placement and closing cases." Individuals will receive services tailored to their particular needs and as a result may receive services for fairly long periods of time:

Under the current State vocational rehabilitation program, services are terminated upon achievement of an established vocational goal; under the supported work initiative, arrangements must be made to maintain the needed level of support services after vocational rehabilitation services are terminated.

In light of the expected increase in the number of persons who can benefit from and will desire supported work, we are considering ways within current resource levels to expand the availability of supported work opportunities.

#### BASIC STATE GRANT PROGRAM: REASON FOR INCREASE IN REHABILITATIONS

Question. You mention the increase in 1984 in placement and persons served by the rehabilitation system—the first in several years. While you attrbute it to in-creased efficiencies in the system, isn't it more accurately attributable to declining overall unemployment rates and increased funding for rehabilitation?

Answer. We do not thoroughly the effect of unemployment rates and funding levels on State vocational rehabilitation caseloads. We are studying both caseload trends and placement practices at the present time.

It may be important to note that the total number of persons served did not increase in 1984, although the number of severely disabled persons served-did go up that year. It is with rehabilitations, however, that we believe the effects of increased enticiency are seen. Not only did the actual number of persons rehabilitated increase in 1984 but the rehabilitation rate also rose.

#### EVALUATION

Question. The 1984 Amendments reinstated a requirement in Section 14 that the Question. The 1984 Amendments reinstated a requirement in Section 14 the the Secretary establish and use standards for evaluating the imperior of a construct authorized by this Act. Please, tell me specifically, how the Departmer data interprete ed this language and how you are implementing this requirement?
 Have the State Vocational Rehabilitation agencies been included in this evaluation process and if so, how? What proportion of the evaluation funde has the Department used and what proportion has been given to RSA to use in evaluation?
 Answer: Establishment use of standards for evaluation: The Department has established the following principles in developing standards and conducting evaluations.

tablished the following principles in developing standards and conducting realuations of the formula grant program and project authorities authorized by the Rehabilitation Act.

Standards for evaluation will be developed on a case by case basis to guide the 1 which is being conducted evaluation of the specific prop

The primary purpose of the standards is to establish uniform and objective criteria for describing program characteristics and measuring program impacts (e.g., the numbers served, types of clients, outcomes of services).

Where it exists, statutory language will be used to define study objectives and standards for evaluation criteria to ensure that statutory mandates are satisfied.

State inclusion in the evaluation process: Each major evaluation project has an advisory committee consisting of representatives of national organizations, interest groups and consumers upon whom the evaluation will have an impact. Since VR agencies are represented on all advisory committees for evaluations which impact directly or indirectly upon State VR agencies. In addition, RSA evaluation activities are discussed twice yearly between RSA representatives and State VR Directors at the Evaluation Committee session during the meetings of the Council of State Ad-ministrators of Vocational Rehabilitation.

Proportion of evaluation used by the Department and RSA: All coaluations are conducted by the Department. Different studies are managed by different offices ate the impact of all prog. ars authorized by this Act. . . . " In accordance with that responsibility, the repartment has established an evaluation coordinating committee consisting of representatives from the Office of Special Education and Rehabili-tative Services (including specific representatives from the Rehabilitation Services Administration) and representatives from the Department's Office of Planning, Budget, and Evaluation. The plans for Evaluation are decided upon in this committee.



In 1984, RSA managed studies involving approximately 53% of the funds and OPBE managed studies involving approximately 47%. The 1985 studies have not all been funded yet so 1985 figures are not available.

#### BASIC STATE GRANT: STATES SERVING LESS SEVERE POPULATIONS

Question. As part of the August 1, 1984 hearing held by this subcermittee, you provided information indicating that the RSA program data analysis and the GAO report had identified State vocational rehabilitation (VR) agencies "that serve largely clients with relatively minor as opposed to severe handicaps." These data also identified "problement and high percentages of clients being rehabilitated into non-remunerative or upations, e.g., homemaking." Were States with these problems notified that they compared unfavorably with national averages? When were they notified? What steps have been taken to help correct these problems?

Answer: RSA regional offices monitor the activities of the individual State agencies with the information available to them through their agency contacts, special audits and studies, and data compiled and analyzed in the RSA central office. Monitoring is less an occasional activity with sol dates and more an ongoing process. Regional offices will, therefore, notify agencies of possible anomalies in their operations as seen in reported data as soon as this information is available. Once a problem is, indeed, discovered, its resolution will be tailored to the particular circumstances involved. The monitoring proces is working with respect to the provision of services to increasing numbers of severely disabled persons and the attempt to reduce the frequency of the homemaker closure.

RSA regional offices monitor the number of severely disabled persons in the caseloads of State rehabilitation agencies on a quarterly basis. This effort began in 1974 when only 31.6 percent of all rehabilitated persons were severely disabled and has ont sued to the present time with the proportion reaching 58.9 percent in the first hall of Fiscal Year 1985.

A special RSA study of the homemaker closure was conducted three years ago by the RSA central office and released to RSA regional offices. Among other things, the study revealed that high proportions of homemaker closures were not a national phenomenon but, rather, affected a minority of agencies. RSA regional offices immediately followed up on the report to mestion those agencies in their region with particularly high proportions of homemaker closures to ensure that eligibility and closure standards were being adhered to.

Since then, the proportion of rehabilitated persons classified as homemakers has gone down fairly rapidly from 15.7 percent in Fiscal Year 1981 to a preliminary 12.5 percent in Fiscal Year 1983. RSA regional offices will continue working with agencies that may still be having problems with the homemaker closure.

The GAO report cited some examples of persons with minor handicaps receiving services. In order to insure that only eligible persons were being served RSA shared the GAO findings with State agencies and provided additional instructions on eligibility. In addition regular reviews of client cases are made by Regional Office staff to monitor the situation.

# GRANTS TO AMERICAN INDIANS

Question. What is the status of grant awards to American Indians? If several awards have been made, as the Administration has planned, are any of the awards large enough to provide comprehensive vocational rehabilitation services to Indians living on reservations? Do you feel these awards should replace State VR agency activities on these reservations?

Answer. It is expected that awards totaling \$715,000 will be made to three Indian tribes in FY 1985. This is the same amount as was awarded in one grant in FY 1984 to the Navajo Nation. Section 130 funds replace some Stat / VR funds but basically they are used to provide outreach and culturally relevant services to handicapped Indians on the reservations who would not normally be reached by the State VR agency. The projects attempt to provide or coordinate the provision of comprehensive services but the extent of their efforts would new samily be limited to the funding level provided by the grants. It is expected that the funding of these projects, in conjunction with services provided by the State VR agencies, will be sufficient to provide comprehensive rehabilitation services to Indian clients.



#### TRANSITIONAL SERVICES FOR HANDICAPPED YOUTH

Question. Please describe the involvement of the RSA and the State VR agencies in the transition services the Administration is initiating to improve services to

In the transition services the Administration is initiating to improve services to handicapped youth completing education programs. Answer, RSA has identified and catalogued cooperative agreements between VR and Special Education programs. A review of those agreements, and a contract funded by NIHR on exemplary transition programs, has led into current year activi-ties. These activities include a leadership conference in each region that will bring together key people from rehabilitation, special education, vocational education, consumers and parents. The meetings will provide the opportunity for participants to learn how each agency and program can work with others to enhance the transito learn how each agency and program can work with others to enhance the transi-tion from school to work. RSA is enco. ging cooperative programs and is providing technical assistance at the State and here well to improve the effectiveness of cooperative programs. In addition, State age is are being encouraged to develop in co-operation with other State and local agencies or schools at least one new transition project in each State.

#### TRANSICION SERVICES

Question: What is the status of the information which states are required to collect projecting demand for transition services?

Answer. The data regarding student exiting special education programs required by Section 618(b/3) of the Education For Handicapped Children Act, as amended by P.L. 98-99, is currently being collected by the Special Education Program from State Education Agencies. The Rehabilitation Services Administration is presently in the process of informing State The abilitation Agencies that this information should be taken into account when developing State Plans. The Administration on Develop-mental Disabilities (JED) a similar requirement to address the exiting data in State Developmental Disabilities of the requirement. their respective State rograms of the requirement:

### CAP AND SECTION 504 TRAINING

Question. The 1981 amendments require that rehabilitation training include preparation for the delivery of services in independent living centers and client assistance programs. The amendments also require that training provided to rehabilitation counselors include training in the applicability of Section 504. In what ways is the Administration implementing these requirements?

Answer. The 1984 amendments authorize but do not require, training of person-nel for services in independent living cen RSA will continue its support in Fiscal Year 1985 of an on-going training project desized to upgrave the manage-ment skills of administrators of Center for Independent Long Programs. The train-ing will include participants from all sections of the contract. Person 4 will also be prepared for independent living service delivery units tablished long-term rehabilitation facility training programs. Relative to Section 504 training, a funding priority has been established for new

Fiscal Year 1985 rehabilitation counseling projects. All projects awarded new reha-bilitation counseling grants in Fiscal Year 1985 will include training content on Sec-tion 504 and its implications for placement of disabled individuals. RSA has also identified Section 504 training for employed rehabilitation counselors as a priority under the Rehabilitation Continuing Edvoation Program and the State Vocational Rehabilitation Unit In-Service Training Program in Fiscal Year 1985.

In Fiscal Year 1986, rehabilitation training funds will be allocated for training to upgrade the skills and increase the capacity of cleant assistance program personnel to deliver services more effectively. The trainin -11 include participants from all sections of the country .

#### EVALUATION AND PROGRAM MONITORING-CO'VTRACTING OUT FOR SERVICES

Question: The RSA has suffered a significant reduction in workforce in the last four years. Has this produced an increase in contracting out for various forms of evaluation and program monitoring? If so, what kind of savings have actually been effected with the more expensive services?

Answer. There has been no increase in contracting out for various forms of eval-uation and program monitoring in RSA during the last four years. Program evalua-tion is routinely contracted out by the Department and RSA. This is a form of pro-gram monitoring by outside sources. RSA staff conducts program monitoring through both its Central and Regional Offices.



### PROGRAM EVALUATION: INDEPENDENT LIVING, CLIENT ASSISTANCE, PWI

Question. The 1984 amendments require evaluation studies of the independent living centers, client assistance programs, and projects with industry. Results of these evaluations are to be submitted to the Congress by February 1, 1986, and are needed for the reauthorization process. Do you anticipate that these studies will be completed on time? Are the contractors doing the evaluations assessing the effects of these programs on the handicapped persons participating in the programs?

Answer We do anticipate that the evaluation studies for Independent Living Centers, Client Assistance programs and Project with Industry will be completed on time. Each of the contractors for these studies will utilize evaluation standards data to determine the effectiveness of each program. Data collection methodology for the studies include client surveys.

# PROGRAM EVALUATION: MIGRANT WORKER, AMERICAN INDIAN, ET CETERA

Question. The Department of Education budget request for FY 1986 states that evaluations are being done on the migrant worker and American Indian rehabilita-tion programs, the projects for the severely disabled. State VR programs, private sector rehabilitation programs, and the research and training centers of the Nation-al Institute of Handicapped Research. Would you please furnish the date that each of the evaluation studies is to be completed? Could you explain the methods to be used in these evaluation studies, including whether information from clients of the programs is being included in the evaluations?

Answer. The date of completion for FY 1985 rehabilitation evaluation projects is as follows:

American Indian, June 1986; Research and Training Centers, December 1986; Mi-grant Workers, October 1986; Severely Disabled, November 1986; State Policies on Management In the Severely Disabled, July 1986; Impact of Department-Sponsored Management Improvement Efforts, July 1986; Private Sector Rehabilitation, July 1987; and Transi-tional Youth Design Project (SEP Project with rehabilitation component); April 1986

Standards will be developed for each evaluation which will help determine which methodology is appropriate to the subject matter. Data will be collected either at State VR agencies or project sites. In all cases, before the actual data collection, pre-liminary visits will be made to representative sites to determine the scope of the problems to be evaluated and/or to pretest data collection instruments.

Information from clients will be included in the following evaluation projects: American Indian: Migrant Workers; and Severely Disabled.

### TRAINING HEPORT

Question. The 1984 amendments require that training funds be-targeted to areas

Advection. The 1985 amendments require that training funds be targeted to areas of personnel shortage abown in the connucl budget request. This information was not provided in the Administration's FY 1986 budget request. When will the Congress be provided with the report documenting rehabilitation manpower shortages. Answer, T' - Department has awarded a contract to develop a system for setting priorities and allocating training funds based on training needs. The report of this evaluation study will be available in January or February of 1986. It is expected that RSA; making use of this report and other appropriate information, will have an allocation system in place by the write of 1986. an allocation system in place by the spring of 1986

### INDER EVELOT DIVING STATUS OF FART 4 PUMOS

Question. What is the states of independent living? How are the States utilizing these funds? Are Part A programs being effectively coordinated with Part B centers for independent living?

Answer, Part A requires submission of a three-year State plan which, is the Answer. Part A requires submission of a three-year State plan which, is the State's commitment and presentation of its goals, and plans for services, the plan is based upon statutory requirements and implementing regulations. The State plan or mass sent to the States April 17, 1985 and is now being completed by the State State VR agencies have submitted their State plans to RSA for w and approval. We anticipate that all State plans will be approved and all I cue all grants awarded by the end of August.

Of the 26 State plans that have been approved, we are able to report that 21 VR agencies are coordinating the Part A IL program with the IL Center program under Part B. Some State agencies also plan to use a portion of their grants to plan for Statewide independent living service systems.



### SUPPORTED EMPLOYMENT-RSA'S ROLE

Question. The Administration is initiating projects to demonstrate that very severely handicapped persons can work in the competitive labor market if sufficient support is provided to such persons. What part will the RSA play in the supported employment initiative being developed by the Office of Special Education and Rehabilitative Services? Are State VR agencies to participate in this initiative at State and local levels?

Answer. The Rehabilitation Services Administration (RSA) has the lead role in administering the supported employment initiative in cooperation with the Administration on Developmental Disabilities and the National Institute of Handicapped Research (NIHR). Similarly, RSA staff are participating in the review of NIHR cotracts to provide technical assistance and to develop performance measures in Supported employment. Within RSA, this role is assigned to the Office of Developmental Programs (ODP) which manages all of RSA's discretionary grants programs. Several ODP staff have been involved with this initiative beginning with the OSERSwide position paper on supported employment and continuing through the development of proposed enabling regulations, analyses of public comments on these proposed enabling regulations, analyses of public comments on these proposed enabling regulations and the closing date announcement for applications for publication in the Federal Register, development of the application kit of information materials, selection of Peer Reviewers who will evaluate and rank all applications submitted, and arranging the logistics of the Peer Review meetings. This role will continue in the day-to-day management of these projects once final selections have been made in late August.

Eligible applicants for these grants include State rehabilitation agencies. Early in the process a joint RSA, NIHP, and Council of State Administrators of Vocational Rehabilitation Work Group was formed and periodic telephone conferences were held. As a result of this Work Group, considerable written information about the supported employment initiative was sent to all tate rehabilitation agencies. ODP staff made arrangements to assure that the State rehabilitation agencies received copies of the application kits as soon as they were ready for mailing. In addition, ODP staff have provided in person and telephone technical assistance to all prospective applicants including State rehabilitation agency staff. Once the grants are awarded to successful applicants, it is expected that the granters will work with and assist local agencies to actually implement supported employment models. To assist them in this effort, the NIHR has awarded a contract to provide technical assistance, support; and training to enhance the statewide operations as well as local initiatives.

### SUPPORTED FMPLOYMENT—HHS OVERLAP

Question. Referring to the supported work initiative which has been developed by the Office of Special Education and Rehabilitative Services—Does this not overlap with the Department of Health and Human Services' programs for the developmentally disabled on this initiative and if not, how is such overlap being avoided?

Answer. There is no overlap between the administration on Developmental Disabilities (ADD), Department of Health and Haman Services and the Department of Education's Office of Special Education and Rehabilitative Services (OSERS) initiative in statewide supported employment. In fact, through formal written agreement, ADD is transferring \$500,000 to OSERS to enhance available funds in what is a unified, coordinated effort. ADD will assist in the review of statewide supported employment applications submitted to OSERS in August 1985. ADD has already assisted the National Institute of Handicapped Research, OSERS, in the review of technical assistance and performance measures contracts in statewide supported employment. It is planned by OSERS that this coordinated and cooperative effort with ADD will continue as the statewide supported employment projects are approved and become operational. Cooperative monitoring and the dissemination of information about these projects are only two examples in which ADD and OSERS will work together.

Both OSERS (Rehabilitation Services Administration, Office of Special Education and National Institute of Handicapped Research) and ADD have in the past assisted different types of discrete, locally sponsored demonstration projects for the purpose of expanding employment opportunities for severely handicapped individuals. More recently, some of these projects have explored supported employment methods but not on a statewide basis Some of the earlier projects assisted by the Rehabilitation Services Administration at the University of Washington, University of Vermont, the Virginia Commonwealth University, and other localities, actually developed the



methods and techniques on which the OSERS statewide supported employment initiative is, in part, based. The OSERS statewide supported employment demonstrations will assist severely disabled persons who have a broad range of physical or mental handicaps:

### CLIENT ASSISTANCE PLOGRAMS IN STATE VR AGENCIES VERSUS INDEPENDENTS

Question. The 1984 amendments to the Rehabilitation Act require that the client assistance program not be placed in a State VR agency unless a State had operated such a program in the State VR agency prior to enactment of the amendments. Please compare the effectiveness of client assistance programs operated independently of State VR agencies with those operated within State VR agencies.

Answer. At present, we do not have any data to compare the effectiveness of client assistance programs operated independently of State VR agencies with those operated within State VR agencies

Such a comparison will be made as part of the program evaluation study now in progress: A report to Congress is due in February, 1986.....

Because the programs were not funded until late in FY 1984, the first annual reports will cover FY 1985 and are not due until December, 1985. 'nformation from these ongoing program reports may provide for useful comparisons in the future.

#### BASIC STATE GRANT PROCILAM: INCREASE IN PERSONS ESHABILITATED

Question. In FY 1984, there was a 4.4 percent increase over the previous year in the number of handicapped persons rehabilitated in the basic State grant program. This was the first increase in rehabilitations in six years. What were the major factors contributing to this increased productivity, and what initiatives has the Administration undertaken to help the States continue to rehabilitate more handicapped persons?

Answer. We believe that improved productivity has resulted from (a) greater emphasis on the provision of job-seeking skills, and (b) more job development and placement services. Returns from the first half of Fiscal Year 1985 indicate that rehabilitations may increase again this year, perhaps by two percent.

Initiatives of RSA include efforts (1) to have States place more people into the competitive labor market and fewer into homemaking and unpaid family work and (2) to improve State management of the program making them more efficient and effective in delivering services to disabled people:

Two RSA initiatives have contributed to these increases. They are the Employment Goal and the Management Improvement Goal. As major RSA actions they have been the vehicles used to encourage State agencies to place higher priority on the placement of clients into renumerative employment and to improve the service delivery and support systems to enable the results. In addition to urging, T.A. has been provided and successful results have been identified and shared with other States.

### HELEN KELLER NATIONAL CENTER FOR DEAF-BLIND YOUTHS AND ADULTS

Question. The 4,000 persons who became deaf-blind as a result of the Rubella epidemic of the mid-1960s are now aging out of the education programs and are in need of independent living services and vocational training. Many of these persons may require life-long institutionalization if they are not provided services now. What special efforts is the Administration making to provide services to this population?

Answer. The Office of Special Education and Rehabilitative Services has awarded to the Helen Keller National Center (HKNC) an additional grant to provide technical assistance to both governmental and private organizations providing services to deaf-blind persons aging out of institutions. With this grant the HKNC has conducted a study of approximately 400 State and private agencies currently providing services to this population asking them to identify their priorities and needs. HKNC has offered technical assistance as needed.

Additionally, the Rehabilitation Services Administration has involved all of its Regional Offices and the State vocational rehabilitation agencies in a special initiative to meet the sectional and independent living needs of deaf-blind persons in response to the increasing numbers of deaf-blind persons aging out of educational settings. The initiative included an identification of the strengths and weaknesses in the current delivery system, and the development of strategies to improve and increase services to deal-blind persons.



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## NATIONAL COUNCIL ON THE HANDICAPPED

Question. The 1984 amendments to the Rehabilitation Act established a National Council as an independent agency within the Federal government. Has this designation assisted the Council in moving forward with its work unimpeded by departmental procedures and political considerations?

Answer: The 1984 amendments to the Rehabilitation Act require the Council to assess Federal programs serving the handicapped and submit a report to Congress by February 1, 1986. The report is to include findings and recommendations regarding the extent to which Federal programs provide incentives or disincentives to the establishment of community-based services for handicapped persons. How is the assessment being conducted and what is the status of the report?

Answer. The National Council on the Handicapped is an independent agency of the Federal Government. It has no reporting relationship to the Department of Education. Consequently, we do not have the information with which to respond to this question.

## RESEARCH ADVANCES-HEALTH, AEROSPACE FIELDS

Question. Many research advances of potential benefit to have persons have occurred in the health field, the aerospace industry and other areas not immediately affecting hand, apped persons. How effective have the NIHR programs been in developing innovations for handicapped persons based on medical and technological advances in these other fields?

Answer, Through substantial interagency interaction between the National Institute of Handicapped Research (NIHR), National Aeronautics and Space Administration (NASA), National intutes of Health (NIH), National Science Foundation (NSF), and others, advances nave been made for handicapped persons using medical and technological developments. For the following examples are a sample of interagency interaction:

(1) In close cooperation with NIH, NASA, and NSF, NIHR-has developed an instrument now widely used clinically throughout the United States and the world, known as the Scoliotron. This device uses neuromuscular electrical stimulation of muscles of the trunk to correct curvatures of the spine in adolescents, known as idiopathic scoliosis.

(2) In close cooperation with NASA and NSF. NIHR has supported the design, development, and evaluation of a new basic design wheelchair that is light weight, strong, and appropriately adjustable. This chair was designed and developed by scientists and engineers at the University of Virginia Rehabilitation Engineering Center who worked closely with scientists and engineers from NASA and NSF. The chair, made of the newest composite materials, incorporates the latest available information on ergonomics for optimal; seating and propulsion by handicapped individuals and is being considered for manufacture and sale by at least four firms currently producing wheelchairs.

### INNOVATIVE RESEARCH

Question: The 1984 amendments to the Rehabilitation Act Pathorized the Director of the NIHR to use 5 percent of research funds to test new concepts and innovative ideas in rehabilitation research. For which special purposes are these funds being used?

Answer. NIHR has established, through regulations, a new program called Innovation Grants to fulfill this purpose. In fiscal year 1985, \$500,000 is set aside for this program. NIHR announced a competition and is now receiving and reviewing applications. At this time, the subject matter of specific grants to be funded is not 'nown. The final closing date of applications under this program was July 1, 1985, and the information on the use of the funds should be available in late August.

### RESEARCH DISSEMINATION

Question. What efforts are being made to broadly disseminate research results of NIHR projects to agencies and individuals in the rehabilitation field? How much funding is used for this purpose?

Answer. NIHR's main dissemination project is the National Rehabilitation Information Center (NARIC), operated under contract to the School of Library and Information Sciences, Catholic University of America. NARIC's bibliographic database REHABDATA includes citations on NIHR- and RSA-funded research. NARIC continually engages in outreach efforts to reach rehabilitation agencies and other organizations and individuals in the disability field. These efforts include: attendance



and presentations at conferences, such as meetings of the Council of State Administrators of Vocational Behabilitation and the National Rehabilitation Association; representation of rehabilitation agencies on NARIC's Advisory Board; advertise-ments and articles on NARIC's resources in the "Journal of Rehabilitation Administration" and other perio. Lals whose readership includes state administrators and practitioners; special mailings to agencies and individuals regarding NARIC's serv-

ices and products: and numerous informal contacts. In addition, NARIC's "Rehabilitation Research Reviews" (state-of-the-art summaries of research findings in key topical areas) have been produced with the needs of rehabilitation agencies in mind. Topics include the following: Client Vocational Assessment, Delivery of Vocational Rehabilitation to Rural Populations, Case Management Techniques, and Computers and Vocational Rehabil tation.

NARIC is funded at a level of \$800,000 per year for the current three-year contract (11/83-10/86).

NIHR has also funded two diffusion projects (Southwest Educational Development Laboratory, Austin, Texas, and the Human Interaction Research Institute, Los Angeles, California) which identify innovative field generated programs and innovations in practice, test them, and promote adoption of exemplary programs and validated practices. Rehabilitation agencies are the targets of these dissemination ef-forts. The Southwest Educational Development Laboratory and the Human Interaction Research Institute are funded at a level of \$250,000 and \$150,000, respectively, for each year of a five-year award (1983-1987).

The Rehab Briefs, developed under contract, are another dissemination mechanism designed to reach State and private administrators and practitioners in the rehabilitation field. Each of the 12 Briefs produced yearly translates findings from a significant research project into concepts understandable and usable by rehabilita-tion counselors and other professionals. Thirty thousand copies of each Brief are distributed. The Rehab Briefs are funded as a level of \$90,000 annually.

In addition, NIHR sponsors two international activities which serve to promote use of information gained from rehabilitation research conducted by other countries. The World Rehabilitation Fund, through its international exchange of experts and information in rehabilitation, produces monographs and study reports on exemplary programs, practices and policies developed by other countries, and disseminates this information to rehabilitation professionals in the United States. The World Rehabilitation Fund is funded at \$237,097 annually. Also, NIHR is currently an organizational member of Rehabilitation International. Rehabilitation organizations in more than 70 countries are members of Rehabilitation International, which provides the major institutional framework for international cooperation and networking.

Also, each research center or project has a dissemination/utilization component built into it

# RESEARCH AND TRAINING CENTER-PACIFIC BASIN

Question. The 1984 amendments to the Rehabilitation Act required the Director of the NIHR to establish a research and training center in the Pacific Basin. In addition to providing assistance to rehabilitation personnel and handicapped persons in Hawaii where the center is located, is this center assisting rehabilitation personnel

and handicapped persons from the more remote areas of the Pacific Basin? Answer: Yes: While the Rehabilitation Research and Training Center (RRTC) is quite new, it is already demonstrating a dedication to serving remote areas of the Pacific Basin.

The Spring meeting of the RRTC's advisory committee was held in Guam. Com-mittee members were from American Samoa, Trust Territories of the Pacific Islands, Federated States of Micronesia, Guam, Commonwealth of Northern Mariana Islands, and the Republic of Belau.

The Pacific Basin RRTC has begun operation of a Satellite Communications Project. It is projected that electronic mail will increase simultaneously among Pacific Basin rehabilitation and mecial education facilities and the RRTC.

The RRTC has initiated a L habintation Technician Training Program. Two Re-habilitation Technicians have been placed in the Republic of Belau, and three others are currently in training from the Federated States of Micronesia and the Marshall londs. The Rf. 2 has surveyed eight vocational Rehabilitation Coordinators and their

staffs in the Pacific Basin. Results from this survey will determine training and research needs which the Center can pursue.



Mr. WILLIAMS. We very much appreciate your patience today and appreciate your being with us. This hearing of the Subcommittee on Select Education is ad-journed.

[Whereupon, at 12:20 p.m., the subcommittee was adjourn d.]

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# REAUTHORIZATION OF THE REHABILITATION ACT OF 1973

# **TUESDAY, JUNE 25, 1985**

# HOUSE OF REPRESENTATIVES, SUBCOMMITTEE ON SELECT EDUCATION, COMMITTEE ON EDUCATION AND LABOR,

Washington, DC.

The subcommittee met, pursuant to call, at 9:45 a.m., in room 2261, Rayburn House Office Building, Hon. Pat Williams (chairman of the subcommittee) presiding.

Members present: Representatives Williams, Martinez, and Bartlett.

Staff present: S. Gray Garwood, staff director; Celinda Lake, legislative associate; Colleen Thompson, clerk; and Pat Morrissey, senicr legislative associate.

Mr. WILLIAMS. I call this hearing of the Select Education Subcommittee to order. I apologize to my colleague, the witnesses, and people attending the proceeding today for being late. I was in a meeting that is critical to my district, and probably this country, with the Secretary of Commerce about trade imbalance matters. That is the only reason I would be late for the shearing. Members of Congress look out and see all these live grenades in front of us, and we have to decide which six or eight we can pick up and throw back over the wall at the same time and which ones we should allow to just continue to lie there. That is sort of what our job is like, at least on some mornings, and this is one of them.

I want to welcome each of you today to the second in a series of hearings which this subcommittee is holding on oversight for the Vocational Rehabilitation Act. Our topic, as you know, today is technology for the disabled.

Modern technology has revolutionized the chailenges faced by the rehabilitation system. The success of our efforts has been to potentially increase the number of disabled people who can participate in the labor force. Technology has itself been a major force in changing the disabled population. Advances in science and medicine have increased the life span and survival rate of people with many different types and severity of disability.

At the same time we are becoming increasingly aware of technology's potential for improving the quality of life for disabled people including improving communication, mobility, independence, and control of one's environment. Technology can provide important job opportunities for physically disabled persons through adaptation of work sites. As we approach the 21st century, further ad-



vances in microcomputers electronics and materials development can only further expand the frontiers of what we even consider as being possible today.

However, it is clear that many disabled people lack access to the existing technology which could dramatically increase their wellbeing and productivity. This problem has been addressed in the 1982 study of the Office of Technology Assessment, the 1977 White House Conference on the Handicapped, studies by the Urban Institute, and two consecutive conferences on the technological needs of the rural handicapped, and other studies as well. Clearly, our priorities in rehabilitation have missed a major opportunity, given the dramatic difference that technological improvements can make and the cost effectiveness of such investments in removing people from income support programs and increasing their economic independence.

Today we spend \$60 million on research for the disabled. Research for other health care is \$7.1 billion. More important, spending on transfer payments for the disabled is \$35.6 billion. Thus, research and development for technology which would ultimately produce revenue in taxes from employed disabled persons and a reduction in the need for transfer payments represents only 0.02 of 1 percent of the budget for transfer payments. Our policies seem expensive and to some shortsighted. They do not meet the needs of disabled people to be independent and productive.

For the past couple of years, Congress has been interested in the question of how well Government rehabilitation programs directly or indirectly develop technologies and support their use and dissemination. Three major categories of problems have been identified: Problems related to the use and modification of existing technology; problems resulting from the lack of knowledge and training about existing resources; and finally, lack of access to affordable technology. Today we will be examining the role of the Federal Government in addressing these problems.

A national commitment is needed to assure that all disabled Americans, regardless of disabi and financial status, can secure and utilize proven technologies which will enable them to live productive, satisfying lives. We look forward to hearing from each of you today about the scope of the problem and your suggestions as to how we might assist in dealing with it.

Mr. Bartlett.

Mr. BARTLET - . . . . you, Mr. Chairman.

I have looked and for a long time to this particular hearing focusing on technology and its impact on employment of persons with disabilities. This hearing is within the context of a series of hearings designed to help this committee and help Congress reauthorize the Rehabilitation Act in a way that will take it to the next step. As I think everyone has said and knows, the Rehabilitation Act has been, and continues to be today, one of the most successful programs that the Federal Government is involved in.

But as successful as it is, I think this committee has made the commitment to find ways to improve it further. And the improvements essentially would find ways to take what it is happening in the real world, or the non-Federal world, in which oftentimes we



see things that are far ahead of what is being done by the Government, and make sure that we begin to catch up.

Technological advances will be one of those areas in which I think we will look for improvements. Technological advances can for a disabled person make the difference between dependence and independence, between employment and unemployment, between full opportunity and a lack of opportunity. The existence of technology, which I see by some of the technological detices sitting over here that we are going to talk about does not necessarily result in its availability. So I think availability will be the of the issues that we will talk about.

I think the testimony today will reflect the wide range of technology which has been developed and can benefit the disabled, but it will also provide some guidance, beginning thoughts, if you will, on how that technology can be made readily available to those who need it.

I would focus during these hearings on five broad areas that need increased attention.

One: The need for a coordinated and comprehensive information system or a dissemination system of the technology that is availability.

Two: Those incertives for Government and the private sector to become involved in the application in limited markets.

Three: An increased commitment from Government agencies to engage in a joint and comprehensive, cross-cutting across agency lines, priority setting.

Four: A systematic commitment to reducing the cost of technology so it is affordable. The secret to that is capital investment and volume as it is with technology in all other fields of American life.

Five: The increase in early involvement of disabled persons in the research and development technology which may affect their lives: As we begin to look at research and development, we have to make sure that those research and development and technology is used or driven.

Now, one and about costs. It seems to me that as we go down the road in both this, the reauthorization of Rehabilitation and ther acts of the Federal Government, that we need to find ways to

the costs of technology and the costs of the benefits that the hnology offers to the savings that it accrues, to the additional benefits to both the disabled persons and to the <u>Government itself</u>. If a \$100 or \$1,000, or \$10,000 capital cost is required that will mean the difference between dependence and independence, between dependence on a Federal check and independence and full employment, then it seems to me that we have unlimited resources if we tie that initial capital cost, if we tie it to the decreasing stream of income payments that would otherwise be paid.

We know, and I have said it at every hearing, we have in this country today a 16-percent employment rate amo. disabled Americans of working age, and an 84-percent unemploy, ent rate. Technology, the removing of barriers, is one of the ways in which we can begin to increase that employment rate, and increase independent living and full productive and independent and fully employed lives.

I look forward to the hearings, Mr. Chairman.





Mr. WILLIAMS. Patiently waiting for us at the witness table representing the Department of Education is Assistant Secretary Madeleine Will of the Office of Special Education and Rehabilitative Services and the Acting Director of the National Institute for Handicapped Research Dick Le Claire.

Secretary Will, we are pleased to have you here again with us this morning. Please proceed.

STATEMENT OF MADELEINE WILL, ASSISTANT SECRETARY, OFFICE OF SPECIAL EDUCATIONAL REHABILI-TATIVE SERVICES; ACCOM: ANIED BY RICHARD LE CLAIRE; ACTING DIRECTOR OF THE NATIONAL INSTITUTE FOR HANDI-CAPPED RESEARC'S; REPRESENTING THE DEPARTMENT OF EDUCATION

Mrs. WILL. Thank you, Mr. Chairman.

I am pleased to be here today to give you some idea of the ways in which NIHR-sponsored technology research contributes to the overall goals of OSERS and how this research complements that of other Federal agencies.

NIHR is a part of OSERS [the Office of Special Education and Rehabilitative Services] in the Department of Education. It was created in 1978 by Public Law 95-602, the Rehabilitation, Comprehensive Services and Developmental Disabilities Amendments to the Rehabilitation Act of 1973, and modified by subsequent amendments. NIHR provides leadership and support for national and international programs of comprehensive and coordinated research on the rehabilitation of persons of all ages with physical and mental handicaps, especially those who are severely disabled.

The Institute's mission also involves disseminating information concerning developments in rehabilitation procedures, methods and devices which can improve the lives of disabled people. One of the most important goals of the Institute's research efforts is to help disabled persons achieve a more independent lifestyle.

NIHR supports its research activities through grants, contracts and cooperative agreements awarded on the basis of competition. The major categories of grant funding are rehabilitation research and training centers, rehabilitation engineering centers, research and demonstration projects, knowledge dissemination and research utilization projects. Applications for all of these categories are solicited in response to priorities established by the Department.

In order to be responsive to the priority areas deemed important by the researchers in the field of rehabilitation, NIHR in recent years has begun the field initiated and innovative grants competitions where selection is made from field-generated topical areas. NIHR also sponsors the Mary E. Switzer Fellowship Program, which provides support for 1 year to young or midcareer professionals engaging in rehabilitation research.

The Research and Training Center and the Rehabilitation Engineering Center programs involve long-term commitments to a program of research, training and information utilization in specific research areas. This work is carried on primarily in universities where patient/client services, research and training are viewed as interdependent activities. This allows researchers ' benefit from clinical experience, the counsel of training exper: the knowl-



edge of researchers from other disciplines to their comprehensive research.

In the case of the rehabilitation angineering centers, which are not necessarily university-based, each grantee institution is encouraged to establish official working relationships with institutions of higher learning in medicine, engineering, and related sciences for the same reason:

The NIHR cooperates closely with other Federal technology re search programs. The Director of NIHR is the Chairman of the Interagency Committee on Handicapped Research, which is responsible for promoting cooperation and collaboration in rehabilitation research carried on by the U.S. Government. Eight active ICHR subcommittees on vocational rehabilitation, technology, disability demographics, low vision, hearing impaired persons, mental retardation and developmental disabilities, children with special needs and their families and international studies keep NIHR and other agency research personnel in close contact.

Such contacts have resulted in interagency agreements, state-ofthe-art conferences and collaboratively funded Research and Training Centers, Rehabilitation Engineering Centers, research and demonstration projects, and information utilization projects.

Five jointly inded rehabilitation research and training centers, one for the aged dicapped two for psychiatrically disabled perseriously emotionally disturbed children, all funded with the dional Institute for Mental Health.

A rehabilitation technology research project with NASA, the VA, the Administration on Aging, and the National Institute on Aging to develop a memory device for mentally retarded persons and others with diminished memories.

A cost-benefit analysis research and ionstration study with the Social Security Administration of ansiticnal training program for mentally retarded individuals receiving Supplemental Security Income payments.

An example of this interagency cooperation is that of the Veterans Administration, the NASA-Langley Pesercoli Center and the University of Virginia Rehabilitation Engineering Center in wheelchair design. NIHR and NASA have collaborated in applying advanced, composite materials technology to the design and manufacture of a lightweight, general-purpose wheelchair. Computer-aided design and evaluation have been used to incorporate many important user benefits into the resulting wheelchair.

The chair has been tested at the University of Virginia and t the Veterans Administration Hospital in New York City and found extremely useful, and was offered to manufacturers at a bidders' conference on June 11. That is the wheelchair [indicating].

Rehabilitation engineering research began within the area of prosthetics and orthotics. This tradition continues, but now using advanced technology. For example, the Northwestern University Rehabilitation Engineering Center is building several prosthetic and orthotic devices that will soon become commercially available, including a new knee brace and a new mycele tric controller for an available arm prosthesis. In a rehabilitation engineering project at the Research Triangle Institute in North Carolina, computers are





being used to design prosthetic footwear. This will make custom shoes more readily available in a shorter time than ever before.

The rehabilitation engineering program of NIHR has been expanded far beyond prosthetics and orthotics because of advances in science and technology. Projects and centers are now conducting research in such areas as transportation, work and educational environments, housing, and recreation and leisure time activities for disabled persons. For example, the Northwester University REC is working on a device that allows a person with very little or no use of his limbs to use one motion to turn on lights, adjust the hear and air conditioning, or do v hatever else is necessary to control 1 home or work environment. Researchers at N inthwestern are alworking on a computer interface for severely disabled persons and a new technique for handling bone cement, which greatly increases

its strength and durability. The use of functional electrical stimulation techniques, which began with research projects in Yugoslavia funded by NIHR's predecessor—the rehabilitation research program of the Rehabilitation Services Administration—are being used to correct curvature of the spine in young women with scollosis, to assist persons with spinal cord injury to exercise, and to control urinary incontinence in elderly women. This r search promises to help restore functional performance to disabled people, enabling them to lead more comfortable, productive, and independent lives:

Other rehabilitation engineering efforts, funded by NIHR or its ther rehabilitation engineering efforts, funded by NIHR or its e horating agencies, are vitally important in making disabled persons employable by increasing their mobility. Mobility aids for blind and visually handicapped persons have increased the number of people who can work. "Talking lights" can put public transportation more easily at the disposal of blind persons. Lighted alarm systems can warn deaf travelers of other emergencies, making business stays in hotels safer for them. Memory devices are being explored for mentally retarded or developmentally disabled persons to help them keep on regular schedules. New generation hearing aids are being developed at the Lexington Center for the Deaf in New York City to utilize the latest technology in sound reception and to improve the quality of current hearing devices for hearing paired persons.

thin the Office of Special Ed

NIHR serves as the nexus be ciministration and the Office of collaboration helps to focus ion and Rehabilitative Servthe Rehabilitation Services iel Education Programs. This linate activities toward

common OSERS goals. Disa d persons of all ages and those of us will become disabled n and should benefit from the technological advances achieve, by our society, devices that can save time and energy or increase access to information and communication. The parents of disabled young persons who have seen great progress in their children through special education and educational technology are anticipating further technological advances. OSERS has set as a goal achieving the least restrictive environment, whether in education, work or community living. Part of achieving this goal is a matter of education and attitude adjustment. Another is making use of technology and assistive devices to modify schools, workplaces, rec-



reational facilities, means of transportation, and other settings of our daily life.

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Ar or effort to establish standards for automotive adaptive equipe of is underway by the Society of Automotive Engineers with partial support from NIHR. Progress has been substantial date and is illustrated by the factory developed options for ha centrols and wheelchair lifts and ramps from General Motor Chrysler, and Ford. These options are becoming generally available through the dealerships of these corporations.

Many handicapped peorle are unceremployed in this country because of such factors as the attitudes of employers, lack of adaptive equipment, improper training, and inadequate methods to evaluate their potential for performance. Rehabilitation engineering incorporated into other NIHR research and demonstration efforts is helping to overcome some of those problems.

The transition from school to work is another OSERS priority area. OSERS projects are seeking models of good transition practices throughout the United States and providing technical assistance to replicate them. We need to find creative ways to provide jobs, especially for young people, since the youthful population, enhanced by the successes of special education, is now available to enter the workforce. Pooled jobs in industry in conjunction with job coaches on site to help show promise of putting incre workers out into the community instead of in workshops cut off from the rest of the world. Technology used in industry settings as well as for personal assistive devices will make a significant contribution to this process.

The Job Accommodation Network, which is cofunded by NIHR with the President's Committee on Employment of the Handicapped, provides information from its computerized data files about accommodations employers have made to assist disabled workers. Information about such modifications to the job sites, many of which are at little or no cost, can be used to change attitudes and encourage employers to hire handicapped persons.

The Rehabilitation Engineering Center at the United Cerebra! Palsy Research Foundation and Wichita State University are developing modifications to the work c vironment using technology. l'echniques of analyzing performance of tasks by handicapped persens it lizing special tools or automated equipment such as robots are being developed and used effectively. As a result of these uses of technology at the work site, many severely handicapped individuals are now working in competitive industry and are meeting or exceeding production requirements. Under the OSERS initiative for transition from school to work, similar task adaptations are being developed and utilized for handicapped students in the school en...ronment.

The National Rehabilitation Information Center fills a vital role in the dissemination of information about technology. The NARIC database, ABLEDATA, documents over 11,000 commercially available assistive devices. The detailed ABLEDATA indexing scheme allows for retrieval of information on devices for very specific needs such as tactile carpentry tools for visually impaired persons, speech amplifiers, and typewriters and work stations adapted for a variety of needs.

-- NARIC provides ABLEDATA product information to consumers and professionals and also trains professionals who wish to access ABLEDATA directly using their own computer terminals. Searchers may join the ABLEDAT's Users' Group, which periodically receives information designed to facilitate effective retriever of product information.

Rehab Briefs, developed under contract for NIHR, is another dissemination mechanism designed to reach State and private administrators and practitioners in the rehab field. Each of the 12 Briefs produced yearly translates findings from a significant research project into concepts understandable and usable by rehabilitation counselors and other professionals: Twenty-two thousand copies of each Brief are distributed.

With respect to the transfer of techniques and new concepts, NIHR is developing a Rehabilitation Diffusion Network, modeled on the Department of Education's National Diffusion Network, to identify exemplary rehabilitation programs and practices and promote their adoption by rehabilitation practitic ers and administrators. There are currently two RDNs, one in i gion VI and one in region IX. NIHR hopes to establish one in each region.

Thank you for providing me an opportunity to appear before you. I would be pleased to answer questions and, as requested, we are prepared to demonstrate some of the recent technological advances developed under the rehabilitation engineering program. I have one that I would like to talk about; I think it is very ingenious.

This is a pair of glasses with an array of apertures spaced in such a way that it makes it easier for someone with cataracts to read, and it also protects someone who is light sensitive. This pair of glasses cost about \$1,000 to \$1,500 to develop and will be sold at about \$30-\$35. This is the sort of very simple device that can really make a difference in the life of a disabled person. I will pass that around.

I would like to ask Mr. Le Claire to talk about some of the other devices that we have brought:

[The prepared statement of Madeleine Will follows:]

PREPARED STATEMENT OF MADELEINE WILL, ASSISTANT SECRETARY FOR SPECIAL EDUCATION AND REHABILITATIVE SERVICES; U.S. DEPARTMENT OF EDUCATION

Mr. Chair nan and Members of the Subcommittee on Select Education, I am pleased to be here today to give you some idea of the way. in which NIHR spon-sored tech: ology research contributes to the overail goals of the Office of Special Education and Rehabilitative Services (OSERS) and how this research complements that of other federal agencies.

I am plented to present Richard Leclair, the Acting Director of MIHR, who will be with me today to assist in answering any questions you may have on the NIH . o gram.

## NIHR MISSION AND ACTIVE Y.

The National Institute of Handicapped Research (NIHR) in a part of the Office of Special Education and Rehabilitative Services (OSERS) of the U.S. Department Education; along with the ehabilitation Services Administration and Special Ed-cation Programs. It was cated in 1975 by Public Law 95-602. The Rehabilitation, Comprehensive Services and Developmental Disabilities Amendments to the Reha-bilitation. Act of 1973 and modified by subsequent amendments. NIHR provides bilitation Act of 1973, and modified by subsequent amendments. NIHR provides leadership and support for national and international programs of comprehensive and coordinated research on the rehabilitation of persons of all ages with physical and mental handicaps, especially those who are severely disabled. The Institute's

mission also involves disseminating information concerning developments in rehabilitation procedures, methods and devices which can improve the lives of disabled people. One of the most important goals of the Institute's research efforts is to help disabled persons achieve a more independent lifestyle.

Air and the supports its research activities through grants, contracts and cooperative at eemenis awarded on the basis of competition. The major categories of grant funding are Rehabilitation Research and Training Centers (RTCs); Rehabilitation Engineering Centers (RECs); Research and Demonstration Projects; and Knowledge Dissemination and Research Utilization Projects. Applications for all of these arts Dissemination and Research Utilization Projects. Applications for all of these categories are solicited in response to priorities established by the Department. In order to be responsive to the priority areas ceemed important by researchers in the field Grants competitions, ere selection is made from field-generated topical areas. NIHR als sponsors the Mary E. Switzer Fellowship Program, which provides support for o year to young or mid-career professionals engaging in rehabilitation re-

The Research and Training Center and Reliabilitation Engineering Center programs involve long-term commitments to a program of research, training and information utilization in specific research areas. This work is carried on primarily in universities, where patient/client services, research, and training are viewed as interdependent activities. This allows researchers to benefit from clinical experi-ence, the counsel of training experts, and the knowledge of researchers from other disciplines to their comprehensive research. In the case of the Rehabilitation Engineering Centers, which are not necessarily university-based, each grantee institution is encouraged to establish official, working relationships with institutions of

highe: tearning in medicine, engineering and related sicences for the same reason. The NIHR cooperates closely with other federal technology research programs. The Director of NIHR is the chairman of the Interagency Committee on Handi capped Research (ICHR), which is responsible for promoting cooperation and col-laboration in rehabilitation research carried on by the U.S. Government. Eight active ICHR subcommittees—vocational rehabilitation, technology, disability demographics; low vision, hearing impaired persons, mental retardation and developmental disabilities, children with special needs and their families and international studies-keep NIHR and other agency research personnel in close contact. Such contacts have resulted in interagency agreements, state-of-the-art conferences and collaboratively funded Research and Training Centers (KTCs), Rehabilitation Engineering Centers (RECs) research and demonstration projects, and information utili-

Examples include:

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An example of the interagency cooperation is that of the Vet rans Administre-tion, the NASA-Largiev Research Center and the University of Virginia Rehability tion Engineering Center in wheelchair design. NIHR and NASA have collaborated in applying advanced, composite materials technology to the design and may facture of a light weight, general purpose wheelchair. Computer-aided design and evalaction have been used to incorporate many important user benefits into the resulting wheelchair. The chair has been tested at the University of Virgin and at the Veterans Administration hospital in New York City and found extremely useful and was offered to manufacturers at a bidders' conference on June 11:

# Rehabilitation engineering

Rehabilitation engineering research began with in the area of prosthetics and orthotics. This tradition continues, but new using advanced technology. For exam-ple, the Northwestern University Rehabilitation Engineering Center is building sev-eral prosthetic and orthotic devices that will soon become commercially available. including a new knee brace and a new myoelectric controller for an available arm prosthesis. In a rehabilitation engineering project at the Research Triangle Institute



in North Carolina, computers are being used to design prosthetic footwear. This will make custom shoes more readily available in a shorter time than ever before. The rehabilitation engineering program of NIHR has been expanded far beyond

prosthetics and orthotics because of advances in science and technology. Projects and centers are now conducting research in such areas as: transportation, work and educational environments; housing, and recreation and leisure time activities for disabled persons. For example, the Northwestern University REC is working on a device that allows a person with very little or no use of his limbs to use one motion to turn on lights, adjust the heat and air conditioning, or do whatever else is necessary to control his home or work environment. Researchers at Northwestern are also working on a computer interface for severely disabled persons and a new technique for handling bone cement, which greatly increases its st ength and durability.

The use of functional electrical stimulation techniques, which began with re-search projects in Yugoslavia funded by NIHR's predecessor (the rehabilitation re-search program of the Rehabilitation Services Administration) are being used to correct curvature of the spine in young women with scoliosis, to assist percons with spinal cord injury to exercise, and to control urinary incontinence in elderly women.

spinal cord injury to exercise, and to control urinary incontinence in elderly women. This research promises to help restore functional performance to disabled people, enabling them to lead more comfortable, productive and independent lives. Other rehabilitation engineering efforts, funded by NIHR or its collaborating agencies, are vitally important in making disabled persons employable by increasing their mobility. Mobility aids for blind and visually handicapped persons have increased the numbers of people who can work. "Talking lights" can put public transportation more easily at the disposal of blind persons. Lighted alarm systems can warn deaf travelers of fire or other emergencies, making business stays in hotels safer for them. Memory devices are being explored for mentally retarded or develop-

mentally disabled persons to help them keep on regular schedules. New generation hearing aids being developed at the Lexington Center For The Deaf in New York City utilize the latest technology in sound reception to improve the quality of current hearing devices for hearing imprired persons.

# HOW NIHR TECHNOLOGY RESEARCH SUPPORTS USERS GOALS

Within the Office of Special Education and Rehabilitative Services, 21HR serves as the nexus between the Rehabilitation Ser ices Administration and the Office of Special Education Programs. This collaboration helps to focus and coordinate activi-ties toward common OSERS goals.

## The least restrictive environment

Disabled persons of all ages are those of us who will become disabled, can and should benefit from the technological advances achieved by our society-devices that can save time and energy, or increase access to information and communica-tion. The parents of disabled young persons who have seen great progress in their children through special education and educational technology are anticipating further technological advances. OSERS has set as a goal achieving the least restrictive environments, whether in education, work or community living. Part of achieving this goal is a matter of education and attitude adjustment, another is making use of technology and assistive devices to modify schools, workplaces, recreational facilities, means of transportation and other settings of our daily life.

A major effort to establish standards for automotive adaptive equipment is under way by the Society of Automotive Engineers with partial support from the NIHR. Progress has been substantial to date and is illustrated by the factory-developed op-tions for hand controls and wheelchair lifts and ramps from General Motors, Chrys-ler, and Ford. These cptions are becominerally available through the dealerships of these corporations.

### Employment

inderemployed in this country because of such fac-Many hand, apped re tors as the attitudes of en. ployers, lack of edaptive equipment, improper training, and inadequate methods to evaluate their potential for performance. Rehabilitation engineering, incorporated into other NIHR research and demonstration efforts; is helping to overcome some of those proviems.

The transition from school to work is another OSERS priority area. OSERS projects are seeking models of good transition practices throughout the United States and providing technical assistance to replicate them. We need to find creative ways to provide jobr, especially for young people, since the youthful population, on-hanced by the successes of special education, is now available to enter the work-



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force. Pooled jobs in industry, in conjunction with job coaches on site to help, show promise of putting more workers out into the community instead of in workshops, cut off from the rest of the world. Technology used in industry settings as well as for personal assistive devices will make a significant contribution to this process. The Job Accommodation Network (JAN) which is co-funded by NIHR with the

The Job Accommodation Network (JAN) which is co-funded by NIHR with the President's Committee on Employment of the Handicapped, provides information from its computerized data files about accommodations employers have made to assist disabled workers. In ormation "bout such modifications to the job sites-many of which are at little or rocost-can be used to change attitudes and encourage employers to hire handicapped persons."

The Rehabilitation Engineering Center at the United Cerebral Palsy Research Foundation and Wichita State University are developing modifications to the work environment using technology. Techniques of analyzing performance of tasks by handicapped persons, utilizing special tools or automated equipment, such as robots, are being developed and used effectively. As a result of these uses of technology at the worksite, many severely handicapped individuals are now working in competitive industry and arc meeting or exceeding production requirements. Under the OSERS initiative for transition from school to work, similar task adaptations are being developed and utilized for handicapped students in the school environment.

## THE UTILIZATION OF RESEARCH INFORMATION

The National Rehabilitation Information Center (NARIC) fills a vital role in the dissemination of information about technology. The NARIC database ABLEDATA documents over 11,000 commercially-available assistive devices. The detailed ABLE-DATA indexing scheme allows for retriever of information on devices for very specific needs, such as tactile carpentry tool for visually impaired persons, speech amplifiers and typewriters and work stations adapted for a variety of veds.

NARIC provides A DLEDATA product information to consumers and professionals, and also trains the circle with the access ABLEDATA directly using their own computer terminals. Searchers may join the ABLEDATA directly using their periodically receives information designed to facilitate effective retrieval of product information.

Rehab Briefs, developed under contract for NIHR, is another dissemination mechanism designed to reach State and private administrators and practitioners in the remainstration field. Each of the 12 Briefs produced yearly translates findings from a significant research project into concepts inderstandable and useable by rehabilitation counselors and other professionals. Twenty-two thousand copies of each Brief are distributed.

With respect to the transfer of techniques and new concepts. NIHR is developing a Rehabilitation Diffusion Network. (RFN: nodeled on the Department of Education's National Diffusion Network, to identify exemplary rehabilitation programs and practices and promote their adoption by rehabilitation practicioners and administrators. There are currently two RDNs—one in Pegion VI and one in Region IX. NIHR hopes to establish the in each region.

Thank you for providing me the o portunity to appear before yo . I would be pleased now to respond to any questions and as requested we are prepared to der onstrate recent technological advances der eloped under the rehabilitation engir ing program.

Mr. WILLIAMS. Mr. Le Claire, do you have a statement, or do wish to provide us with additional information?

Mr. LE CLAIRE. I would just like to go over some of these Levices we have very quickly, Mr. Chuirman, if you will allow me.

This is the wheelchair mentioned by Secretary Will that was developed by NASA and us, NIHR, and also tested by VA. It is made of a composite material, and it is about the lightest wheelchair there is in terms of strength to weight ratio. It is really dependable and durable.

It was tested, as I said, at the VA; and also at the University of Virginia Rehab Center. Right now, we have had a bidders' conference and we are waiting for the final decision.

Again, it is a good example of something where we worked together as agencies.



Mrs. Will. Dick, show the back

Mr. LE CLARE. The back end is made of Velcro. It can come apart and stretch out. The seat is made rigid. This is research that we did many years ago at the Terrer Institute for Rehab Research where we found what pressure on the left in any she chains do. In other words, if you have a sagging seat, which many she chains do. Not have a better chance of having pressure sort. But it you have a solid seat, the chances are much better that the second dot is other publics So actually it combines some of the tork due to other publics with what we know now.

It has many, many other advantages. It was outst have arms. That is an option: You can have arms if you want to, side arms, and there are other variations that can be reade.

Now to go quickly on to other things I can an aver more questions on that if you would like. We feel that it is a real good example of interagency coordination and also working are industry.

Next, I thought I would go to the speaking b arc for people who have speech problems, both children and adults.

We have with us several people from the Tuits Rehab Engineering Center who will show us how it works. This is Mr. Michael Demasco.

Michael, if you could show us how the Speaking Board works for nonvocal people.

[Demonstration.]

Mr. WILLIAMS: Can that answer questions if we have questions for it? [Laug iter.]

Mr. LE CLAIRE. The beauty of this is that the voice is probably the best I have ever heard. It is developed by Digital Equipment Corp., and, of course, the Tufts Rehab Engineering Center is developing the boards.

Again, we find in utilization and we are learning after many years of experience that the best thing to do is for our grantees or engineering centers to start very early on working with industry, so that when they finish the development that industry will pick it ip and produce and market it. The earlier you start, the better off we are, and this is a good  $\leftarrow$  imple. It is still in the developmental stages. By the way, there are other boards like this developed at the Trace Center in Madison, WI, but I think here that we are talking about the latest development and the best voice that we have been able to find. Hopefully this will be marketed, produced and distributed because it is partly owned by industry right new. The next thing I thought we would show is this little commercially available robot, and there we are getting into various equip-

cially available robot, and there we are getting into various equipment and devices that are beneficial from a vocational point of view. There is nothing that unique about it, but it is for us. We have not gone into using too many robots, commercially available robots, for use by disabled individuals. This particular one is to be used—right now it is being tested clinically with severely disabled children, to get them used to manipulating robots. Later on, in a work site situation, they could use this robot no matter how disabled they are and function in a work capacity

We have got several centers doing this now. One at Wichita Reheb Engineeting Center is also experimenting. This one is from Tufts. If we could take a minute, we will show you how it works.



Hopefully, this gentleman can do that for us This is Scott Minneman.

[Demonstration.]

Mr. LE CLAIRE, i guess what this shows is that by having different types of switches, depending on the person's hundicap, they can operate a robot. It could be a voice-activated switch, it could be an elbow switch, it could be almost any kind of a switch that you could adapt for the me vidual and make it possible for that person regardless of their handicap within limits to operate a robot of this type at a work site.

Mr. WILLIAMS. M. Martinez, do you have a question?

Mr. MARTINEZ. Yes. What makes this different or distinguishes it from that already in play in many industries that I have seen where they have the exact same thing?

Mr. LE CLAIRE. The difference here is that we are experimenting with different types of switches so that they can operate the robot. Mr. MARTINEZ. So it is not the principle there, it is the switching mechanism?

Mr. LE CLAIRE. No, not the robot, it is the switching. That is correct, sir.

Mr. Martinez. OK

Mr. LE CLAIRE. That varies with the individual's disability whatever that might be

Mr. MARTINEZ. Most of them that I have seen are actually operated by punching keys.

Mr. LE CLAIRE. Yes, that is correct. But you could actually operate this by voice. You program it with voice commands to tell it to move and whatever and it will do that if you don't have any handarm dexterity at all.

Mr. MARTINEZ. So really the project is to develop a way that a handicapped person, and not just with one single handicap but maybe a varied number of handicaps would be able to operate any mechanism. This is just an application of that, but that could be an application to something else.

Mr. LE CLAIRE. It could be.

Mr. MARTINEZ. While I am on it, I never really did understand that voice box, since we have tape recorders and you can pretape a message into a tape recorder and break it up any way you want to. How does this differ from that that is already available?

Mr. LE CLAIRE. OK.

Mr. DEMASCO. I didn L lear the question.

Mr. MARTINEZ. How does this differ from what is already available through all the varied and multiple different kinds of tape recorders that we have already? As I understood, you prerecorded a message and that person, then, who wasn't able to speak could press a button and that message would come on.

Mr. DEMASCC. The board itself will accept words, messages or letters and has a limited speech capability. At can say essentially, anything. That was just a particular square that was programmed——

Mr. MARTINEZ. So when the chair nan asked if it could answer a question, it could?

A VOICE FROM THE VOICE BOARD. Yes. [Laughter.]

Mr. LE CLAIRE. In other words, 'e had tape-recorded a message in there because we didn't know how much time we had so we could show the voice—

Mr. MARTINEZ. But you have a lot of words that are programmed in there so in some way you could respond to almost anything that a person asked?

Mr. DEMASCO. As well as the alphabet. So, if a word or message isn't on here, you can always spell it out.

Mr. MARTINEZ. Spell it out.

Mrs. WILL. Do you have any idea how much it cost, the development? Can you answer on the board? I am trying to think of a question-you could answer on the board.

How long did it take to develop this?

A VOICE FROM THE VOICE BOARD. Six months.

Mr. LE CLAIRE: And on the cost, I don't know. I could get those amounts for you, but it is one of the many sub-projects of the Tufts Rehab Engineering Center.

Mrs. WILL. Young people use boards of this sort. They are extremely dexterous with them. They communicate with you very, very rapidly. Lots of sentences.

Mr. LE ČLAIRE. The difference with this board now is that the voice is much, much better. Some of the r boards you could barely understand the voice. Now we as used because of this company that made a very good voice.

Mr. DEMASCO. There is another message on here.

[Demonstration.]

Mrs. WILL One of tasks for developers is to come up with a more normal sounding voice. This represents an achievement in technology. Women, for example, would like a board that had a voice with female tones.

Mr. LE CLAIRE. That has been very difficult, to come up with a voice that speaks like a female.

Mrs. Will. They say the board sounds like Donald Duck; and they don't want to sound like Donald Duck.

Mr. LE CLAIRE. If there are no other questions, I can move on rather quickly. We have here an artificial arm for a child. This is how it looks on the child. This was developed at the Northwestern Rehab Engineering Center and the Rehab Institute of Chicago. This is for a child that has no arms at all. Fortunately, there aren't too many of them, but when we have that kind of a situation there are few devices, and this is one of them, that can be placed on a child for at least feeding purposes and to some extent for dressing, out they have to learn to do that. It is mostly for feeding and for toiletry, brushing your teeth and what have you. It is somewhat limited but still has quite a bit of range of motion and can do quite a few things, especially feeding.

This is one example of a prosthetic device that we do develop, and I guess one of the few that focuses on children's prosthetic devices. There aren't too many working in this area at the present time. This is an example of the fairly recent new development in



upper extremity prosthetic devices. But very limited, just for children who have no arms at all.

Finally, we have a Lrinary incontinence device and a developed in Yugoslavia. They have a project in Ljubly stavia, for control of stress incontinence in older ladies. We this has great potential. It is being tested this summer in nursing homes. If it works, we think that it would mean that we could some extent control incontinence in older ladies, which could mean that we could delay their entering nursing homes in many cases. It seems like a minor thing, but we feel it is probably one of the biggest developments we have come up with in many years.

It uses functional electrical stimulation, and that is one of the spinoffs that was mentioned in Mrs. Will's presentation. It is being tested this summer, and we hope that it will be manufactured; produced and sold in this country if it passes the FDA and the tests that it is going through.

Those are some of the things that we have that we thought we would bring to show you. I would be glad to answer any more questions on these.

Mr. WILLIAMS. Mr. Le Claire, we appreciate you and you associates taking time to set up this demonstration and share it with us.

Mr. Martinez, do you have any other questions of Mr. L- Claire or any questions of Mrs. Will?

Mr. MARTINEZ. Mrs. Will, what policies and programs does the administration have in place that are designed to encourage or share effective involvement of the disabled in the development and delivery of these technologies?

Mrs. WILL I think there is extensive involvement of discipled people in the decisionmaking process. We first include disabled people on our peer review parts. That is as a matter of policy now. We are obligated to work with the National Council on the Handicapped, is now an independent agency, to develop priorities. This is an ongoing process.

We have, in addition, created a number of consumer advisory committees. I created one this past year that is made up of parents and disabled consumers, and the purpose of the committee is to advise us as to the needs of disabled people and families of disabled individuals.

We work closely with the professional organizations such as the Rehabilitation Engineering Society of North America. A large portion of the membership of that organization is made up of disabled individuals.

We are eager to gather information, to seek advice from disabled individuals and we will continue to do so. I would say lastly that in the formal process of developing priorities we bring together a large number of individuals, professionals as well as consumer; to develop a long range plan for the National Institute of Handicapped Research, and we will continue to do that:

Mr. MARTINEZ. Has any assessment been made to ensure that those policies are effective? As you have gone through, have you done any assessment to see that that is the best way of reaching most of the people that are available to give input, and that the best decisions are being made?



Mrs. WILL. Well, we think there is no better way to evaluate a policy concerning the involvement of disabled people in the process than to talk to them. I think we have created avenues for input from disabled individuals and, of course are always receptive to new ideas, new strategies for seeking their inputs. The State agencies of vocational rehabilitation have advisory committees and other organizations have advisory committees at the local level. We encourage the participation of disabled individuals in these working groups.

Mr. MARTINEZ. One last question. You mentioned when you were referring to the glasses that they cost \$15,000?

Mrs. Will. No, it was \$1,500 to develop, but they will be marketed at \$35:

Mr. MARTINEZ. What you referred to is the cost of the research and the engineering and all that.

Mrs. WILL. Right.

Mr. MARTINEZ. But the actual manufacturing should cost somewhat less:

Mrs. WILL. Right.

Mr. MARTINEZ. And be able to be marketed at \$30?

Mrs. WILL. Um hum.

Mr. MARTINEZ. Thank you.

Mr. WILLIAMS. Mr. Bartlett.

Mr. BARTLETT. Thank you, Mr. Chairman. It is good to see my good friend the Assistant Secretary, who is doing such a great job for all of us at the Department and in the administration.

Mrs. Will. Thank you.

Mr. BARTLETT. I would like to switch over a little bit to address the question from the viewpoint of the consumer. I wond r if you could—when we discussed earlier the 34-percent uner doyment rate among disabled persons and such. I wonder if you could tell us with as much specificity as you have available how core ners who have needs for the new technologies that are emerging to are currently not using them, and therefore that may well me that they are unemployed or that they can't lead indep indent lives: First, and maybe those consumers are on SSI or SSDI, or make they are not; maybe they are just depending on their own resources.

First, typically how do consumers learn of the new products that are available? And second, how do employers learn in today's world of new products and new technologies that will make their job sites accessible to disabled persons? And third, how are the products and for?

Frealize that that could take about a 3-day seminar just going

We with the me take each question separately. There is extension of the asseminate information about technology. It just permeates NIHR and the awards that it makes. I mentioned the National Rehabilitation Information Center, NARIC, and ABLE-DATA, which contains information about 11,000 discrete devices and pieces of technology. There is an ongoing effort on the part of NARIC which is funded I think at the level of \$800,000 to disseminate information through periodicals, through sending of staff to participate in workshops and contenences: to taking advertisements in professional periodicals. We publish rehabilitation research re-



views which are state-of-the-art summaries of research findings in key areas. For example, the delivery of vocational rehabilitation to rural populations. We have briefs, again, technological advances in crafting an issue around that piece of advance. We circulate about 22,000 copies of those We have the Rehabilitation Diffusion Networ. System, which i an attempt to duplicate something that was a project created in Department, or an initiative created in the Department whereby you identify exemplary projects and highlight them in a variety of ways.

There is some interest in developing volunteer dissemination systems at the local level. There have been some created in Australia and Britain, and there is an effort underway to do that here and it seems to be working very well. Volunteers identify disabled people, their needs, and they bring the information to them.

Mr. BARTLETT. Madam Secretary, if I could interrupt you at that point. I wonder if you could, if you have information available; if not, if you wouldn't mind if we would leave the hearing record open. I see Alton Hodges over nere and other people in your department that could, perhaps, quantify for us. What you are describing is how the information goes out.

Mrs. WILL. Right.

Mr. BARTLETT. What I am asking is what evide be do we have as to how much of the information is being receive and used? How many consumers have said, oh, yes because I beard about this from the data base, from the Ne data base, I, therefore, learned of a device that let me see me work? Or, how many employers actually can take our dense is se and use it, or insurance companies?

That is a long question which you may not be equipped to answer today.

Mrs. Will. It is a question that the answer to which has to be based in data, and I don't know that we have the data. We have continually sought to refine the kinds of information that we have about disabled people. A better sense of the severity of their disability and the kinds of accommodations that would enable them to function in the workplace. I really don't think that we have the kind of specific information that would—where we can—

Mr. Martinez. Would the gentleman yield?

Mr. BARTLETT. I would be happy to yield.

Mr. MARTINEZ. Mr. Bartlett brings up a good point: Because not too long ago I was on an airplane and I saw a film on a new prosthetic device; a foot that allowed a person to walk normally, as nor mally as possible. Later I was talking to a person that had his foot amputated because of cancer, and I was telling him about this device. He didn't know about it. Through my office we did research or it and found out where we could get the information for him. He has it today and it is working quite well for him.

But when Mr. Bartlett started to ask that question I thought about him. He had been in a hospital, had a foot amputated, and not one person through that whole process ever advised him of what was available. That is what he was talking to me about. You know, he was really disheartened about his condition because he had been quite an active person.



Is there a mechanism and a way that we would know of all the handicapped people in the United States, or is there? Some place they must be registered. They are either handicapped at birth or they have been in for an amputation like this. There has got to be some system. And it intrigues me, the question he asks, because most of the time when we develop things, the people out there that really reed them, a great number of them never really know about it, or realize it. They may live their whole life and never realize it.

Mrs. WILL. I don't think there really is a systematic collection of information about disabled people. We collect a lot of information through special education about handicapped children. We, in other parts of the Federal Government, the Veterans' Administration will have a great deal of information about disabled veterans. But we don't have a systematic, comprehensive system of data collection. We have encouraged the Bureau of the Census, for example, to ask more questions that will lead to more refined information about the disabled.

Disabled people often don't choose to identify themselves as disabled. That is the kind of factor that would affect the information that you have. People come in and out of the disability continuum. They will be injured in an industrial accident and impairs for a period of years, and then they improve to the point that they consider themselves no longer disabled. You have people who have been functioning normally for most of their lives, but through the aging process become visually impaired or hearing impaired. Again, we would not have a way of tracking those individuals.

Mr. BARTLETT. I thank the gentleman for his question. I don't think that we want to go toward a master list by any means. But as we consider this legislation, one of the key issues that we are going to have to look at is a way to legislatively or administratively improve the dissemination of information. The gentleman from California has cited an example and I could cite dozens of examples that happen every day. One happened to my dad 6 months or so ago when he went in to get a—he los<sup>4</sup> his leg in the war and he went in to get a new leg. The old one was only 15 years old or something like that. He sort of had to wade through the VA bureaucracy and finally discovered that there was a new foot on thmarket with which, for the first time in 40 years, he could run. No one tr'd him that. He asked his congressional office to help him and they couldn't help him, either. But he did find it out essentially on his own.

There is no catal g I suppose. So, if we could hold the hearing record open, it is important for us to know whatever data you have available or can assemble as to what kind of information is being received and used by the consumers. And by consumers I mean both the disabled persons, insurance companies and the various agencic dovernment agencies and other agencies, so we will know where we start. And then if you could advise us on any ways to improve the legislation. If, in fact, we discover that that dissemination is not as well received as it is well given, then perhaps there are some ways to improve the legislation to bee that part up.

Now, the whole second part of the question is then, which is not so easy—1 mean, the first one was to gh enough to answer, but the



second one is much tougher. And that is, who pays? And there is a variety of people who pay, and ought to.

Mr. WILL. Well, the answer to that question is a priority of NIHR and we are undertaking studies to examine these sorts of issues, the reimbursement policies and issues, and hope to be able to provide better information for the committee and for the Congress.

The cost of technology and who pays is at the heart of how we successfully utilize----

Mr. BARTLETT. Well, exploring that, I wonder if your department could think through with this committee over the next 6 months. The question is, is there a way to essentially capitalize the cost? There is not an unlimited amount of money in the Government or anywhere else, no: should there be. We have finite resources. But one of the resources it seems to me that is available is that promise to pay of continuing support payments; that is, keeping people warehoused for the rest of their lives, which is an enormous cost. Some estimate just for Government alone \$180 billion a year. That \$150 billion per year, that is a pool of money that is in the form of a promise to pay.

So my question you could think through with us. Perhaps there is some ways both with Government and with insurance companies to back those costs back into a capital cost and pay for the costs of the new-devices out of the newly found employment. That is to say that disabled person will then be able to work and not have to receive the cash benefit on a monthly basis, so perhaps there is a way to back those cash benefits back into the system. No one has yet devised a way that has met all the tests.

But I wonder if you are interested in pursuing it.

Mrs. WILL. Well, I agree totally that if you, as a disabled person, listen to the message that is sent from the Federal Government it is telling you to be dependent. It is so much easier to get into the dependency cycle than it is to find your way into employment and to overcome the variety of barriers. I think we are looking at some of these barriers very seriously. The inability of people to support the cost of medical care. A disabled individual is going to utilize the health care system much more than a nondisabled person, and that always has to be a consideration in deciding whether to work.

Mr. BARTLETT. But a disabled person who is unemployed is going to utilize that medical system a lot more than that same person with the same disability who is employed.

Mrs. WILL. Yes, absolutely. The more people work, the less they use the health care system, the fewer related services and support services they require. The longer a person works before becoming disabled, the faster he is likely to return to work. There are all sorts of correlations that have a profound impact on the cost of disability to the country.

Mr. BARTLETT. You know that we have discussed, and I know that you are not prepared today to have any kind of a position, but I know that you are exploring it. But we have discussed H.R. 2030, which I introduced earlier in the year, which would make the 1619 Social Security permanent, remove that barrier, if you will, to persons who want to go off of SSI and onto full employment, but also

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to provide technical assistance to employers. Not to support them in making the job site accessible but to provide technical assistance to make sure-to disseminate that information on the technology that is available so that employers can make their work sites available to disabled persons.

I wonder if you have any preliminary thoughts as far as the direction of that kind of legislation, and can you tell us what timetable the administration is on in analyzing that legislation?

Mrs. Will. The legislation is being reviewed by the Department of Education. I would hope that in the next month or so that we would have a position developed. To the extent that you are seek-ing to develop legislation that will provide incentives to employ people and to move people into independent living, I applaud you. I don't want to speak to the specifics of the legislation. I am not prepared to do that today. But I think we are at a juncture in the care and treatment of disabled people where we are going to be overhauling our-Federal system, and that system is mirrored at the State and local level, so that barriers are eliminated and incentives to employment are included and incorporated into our service-

Mr. WILLIAMS. The gentleman's time has expired. Mr. BARTLETT. Thank you, Mr. Chairman.

Mr. WILLIAMS. It seems obvious that consumer demand is insufficient to encourage the private marketplace sufficiently to provide low cost, front end equipment such as we see here today at a reasonable price. So my question goes to my uncertainty of how we deal with that lack of economic supply and demand law in this marketplace. Does the public have a mechanism to facilitate transfer of technology and then market it? Is that the National Institute? If so, how is that accomplished through the Institute?

Mrs. WILL. We have undertaken to do market analysis on behalf of private corporations. For really the first time we are beginning to do such studies so that we better understand the problems that private industry faces as they seek to develop devices. There is the issue of cost, the durability, maintenance. There are many devices that individuals indicate they like very much, but it takes months to have the particular device repaired. There is the problem of the acceptance of technology on the part of disabled individuals, and there is a gap between generations. Youngsters are more likely to adapt quickly to technological devices.

Two tasks were written into the long range plan for the Rehabilitative Services Administration. One was the development of a business council, a business advisory, which would bring us representatives from major corporations and small business to discuss the issue that you raised and others, technology transfer and the em-ployment of disabled individuals. We are also interested in better integrating the rehabilitation engineering system in the rehabilitation process. A client comes into an agency and there is an evaluation done and a plan is developed, and an array of professionals are involved in the development of that plan, and then there is supposed to be an employment outcome. One of the concerns that has been expressed by consumers has been the nonintegration of rehabilitation engineers in that process.

On the employer's side we have a number of information centers where an employer can go to answer a question about a particular



emplyyee, or a potential employee. I would like to hire this disabled person but I don't know how he is going to operate the telephone or sit at the desk, and so forth. So we have the job accommodations network which can provide information very quickly to an employer about the specifications for the job accommodation. Incidentally, one of the most important side benefits of this information about job accommodations is helping to destroy this perception out in the country that accommodation costs are exorbitant. That if you hire a disabled person it is going to cost you \$30,000 in order for that person to get into your building. That is not true. Our statistics have shown again and again that 90 percent, or more than that, 95 percent of accommodations cost less than \$200 or \$300. So information systems like JAN that provide information to employers are of real benefit to the disabled.

We are also evaluating the kinds of technology that we develop. We look at technology that exists and evaluate it in terms of whether it might be modified because that often can be done inexpensively. The Electronics Industries Foundation is an organization that we work with very closely, and it is involved in the market analysis and the evaluations that I spoke of earlier.

Mr. WILLIAMS. All of that probably assists in providing, I will use the term industry or business, with some financial gain or assistance which otherwise they would have had to provide on their own. If they had to do that, of course, it would limit even further their profit margin. So those things that you are describing assist the dilemma that I presented to some degree, but it seems to me that an even more significant public role, financial role, would be required if we were to level this uneven playing field of supply and demand that obviously exists in this marketplace.

My question is, is there any public mechanism or mechanisms which assist in a very direct way in changing that supply and demand equation that so runs against disabled people being able to afford this type of equipment? Now we do it in many areas in America. We have found that getting oil out of the ground is in the public's best interest and so we provide enormous tax mechanisms by which we can do that and the industry can make money. Do we have any mechanisms like that for the industry that provides this type of assistance to people in need?

Mr. LE CLAIRE. If I may, to my knowledge we have no real mechanism at the moment. In many cases, too—each case is different. I guess we have to look at individual situations. One way that we know, and I can suggest a number of ways, is to take something like the synthesized voice. It was developed really by us, starting 20 years ago with MIT, for the blind. We developed a voice for the blind, so that we could put it on a computer. Ir these days we didn't have computers. I am thinking of sc. y could get up on a scale and know how much they weigh.

Well, down the road we found that the synthesized voice, about 8 years ago, was about \$6,000. Well, that was two expensive for us to do anything with it. So then we started trying to think, just the few of us, how could industry use something like this. In those days industry wasn't interested. Suddenly the idea came up, that it could be used for a toy. If some industry could pick it up and use it



in a toy, then the price would go down. That is exactly what happened. We had very little to do with that, but eventually Texas Instruments picked it up, put the synthesized voice the in a toy, and in no time at all the price went down. Now we can use the voice all over the place for all kinds of different things, including on a scale and on a thermometer and what have you.

Right now Electronics Industries Foundation, a big grantee that we have, is trying to struggle through some of these concepts. One way is to try to think of things that can be commercialized more broadly.

Also, it expanded overseas, strangely enough: A small company did develop something, really a talking computer for the blind with the voice in the thing. Pretty soon he had saturated the market in this country and it was quite expensive. And someone suggested to him:

"Well, why have you ever tried using it overseas?" "Well, no."

He is just a small company in California.

"I never thought of going overseas.

"Why don't you put a French voice on it, a German voice on it, even a Japanese voice on it, and see if you can't market it overseas?

That is exactly what he has done; and now he has expanded his market.

There are certain techniques that we know about but no general rule at the present that we can come up with. I can suggest certain things that people overseas do. The Swedes, for example, have been into this for many years. They have a program which is really a contingency fund that the Government provides to small industries to be able to do development in technology for the disabled. If that company is able to make a profit, they have to repay the contingency fund. So that is one approach that they use. I am not too sure how successful that is. The last I heard the fund was empty. That was about eight months ago when a Swedish gentleman came by and said, "We have no more money in the fund. Now we have to go back and get the Government to put more money in the fund." How long it lasted I don't know.

There are certain kinds of incentives that the Electronics Industries Foundation is looking at and it is only a beginning. One of them is providing small companies technical assistance in terms of how to get through the system for patents and what have you. They are providing them with all kinds of, or trying to help them with market surveysand so on, other incentives that they could provide.

It is not a solution to the problem. No, it isn't. I would say that we need to do much more study in terms of how we can resolve this problem. These are merely potential solutions in certain areas, but not an overall plan on how to resolve it.

Mrs. WILL I think this is a fertile area for interagency coordination. Because NIHR can study the reimbursement questions, we know that we don't understand those yet, but the reimbursements come from another part of the Federal Government. Probably the Health Care Financing Administration, Medicaid, for example, and there it seems that the regulations and even statutory language



are not clear about whether reimbursements for devices can be made or not made. We see our role as that of having to do the research and develop these devices, create the prototypes to reduce the costs so that they are affordable, and then to disseminate that information to employers.

One motivation, or one very stark fact that I think is propelling employers in the direction of seeking information about devices and technology, is the cost of supporting a disabled employee who has to leave the firm because he has had a stroke or whatever. It is enormously expensive for industry, and we are getting tremendous interest in the development of disability management at the work site on the part of the business itself developing its own rehabilitation unit to make sure that it doesn't lose the valued employee who worked for the firm for 15 years and who had the stroke or the heart attack. This is an area that we are watching very closely, and it is just growing enormously, expanding tremendously.

Mr. WILLIAMS. Well, there is a debate raging—I think that is the accurate term—a debate raging now over the success or the viability of certain public mechanisms that have interceded in the marketplace. It seems to many of us that during the past 50 years public intercession on behalf of certain segments of our economy has really reaped massive good fortune for the country. I can think of two: energy and agriculture. We haven't been perfectly successful with either, but our successes in both have far outstripped those of any other nation.

The public has interceded when it has found that supply and demand do not work well in a certain segment of the markstplace but with a public mechanism it can be made to work better. It would seem to me that although we are dealing with a far smaller client population here than we are with regard to those other two areas I mentioned—agriculture and energy—nonetheless, this is a very important matter; this leveling the playing field equally for all Americans. It would seem to me that it is long overdue that there be some type of a public interest expressed and a mechanism created to assist getting equipment; material and aids such as we see before us on the table to those who need them at a very inexpensive cost.

My colleague, Mr. Bartlett, has a followup question. I-will have to leave for a few minutes to attend another committee hearing, and I will ask Mr. Martinez to chair this hearing for a short while.

Mr. BARTLETT. I would like to follow up on your comment that Medicare—there is some uncertainty under what circumstances Medicare will pay for medical devices. Can you tell us where the uncertainty is and under what circumstances does Medicare pay for devices that accrue to independent living and what circumstances does it not?

Mrs. Will. I am not sure I can answer that question. I would like to answer that in writing.

Mr. BARTLETT. OK, we will hold the hearing record open. You might also answer it for us for vocational relate agencies, and also, if you have any data, on private insurance companies, which may be a larger pool than all of the above:



Mrs. WILL. Rehabilitation dollars are used to purchase devices because it enables the person to become employable, but I really need to look at the Medicaid regulation.

Mr. BARTLETT. You could give us a number of the total dollars for vocational rehabilitation, how much are used to pay for devices, essentially what are the rules, and such as that. I am particularly interested in insurance companies. It seems to me increasingly apparent to insurance companies who are rapidly discovering that it is far less expensive to retrain and retain a disabled employee than it is to merely keep them and pay them disability payments for the rest of their lives, and sometimes that means job accommodations and oftentimes it means various technological devices. So, if you have any kind of a sense as to what insurance companies are typically doing with paying for devices it would be very helpful.

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[The information follows:]



1. HOW MANY CONSUMERS HAVE HEARD ABOUT THE TECHNOLOGICAL. REHABILITATION DEVICES AND ARE CURRENTLY USING THEM? WHO USES THEM? NOW MANY USE THEM?

A. We do not have reliable information on numbers of consumers who are aware of particular types of technological rehabilitation devices. The best source of this data is manufacturers and distributors that use such data in developing and marketing these devices.

ABLEDATA, a database on devices which we fund at the National Rehabilitation Information Caster, receives approximately 1300 inquiries each month from rehabilitation centers, State Vocational Rehabilitation agencies, howitals, Independent Living Centers, and ...dividuals regarding technologies for the handicapped. The most frequent users, however, are dibabled persons and families that need information on specific devices. There is a trend for increased use of the system by both professionals and individuals.

The most recent national survey on the use of assistive devices was the 1977 Health Interview Survey conducted by the National Center for Health Statistics. The survey was not designed to highlight the use of technologically advanced devices but gave the following estimates of persons using mobility aids in the civilian noninstitutionalized

		e_of_aid:	5,292,000
	two types		845.000
three or	more types	of alds:	322,000

TOTAL using aid: 6,455,000

Use of specific aids:

Canes;	2,714,000
-races:	1,402,000
Crutches:	613,000
Walkers:	689.000
Wheelchairs.	645,030
Artificial Limbs:	205,000
Special Shoes:	1,492,000
Other Mobility Aids:	205,000

Due to the age and the content of this survey there is a need to collect idditional national data on the use of technological devices, particularly computers and computer-driven equipment developed since 1977. There is also a need for data on both the types and numbers of disabled persons who need, but do not have, assistive devices in order to improve, maintain, or achieve independence in critical areas of recreation, such as employment, education, transportation, and

The National Institute of Handicapped Research is proposing\_research, to be carried out, under contract in FY 87, that will involve the survey of a statistical sample of consumers to determine use of aids and devices, unmet needs, and the impact on the individual of the absence of needed equipment.

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2. Q. IS THERE ANY WAY TO MORE EFFECTIVELY PROVIDE INFORMATION TO CONSOMERS?

A. At present; the Department provides information to consumers through data base management systems, meetings with disability consumer organizations, participation at conferences, publications, two rehabilitation diffusion networks, and a volunteer network.

Information can be disseminated to consumers directly; through professionals and through organizations serving their interests. We are sponsoring some publications that provide the information directly to consumers. Through such sponsored publications as the Sensory Aids Foundations Update, we are providing information about devices for sensorily deprived persons-one of our many potential consumer audiences. By sponsoring "Breaking New Ground" at Purdue University, we are tailoring information about aids to the particular needs of disabled farmers. We reach consumers directly, too, through exhibiting at conferences and through meetings and conferences. This activity has been very modest, however. Cable television could also be a good medium for reaching disabled persons in their homes with programs about such topics as modifying a house, recreational facility or worksite to accommodate their needs. This would provide a means of "showcasing" new technology in a setting that gives it practical credibility.

We are reaching some professional audiences through the <u>Rehab</u> <u>Briefs</u>, digests of research findings which are disseminated to some 22,000 persons annually. A recent issue focused on the idea of low cost technology as an appropriate response in many instances. One of the <u>Rehabilitation Research Reviews</u>, produced by NARIC also concerned this topic. We announced a competition for a plan to use satellite networking capabilities to provide professionals with demonstrations of new technology.

We are also exploring the many hetworks that can spread information more effectively and widely than most direct information\_outreach can dol. We are directly funding\_two\_prototype centers for a proposed Rebabilitation\_Diffusion\_Networks-one serving Region VI and\_one\_Region\_IX. We plan to expand these, within existing resources, to one in each Federal region. They diffuse knowledge about exemplary practices and provide technical assistance to help them become adopted. These networks, once they are inflace, could also provide information about devices. We are inferasted in setting up locally based cechnical assistance centers where

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disabled persons and their families can obtain. Informat assistance readily. Some of thest conters could have sa available to "try out" before they are purchased.

It is not possible or, perhaps even desirable, for the government to attempt to directly establish and support networking fabric needed for our various target audienc Therefore, are exploring ways to provide "surge" mon establish or boost\_specific volunteer networks so that transmitting information can be shared. We have funded successfully the National Rural Independent Living Netw by community volunteers and housed in volunteered space fifteen rural sites to exchange needs and solutions inf including information about devices, using the electron communication capabilities of supplied computers. We hanounced a competition for a demonstration project to Rehabilitation Engineering Service Delivery National Sy Applications have been\_received and are now in review fi in FY 1985. Such a system will have to contain informa resources on Services for technology to assist handicapt

There are many well developed networks of disability con organizations such as Easter Seal, United Cerebral Palsy which have for many years provided assistance and inforr their constituencies. We need information about the pain needs\_of these transmitters of information, so we can he information which they can disseminate to consumers.





 Q. (Capitalization of costs) Who pays for technology: Is there a way to capitalize the costs?

 Q. When do Medicaid/Medicare, private insurance companies, and VR agencies pay for rehabilitation devices?

A: Because of the close relationship between these two questions, we are providing a combined answer.

A large majority of rehabilitative equipment and devices, necessary for the rehabilitation of persons with disabilities, is paid for through third party funding sources. In particular, third party programs are responsible for a large proportion of the dollar volume of purchases and rentals of rehabilitation equipment.

A number of third party funding programs have evolved, with different client bases and different restrictions on the use of their funds.

The following are the seven primary third party sources of funding available to help-procure rehabilitative equipment: Medicare; Medicaid; the Veterans Administration (VA); Vocational Rehabilitation (VR); Social Services covered\_under\_Title\_XX of the Social Security Act; and private insurance Policies. The following\_discussion is intended to provide an overview from the standpoint of the rehabilitation programs we administer.

### Medicare

Under Part A of the Medicare Program, certain aids and devices are purchased to provide appropriate medical care for the patient. In most cases, however, the devices are not acquired permanently for the patient; but will be retained by the provider (hospital). Although certain aids, such as canes or crutches, typically may be retained by a patient on discharge, the intent of Part A coverage of medical equipment is to ensure that accessive available to hospitals for appropriate medical treatment and care.

Rental and/or purchase of Durable Medical Equipment (DME) is paid for under part B of the Medicare program. DME is defined as "equipment which (a) can withstand repeated user and (b) is primarily and customarily used to serve a medical purpose, and (c) generally is not useful to a person in the absence of an illness or injury and (d) is appropriate for use in the home." (USDHES, Medicare Carriers Manual, Section 2100.1). Medicare carriers have traditionally adhered to fairly strict coverage guidelines for DME. The criterion of medical need requires Part B beneficiaries to submit a physician's order for a piece of equipment, demonstrating the individual's diagnosis, prognosis, and associated medical need for a piece of durable equipment.

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If the criteria for coverage of durable medical equipment are satisfied, the regional Medicare carrier will reimburse either the beneficiary or the supplier 80% of what they consider to be the reasonable cost of the medically necessary equipment. This figure is calculated based upon the customary charge of the supplier and the prevailing charge of other suppliers in the area. The remainder of the actual cost of the equipment is covered\_either by the beneficiary; or by an auxiliary private insurance program, a... so-called "Medi-Gap" insurance plan; or, in some cases, is absorbed by the supplier.

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Eligibility for Part B of Medicare is largely restricted to persons who qualify under Part A (i.e., persons 65 years of age or older who qualify for a Social Security pension, persons younger than 65 who have been disabled and have been enrolled in Social Security Disability Insurance for at least two years, and persons with End Stage Renal Disease). Eligible enrollees subscribe voluntarily to the program. A monthly premium of \$15.50 is required, as are a \$75.00 annual deductible and a

Devices which do not meet the classification of medically necessary are not paid for by Medicare. Traditionally, these types of Medicare-excluded equipment have included sensory and computers used either for purposes of communication, environmental control, or any other use. The Medicare Carriers Manual contains an extensive index of device types which are typically covered or excluded from coverage as DME.

### Medicaid

Medicaid is a federal/state p.ogram which is administered at the state level. Although eligibility requirements vary by state, Medicaid is designed to help needy individuals, in particular Aid to Families with Dependent Children and Supplemental Security Income recipients. Many program policies are established by each state beyond the federally mandated minimum service range, so that procurement of rehabilitative equipment varies Somewhat from state to state. However, many of the primary criteria by which a decision is made to fund or not fund equipment procurement. closely follow criteria used in the Medicare program. For instance, many Medicaid p.ograms typically stress the medical necessity of a device.

### Veterans Ac .... istration (VA)

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Within the limitations of Title 38, the Veterans Administration can furnish certain rehabilitation technology for all veterans with serviceconnected disabilities as well as for eligible veterans with nonserviccconnected disabilities. Service is provided through VA-based facilities, typically by the prosthetics and orthotics department affiliated with each

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hospital. Devices are provided for the eligible client at no cost to the individual. There are no co-payments or deductibles for device acquisition.

All veterans with service-connected disabilities will be provided with required medical equipment and devices. Need for devices is based on the doctors' evaluations through which the severity of the disability is assessed and a determination is made as to what is required to insure that the individual is maximally functional. Provisions will be made both for devices which are medically necessary and which will enhance employability. Veterans with service-connected disabilities have access to funds for device acquisition as long as their conditions persist. Financial need is not a criterion for eligibility.

Veterans with nonservice-connected disabilities who can demonstrate financial need will be provided with those devices which are absolutely medically necessary to complete the treatment provided in a VA hospital. The goal of device provision is to stabilize the client's condition. Once the condition is stabilized and the veteran is released from the hospital, no funds are readily available to purchase assistive aids and devices.

## Private Insurance

Privately purchased disability and medical insurance plans have occasionally been used to purchase rehabilitation technology. Private insurance has been used to purchase rehabilitation technology when such aids can be shown to either restore the individual to competitive employment, thus decreasing disability insurance payments, or eliminate the likelihood that the individual will require additional medical treatment within the near future.

Increasingly many large employers are "self-insured." Instead of purchasing health, short term disability or long term disability insurance for employees, these employers provide such benefits directly. Employers are increasingly becoming aware of the value of early rehabilitation intervention and disability management at the worksite. Such actions control the costs of long term disability payments to individuals and return disabled workers to the job as soon as possible to enhance productivity. Often these efforts include worksite modifications, job accommodations, and provision of rehabilitation devices. The Washington Business Group on Health reports that many employers have usualished data on their own programs, and that little system eview of private sector initiatives in rehabilitation and d. ity management has occurred. NIHR has awarded a Switzer Fellows. for 1985-1986 to

Social Services Under Title XX

Under Title XX of the Social Security Act block grants to States "furnish services directed at the goals of (among others): (a) achieving or maintaining economic self-support to prevent, reduce

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or eliminate dependency; and (b) achieving or maintaining self-sufficiency, including reduction or prevention of dependency."

Each state is given broad discretion as to how Title XX funds are to be allocated. It is uncertain how many states use Title XX monies to help pay for rehabilitation equipment or rehabilitation engineering services. However, such uses are clearly within the broad goals of the Title.

### Vocational Rehabilitation Services

The federal/state vocational rehabilitation program purchases rehabilitation technology and rehabilitation engineering services in order to help secure employment for a client. The agency can also provide these technologies under post employment services permitted in the rehabilitation process. These technologies are puid for by the state agency with funds allocated under Section 110 of the Rehabilitation Act.

Devices must be identified as necessary for accomplishment of an objective under an individualized written rebabilitation program. State ageocies have different policies relating to devices; some require cost-sharing or "economic means testing" to qualify for a device. Other agencies limit devices by cost and state policies may require competitive bioding.

The Independent Living State Grant Program (Part A), and the Centers for Independent Living Program (Part B) under Title VII of the Rehabilitation Act can provide services including technology, to address independent living needs of disabled clients. Since Part A is being funded at a minimal level for the first time in Fiscal Year 1985, no data exists on the use of technology. Even though Part B, the Centers for Independent Living Program, has been funded for a number of years, the Rehabilitation Services Administration reports that a small proportion of grant funds awarded to these centers has been utilized for the purchase of equipment and devices.

#### Capitalization of Costs

As described above, there are many federal programs currently available that support the purchase of rehabilitation devices. Though they do not provide for all devices in all circumstances, we do not believe there is a need for new federal intervention in this area.

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Mr. BARTLETT. Thank you, Mr. Chairman.

Mr. MARTINEZ [presiding]. Thank you, Mr. Bartlett.

Thank you both very much for being here and testifying before us. We appreciate it.

Our next witness is Isaac Gillam. He is the Assistant Administrator for Commercial Programs of NASA, representing NASA.

# STATEMENT OF ISAAC T. GILLAM IV, ASSISTANT ADMINISTRA-TOR FOR COMMERCIAL PROGRAMS, NASA, REPRESENTING NASA

Mr. GILLAM. Good morning, Mr. Chairman.

Mr. Chairman and members of the subcommittee, I wish to thank you for the opportunity to appear today to discuss one aspect of NASA's efforts to transfer its technology.

I understand that one of the purposes of your hearings is to explore the role the technology plays in enhancing the employment of persons with disabilities. Although this area falls outside of NASA's charter, my discussion of NASA's Technology Utilitization Program this morning should infer the indirect benefits of our program in bioengineering and rehabilitation that could enhance the employment of persons with disabilities.

It is my intent to describe the NASA Technology Utilization Program and its processes, to give specific examples of technology that have been transferred and some that are in the process of being transferred. The examples will be those that I hope would be most germane to your interest.

The National Aeronautics and Space Act of 1958 set out objectives for the newly created space agency. Among them were some related to technology transfer. First and foremost, NASA was to contribute to the expansion of human knowledge of phenomena in the atmosphere and in space. Another addressed the origins of technology transfer and states, in part, that "the establishment of long-range studies of the potential benefits to be gained from, the opportunities for, and the problems involved in the utilization of aeronautical and space activities should be directed to peaceful and scient.fic purposes." Translated into functions, and later in that law, another objective was that NASA was to provide the widest practical and appropriate dissemination of information concerning its activities and the results thereof.

The NASA Technology Utilization Program, as it is structured today, has resulted from experimental programs and practical evolution. It has been in existence since 1963, and it consists of a small headquarters staff that, among other things, manages programs at NASA Field Centers and contractor facilities. Each NASA Field Center has a Technology Utilization Office that is staffed with experts in the art of transferring technology, and they provide technical assistance and disseminate information to other Federal agencies, State and local governments, and to the private sector.

These Technology Utilization Offices monitor innovation and advances in NASA technology and review contractor reports of innovation for commercial potential and utility. Those that survive the screening process are disseminated through NASA publications such as the NASA Tech Briefs.

Industrial Applications Centers provide public and private interests computerized searches and access to the NASA technology information data bank which includes information from the Department of Defense, articles from scholarly journals, and the NASA technical data. These Industrial Applications Centers are complemented by a Computer Software Management and Information Center [COSMIC] which provides users, both public and private, access to NASA and others computer software programs.

NASA has found that technology is transferred most effectively through person-to-person contact. To improve this aspect of technology transfer NASA has established engineering application teams to understand both public and private sector problems and to seek solutions to those problems through the use of NASA-derived technology. These teams work with mission agencies such as the Department of Transportation, the National Institute of Handicapped Research, the Veterans Administration, and centers to expedite transfer of technology to users. They enter the business world and industry associations as facilitators of technology transfer in order to bridge the gap between problem identification and solution. There are two teams serving NASA and its centers: the Research Triangle Institute in North Carolina, and the Rural Enterprises, Inc. in Oklahoma.

A final element of the program is terrestrial applications consisting of specific applications projects. Conceived in 1971, this program goes one step beyond the aforementioned programs. Personnel from Industrial Applications Centers, engineering applications teams, NASA scientists and engineers from NASA centers, mission agencies and scientists, and user groups, public and private, identify and understand significant problems of national priority and they match NASA technology to the problem. If the analysis of the technology match is good and relevant to the problems and the user is willing to enter-into formalized agreements with NASA, the project will be initiated as a NASA activity. NASA funding for these projects is limited to transferring the NASA technology. It is up to the user to implement and commercialize that technology.

Mr. Chairman, in the interest of time I would like to just summarize one example of each of the kinds of 'echnologies that NASA has used to improve medical diagnostics, treatment and devices to assist the disabled, and give one example of each and have the reinainder of my testimony placed in the record.

Mr. MARTINEZ. With no objection, so ordered.

Mr. GILLAM. In the area of improved diagnostics, approximately 2 million Americans suffer from serious burns each year. Of those hospitalized, 70,000 receive intensive care and 10,000-12,000 patients die from their injuries. Modern treatment is based upon early recognition and removal of dead tissue to reduce infection and hasten healing. Current methods for burn depth determination are inaccurate, cumbersome, or both. Burn depth diagnosis may be aided by NASA ultrasonic technology, which may be used to map precisely and conveniently the depth of the interface between viable and dead tissue in burn injuries.

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Advanced ultrasonic technology developed at Laugley Research Center for the characterization of material is being applied to this program in collaboration with the Medical College of Virginia, the U.S. Army Institute of Surgical Research and the National Institute of General Medical Sciences.

In the area of new or improved treatment, NASA is working with the NIH, Johns Hopkins University and several businesses developing a programmable implantable medication system, known as PIMS. I might digress just for a moment here. The PIMS system is a result of the NASA Viking Program which was an automated lander on the planet Mars. It was a 1975 project. There was an experiment on the planet Mars. It was to search for microbiological-type life on the planet surface. The lander reached down with a scoop and scooped up a sample of Martian soil. To detect life in that sample that was scooped up on the automated device, programmable injections of moisture were induced into that soil so that the experiment could be carried out and the possibilities of life be detected. That technology was used in the development of the PIMS system, which I will describe now.

There are a number of chronic diseases such as diabetes which require long-term infusion or frequent injections of medication. Reliable control of blood sugar levels throughout a diabetic's life is thought to diminish the incidence of complication such as kidney disease, retinopathy, atherosclerosis and heart at.~cks. An implantable, highly reliable infusion pump that could accurately deliver medicine at programmed rates improves control of blood sugar in diabetics and could be useful in other diseases such as leukemia and others.

The PIMS incorporates safety features and reliable delivery rates required to ensure safe medication levels. Space microcircuitry, reliability and quality assurance, microcomputer and digital integrated circuitry, pumping and valving systems from various aeronautical space programs were used in developing this system. The fundamental concept came out of the Viking Program and the search for life on the Martian surface.

In the way of assist devices, we have already seen NASA's efforts demonstrated in terms of the wheelchair. But in another area, there are more than 13 million deaf and hearing impaired people in the United States. Cued speech is a method of improving lipreading intelligibility for the deaf by the speaker's use of finger signals to remove lip shape ambiguities. Manual cued speech, however, required that the speaker know how to cue speech. A wearable Autocuer device using a combination of high-speed, low-power integrated circuit\_technology\_removes the requirement for the speaker to provide finger signals as cues. A pair of glasses is used for presentation of the signals, and with this system deaf persons or hearing impaired persons could improve their speech comprehension in a normal work environment. Working with the National Institutes of Health, the National Science Foundation and the Veterans' Administration, NASA microcomputer/digital integrated circuits from spacecraft and expertise in computer systems, design verification and real-time speech analysis from Gallaudet College are all being combined to develop the Autocuer system. The device is now ready for field evaluation.,





PREPARED STATEMENT OF ISAAC T. GILLAM IV, ASSISTANT ADMINISTRATOR FOR COMMERCIAL PROGRAMS, NATIONAL AERONAUTICS AND SPACE ADMINISTRATION

Mr: Chairman and members of the Subcommittee: I wish to thank you for the opportunity to appear here today to discuss-NASA's effor s to transfer its technology. I note that one of the purposes of your hearings is to explore the role technology plays in enh acing the employment of persons with disabilities. Although this area falls outside of the NASA's charter; my discussion of NASA's Technology Utilization Program should infer the indirect\_benefits\_of\_our program in bioengineering and rehabilitation that could enhance employment of persons with disabilities.

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<u>These Technology</u>Utilization Offices monitor innovation and advances in NASA technology and review contractor reports of innovation for commercial potential and utility. Those that survive the screening process are disseminated through NASA publications such as the <u>NASA Tech Briefs</u>.

Industrial Applications Centers, provide public and private interests computerized searches and access to the NASA data bank which includes information from the Department of Defense, articles from scholarly journals, and NASA technical data. These Industrial Applications Centers are complemented by a Computer Software Management and Information Center (COSMIC) which provides users (public and private) access to NASA and others computer and software programs.

NASA has found that technology is transferred most effectively through person to person contact. To improve this aspect of technology transfer NASA established engineering Applications Teams to understand both public and private sector problems and to seek solutions to these problems through the use of NASA derived technology. These teams work with mission agencies such as the Department of Transportation; the National Institute of Handicapped Research, the Veterans Administration; and with centers to expedite the transfer of technology to users. They enter the business world and industry associations as facilitators of technology transfer in order to bridge the gap between problem identification and solution. Today there are two teams serving NASA and its Centers. (Research Triangle Institute in North Carol na, and Rural Enterprises, Inc. in Oklahoma.)

A final element of the program is "Terrestrial Applications," consisting of specific applications projects. Conceived in 1971, this program goes one step peyond the aforementioned programs. Personnel from Industrial Applications Centers, Engineering Applications Teams, NASA scientists and engineers from NASA Centers, mission agency scientists, and user groups (public and private) identify and understand significant problems, usually of

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a national priority; and then match NASA technology to the problem. If the analysis of the technology match is good and relevant to problems and the user is willing to enter into a formalized funding agreement with NASA; a project will be initiated: NASA's funding for these projects is limited to transferring the NASA technology. It is up to the user to implement or commercialize the technology.

- In the remaining time I shall discuss examples of NASA technology that improve medical diagnostics and treatment; and devices to assist the disabled.

### IMPROVED DIAGNOSTICS

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Approximately 2 million Americans suffer serious burns each year: Of those hospitalized, 70,000 receive intensive care and 10-12 thousand patients die from their injuries. Modern treatment is based on early recognition and removal of dead tissue to reduce infection and hasten healing. Current methods for burn depth determination are inaccurate, cumbersome or both. Burn Depth Diagnosis may be aided by NASA ultrasonic technology which may be used to map precisely and conveniently the depth or the interface between viable and dead tissue in burn injuries.

Advanced\_ultrasonic\_technology developed.at\_Langley Research Center\_for\_the\_characterization of material is being applied to this\_program in\_collaboration: with the Medical College of Virginia, the U.S. Army Institute of Surgical Research, and the National Institute of General Medical Sciences.

The need for a <u>Non-Invasive Intracranial Pressure Monitor</u> has been known for years. Excessive accumulation of fluid within the natural cavities of the brain may result in increased intracranial pressure (ICP), causing transient or permanent neurological dysfunction and even death. Increased ICF can be a complication of head injuries, tumors, CNS infection; hydrocephalus, and meningitis. Fifty thousand people each year who survive is serious head injury are left with an intellectual impairment\_of\_such a degree as to preclude their return to previous employment levels. The extent to which intracranial pressure is elevated is a critical factor in the selection of appropriate therapy. An estimated 300,000 ICP monitoring procedures are performed annually in the U.S., all requiring some degree of invasive procedure. Scientists at the NASA Langley Research Center have developed a concept utilizing state-of-the-art ultrasonic pulsed phase-locked loop technology to non-invasively measure intracranial pressure. The National Institute of Handicapped Research and the National Institute of Neurologic, Communicative Disorders and Stroke and the University of Virginia are working with NASA to test the Langley concept. This device would allow more frequent, safe monitoring of ICP.



# NEW OR IMPROVED TREATMENT

<u>Corneal Topography</u> is unique to opthalmology. This technique aids in correcting refractive errors, and repairing injury to the cornea of the eye and techniques cepends on accurate measurements of the shape of the outer surface of the cornea. Current techniques don't permit the fast, high resolution measurements required before, during and after surgery. NASA optics technology at Marshall Space Flight Center, used to gauge the surface of the space telescope mirror; is being applied to this problem. Optics and computer technologies from the Jet Propulsion Laboratory are also being applied to this problem. NASA, the National Eye Institute and two small businesses are developing a corneal togography measuring system.

In cardiology, NASA technology has produced a real improvement in the lifestyle of the ill and handicapped. In the United States diseases of the heart remain the leading cause of death. Each year over 500,000 new heart attacks occur and approximately 450,000 annually survive the first heart attack. Many of the fatal heart attacks result from a malfunction of the neuroelectric control system that regulates the periodic contraction of heart muscles. NASA joined with the Johns Hopkins University, Applied Physics Laboratory and industry to utilize hybrid electronics from NASA satellites, rechargeable battery technology and space age reliability and guality assurance to develop the first Implantable Rechargeable Pacemaker. The rechargeable aspect introduced a way to sidestep the problem of frequent recurrent surgery caused by battery failure every eighteer, months or so and allowed for a more efficient and energy conserving implantable device. The manufacturer continued to build on the aeroanutics and space technology and has developed a miniaturized cardiac pacer that can be programmed to the patient's heart. This system uses two way communications capability similar to that used to send coded instructions to unmanned satellites.

Currently, NASA is working with the medical community and industry to perfect an <u>Automatic Implantable Defibrillator</u>. This device is designed to detect and counter cardiac fibrillation, a situation wherein the heart suffers a wave of erratic contractions and does not pump blood. This device uses a low energy consumption microprocessor and <u>...memory system to detect</u> cardiac arrhythmias, discriminate between them, institute the appropriate corrective action, warn the patient, and record the episode.

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Another system now being designed will automatically detect hypertension; or high blood pressure; and control the problem through continuous administration of medical agents. In the United States there are over 16 million people classified as having hypertension; representing about 14 percent of the work force, are at serious risk for heart attack and other diseases. For instance in 1980, the deaths of over 32,000 Americans were attributed either to hypertension or hepertensive heart disease. The device is called a Sensor Actuated Medication System and will be developed over the next four years.

NASA, working with NIH, John Hopkins University, and several businesses developed a Programmable Implantable Medication System (PIMS): A number of chronic diseases such as diabetes require long-term infusion or frequent injections of medication. Reliable control of blood sugar levels throughout a diabetic's life is thought to diminish the incidence of complication such as kidney disease, retinopathy, atherosclerosis, and heart attacks. An implantable, high-reliability infusion pump that could accurately deliver medicine at programmed rates improves control of blood sugar in diabetics and could be useful in other diseases such as leukemia, thalassemia, and hormone disorders. The PIMS incorporates safety features and reliable delivery rates required to insure safe medication levels. Space microcircuitry, reliability and quality assurance, microcomputer/digital integrated circuitry, pumping and valving systems from various aeronautical programs were used in developing this system.

Another-project that was developed some years agc was the <u>Human Tissue Stimulator</u>. Chronic pain and involuntary motion disorders can often be treated effectively by electrical stimulation. Electric pulses are sent through wire leads to targeted narve centers or specific areas of the train. Early stimulating devices weren't widely used because they required cumbersome; external power packs which had limited lifetimes. An implantable human tissue stimulator was developed by NASA and a small business in collaboration with the Applied Physics Laboratory of the Johns Hopkins University. This development effort; resulted in a microminiaturized implantable system, roughly the size of a deck of a cards. It includes a tiny rechargeable battery, an antenna and microelectronics to receive and process commands and to report on its own condition via telemetry. This device led to the commercialization of a <u>Neural</u> <u>Pacer</u> that is used today to treat several neural muscular disorders. NASA's satellite telemetry and command system.

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# ASSIST DEVICES

Today we are beginning a new project with the Veterans Administration and the National Institute of Handicapped Research (NIHR) to develop a <u>Miniature Functional Electrical Stimulator</u>. Today there are 645,000 paraplegics or quadraplegics in the U.S. and several laboratories have demonstrated that paraplegics could stand, ride bikes, and walk very, very slowly if a computer was used to provide the proper electrical stimulus to the muscles or nerves involved. The Veterans Administration has requested NASA assistance in the completion of the miniature stimulator and to insure reliability and quality assurance and to facilitate commercialization. At the same time, the National Institute of Handicapped Research is planning to join us in the development of Advanced Sensors. These sensors will hopefully allow manufacturers to develope a "closed loop" system. Microelectronics, reliability and quality assurance, electronic packaging, and system engineering are being applied to this device.

Approximately 700,000 people in the U.S rely on wheelchairs for mobility. For these people, the commercial airplane is a major barrier. Standard wheelchairs are not compatible for use in airplanes, thus limiting access to the lavatory. Employment requiring extensive plane travel is most difficult. Stimulated by various organizations for the handicapped and the Rehabilitation Services Administration and NIHR, NASA entered into a collaborative effort with the handicapped organizations and NIHR to develop a wheelchair designed for use in the airplane environment. The chair was designed for easy seat transfer and access to the lavatory, to be lightweight and easily stored. The resulting <u>Aircraft Wheelchair</u> uses NASA's composite materials and structure analysis technology.

In addition, we have just completed an <u>Advanced Wheelchair</u>. The limitations of conventional wheelchairs include heaviness, frequent repairs, and limited lifetime and resulting high life-cycle costs. Wheelchair design, prototype construction and testing is a costly process. It was felt that the use of improved materials, as well as computer simulation and analysis, could result in a more durable, lightweight wheelchair. NASA and the NHR collaborated with the University of Virginia to use aerospace structure design/analysis techniques and graphite composite materials to develop the advanced wheelchair.

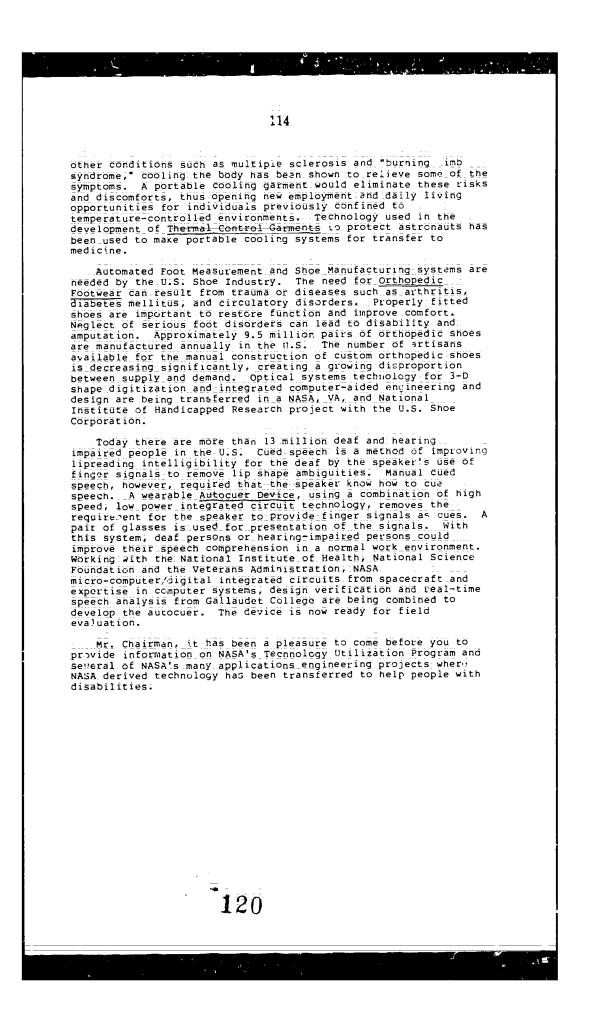
Regulation of body temperature can be impaired by several diseases or injuries including spinal cord injuries and skin disorders. When individuals with these conditions are exposed to even moderately high temperatures, they suffer discomfort and risk hyperventilation, increased heart rate, and heat stroke. In

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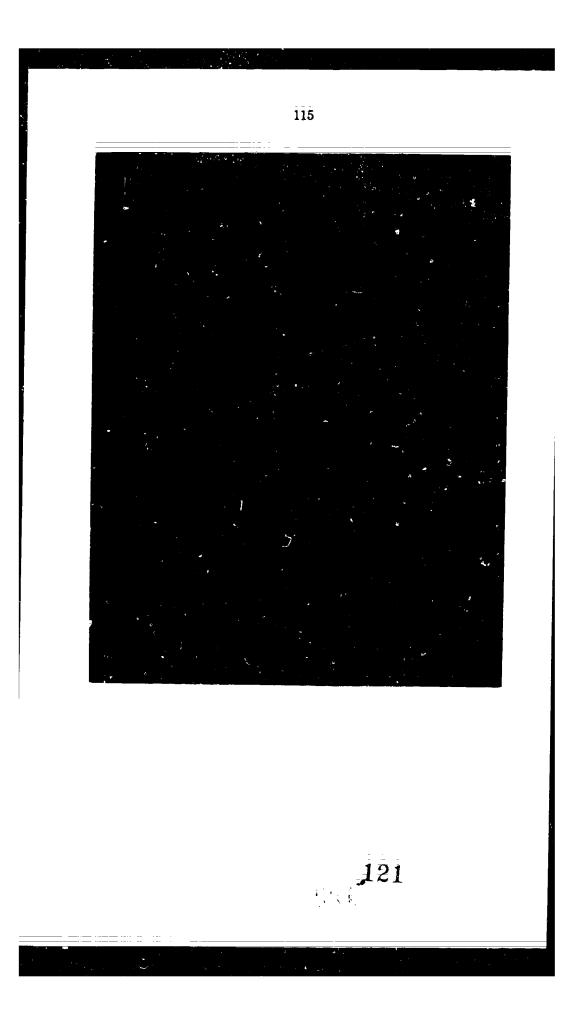
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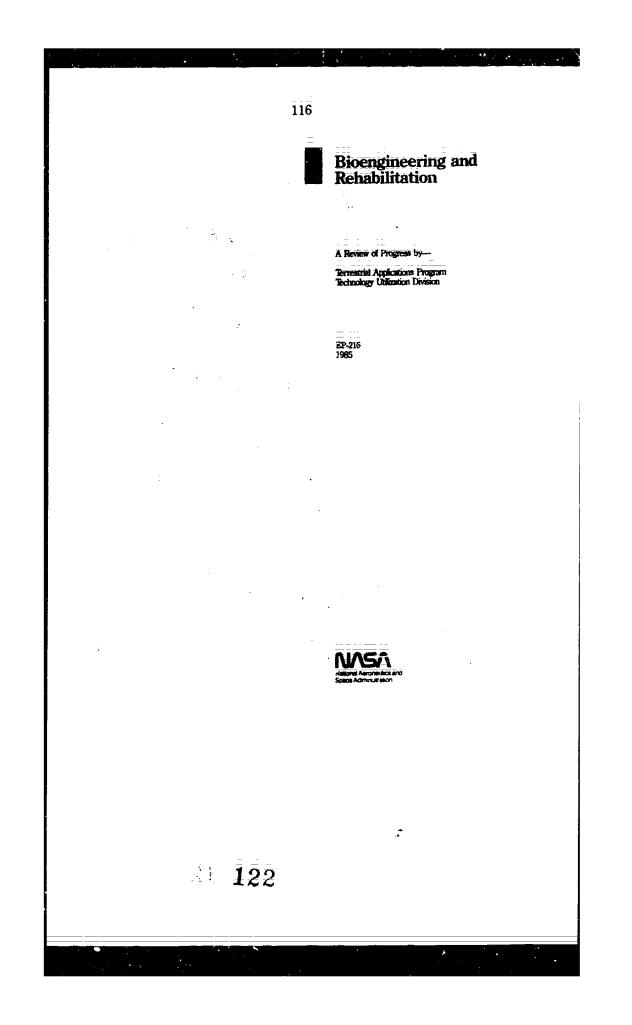














The American space program draws on the best scientific and engineering "An in this country. The combined effort of our Federal, academic, and ardustrial team members has produced an expanding technology base so powerful that many formitable engipowerful that many formitable engipering challenges faced by man are being solved dramatically and expeditoously.

Dougly. It is in the best interest of the United States to use its space technology in as broad a manner as possible. Every citizen benefts directly from rur national investment in space activites: indeed, advances in metaburgy and in the electronic and computer soences benefit many facets of life. The National Aeronautics and Space

The National Aeronautics and Space Administration is particularly prival of the mamner in which the technology of the aeronautics and space program is being applied to specific problems in medicine and physical problems in our technology transfer process has contributed significantly to recent advances in the biomedical sciences. This book has a two-fold purposeto inform and to stimulate. First, we want to show the breadth of the problems in medicine and rehabilitation.

This book has a two-fold purposeto inform and to stimulate. First, we want to show the breadth of the problems in medicine and rehabilitation, which are benefiting through use of ... technology from our acromatics and space program. Second, we want to encourage more individuals and industies to participate in our technology transfer process and to apply this ... technology to an even wider range of medical problems.

Isaac T. Gillam IV Assistant Administrator for Commercial Programs "... for the benefit of all mankind"

These words from the National Aéromutics and Space Administration Space Act of 1958 serve as a mandate for the technology transfer and utilization efforts of NASA. For a quarter of a century, NASA has operated at the pinnacle of high technology within the Federal establishment. It could not be otherwise as we address the enormous challenge of m.wing men and machines at an increasing pace into a multitude of space missions. The success of these missions—stanging from manned exploration of the moon to tervicing of other all satellites—is well known. The advanced technologies deweloped to support these missions are not as well known but are every bit as impressive. Materials that withstand the radical temperature extremes in space, electronic switches which operate at distances of millions of miles, valves functioning with unbelievable.

programs. The National Aeronautics and Space Administration is committed to insuring ibat its technological achievements extend beyond the direct needs of space missions to the general benefit of all citizens. The transfer of aeronautics and space technology to biomedical needs is an excellent example. This report describes a number of efforts in which the stechnology as provided through the NASA Technology Unbration activities and its academic and industrial team immeders, is offering real true improvement in the quality of life to those citizens with medically related problems.

Raymond P. Whitten Chief, Terrestrial Applications, Technology Utilization Division



NASA Technology Transfer

#### Windows Of Opportunity ..... Past, Present and Future

Through i weitly-five years of research and technology development in a vanety - fields, the National Aeronautes, and Space Administration has emassed an array of technologies to meet its mixis mission needs and which, in turn, can be well appied to Earthly problems. These advanced technologes cover such fields as materials, electronics, c-mputer science, hoimedicine and vobotics. Of particular meterest here is the process whereby. NASA technology, is transferred into wedical engineering and the development of systems to support the ill.

NASA organizations, academic in source of the second secon

NASA's approach is to create windows of opportunity that enable poyate organizations to develop marketable products through application of NASA-developed technology. Each windsw locuises upon possible matches between a problem treduring a technical solution and specific, available technologies from NASA. Dis report describes some successes in the "Windows of Opportunity." Programthose in the past when the transfer is complete and products are commercially available, those in the present which was in the future for which initial concepts and development efforts are being formed at this time.

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### The Organization

The key components in the transfer of NASA technology to meet biomedical needs include.

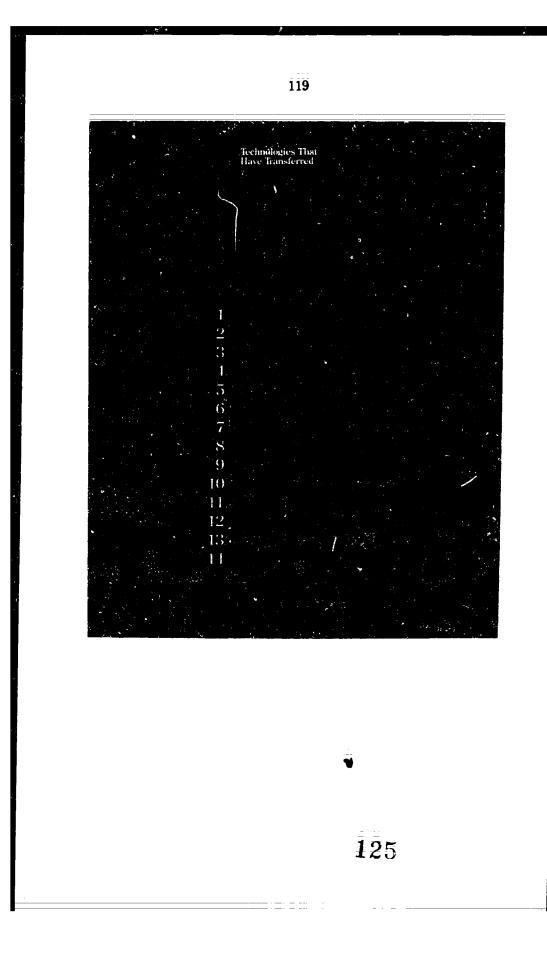
Terrestrial Applications. A branch of the Technology, Unitation Headquarters activity within the National Aeronautics and Space Admunstration, which establishes policy for the bometical transfer process, allorates resources and coordinates activties among the operating mutis. This office serves as the main link in establishing a working relationship with other Federal agencies such as the Veteratos Admunistration and the National institutes of Health Cooperion with these and other Federal agencies is most important in one transfer process.

Technology Utilization Officers. These individuals manage the participation of NASA Centers in all technology utilization activities. They participate in the isentification of problems and survey NASA scientists and engineers for technology and expertise that can be applied to the problem. They also coordinate contracting activities with industry as the technology is being prepared for evaluation and potential commercialization.

Technology Applications Team, Tus team, located at the Research Trangle Institute, North Carolina, and supported by the National Aeronautics and Space Administration, aids NASA Heido Center personnel on specific projects, and provides hasion support with other federal agencies, state of fanizations and industry as reourded. Program methodology and activities of the technology applications team are to (1) identify problems through interaction with clinicians and medical researchers, (2) identify and serven applicable NASA technology that meets the medical nesreds. (3) develop commerculization strateges, and (4) -transfer, potential medical movations for final development and marketing. — Private organizations and individuals may contact the National Aeronautics and Space Administration concerning any bornedical topic which might beneff through the utilization of acronautics and space technology. The following ap shows the general location of points of contact. More detailed in "Spanofi," publication tentiled. "Spanofi," publication and space Administration.









# Wheelchair Development

The ability to move freely is the es-sence of life in modern society. A spe-cial burden for the harvicapped is lack can ouroun for the narrocapped is late of mobility. To ease this burden, wheel-chairs have long been in use. At this time, some 700,000 people in the United States rely on wheelchairs for

mobility. Wheelchairs have a variety of dewheelchars have a variety to be signs developed to meet different needs. There are depot wheelchairs for use in airports and other public places, hospital wheelchairs designed. to meet special requirements (I. V. loct-ties, leg casis, etc.), drugsfore wheel-chairs for short-term users, prescrip-tion wheelchairs for short-term users, prescrip-tion wheelchairs for short-term users. tion wheelchairs for chronic

tion wheelchairs for chronic disabilities, and sports wheelchairs. Power is provided by an attendant, the bandicapped person, or a separate power source such as batteries. Designers are drawing on today's advanced technologies to meet the many requirements of improved wheel-chairs. One requirement is for better strength. Engineers at the NASA Langdey Research Center are working with scientists at the University & Vir-gina Rehabilitation Engineering Center in a oxygram to develop compiterin a program to develop comp ster-

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aided design procedures for wheel-chairs. A structural analysis of wheel-chairs based on a finite element computer program is being utilized to identity critical areas of stress buckling and victation. With this system, a

identity critical areas of stress buckling and viz.atto. With this system, a. sports wheelchair has been modeled using a particular load distribution and set of structural constraints. Results will lead to stronger wheelchairs with better ride quality. —Size and weight also present a prob-lem. Conventional-use wheelchairs fabricated from metallic tubular ele-ments are frequently heavy and diffi-cult to handle—especially chiring stor-ing and retrieving from automobiles. In addition, the metallic wheelchairs are subject to corrosion and fatigue dam-age during normal use. These difficul-ties have been cased recently through efforts of a multi-organizational coop-erative program leading to the devel-opment of a lightweight-folding, con-ventional wheelchair constructed arge:); from advanced composite ma-terialc.

A prototype composite chair was designed by the University or Virginia Rehabilitation Engineering Center in

an effort coordinated by NASA's Re-search Triangle Institute Technology Applications Team and with support from the National Institute of Handi. capped Research and the NASA Lang-ley Research and weights only 24 pounds, about one-half the weight of a standard person is easily folder, and can be stowed with little effort. —The composite chair makes exten-sive use of modern aerospace mate-rials which offer very high strength and low weight. This development pro-gram exemplifies the marner in which aeromatics and space technology is being used to improve the quality of

being used to improve the quality of modern life.



The wheelchair of yesteryear



or mousty. to ease use burden, wrep-chairs have long been in use. At this time, some 700,000 people in the United States rely on wheelchairs for Mobility. Wheelchairs have a variety of de-

motaity. Wheekchairs have a variety of de-nigns developed to meet different needs. There are depot wheekchairs for use in airports and other public places, hospital wheekchairs developed to meet special requirements (1. V. bot-ties, leg casts, etc.), drugstore wheel-chairs for short-term users, prescrip-tion wheekchairs for chronic disabilities, and isports wheekchairs. Power is provided by an attendant, the handicapped person, or a separate power source such as batteries. Designers are drawing on today's advanced technologies to meet the many requirements of improved wheek-chairs. One requirement is for better strength. Engineers at the NASA Langbey, Research Center are working with scientists at the University of Vir-gnia Rehabilitation Engineering Center in a program to develop computer-

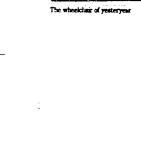
A prototype composite chair was designed by the University or Virginia Rehabilitation Engineering Center in

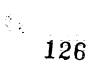
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Hom the Reaconal Institute of Plancin-capped Research and the NASA Lang-ley Research Center. The prototype is made of Lange-yturnished composite materials and weighs only 24 pounds, about one-half the weight of a standard wheelchair. I--an support a 200-pound person is easily folded, and can be stowed with hittle effort. —The composite chair makes exten-sive use of modern aerospace mate-rials which offer very high strength and low weight. This development pro-gram exemplifies the marner in which aeronautics and space technology is being used to improve the quality of modern Me.













Programmable Pacemakers

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# The development of cardiac

pacemakers is an outstanding example of the manner in which biomedical technology can produce a real improve-ment in the lifestyle of the ill and handkapped. The remarkable medical .... achievements seen in this and other fields during the past twenty years are neus during the past twenty years are intraately related to progress in the aerospace sciences. The cardiac pacemaker project also illustratics the manner in which Federal agencies, ac-ademic institutions, and industrial or-ganizations can establish a productive and economic wider or performance

and synergistic working relationship. Diseases of the heart remain the leading cause of death in the United Reading cause of ocan in the sinited States, although the picture instruces every year. Many fatal heart attacks result from a mailfunction of the neu-iales the periodic contraction of heart muscles. With early direction of such mailfunction, a pacemaker can be im-planted to denerate an advertical hulter transfer. planted to generate an electrical pulse that controls heart muscle contractions.

Early pacemakers, developed through a NASA Goddard Space Elight Center program on hybrid circuit tech-nology, used mercury-zinc batternes which were heavy and shortlived. Sur-

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incal replacement of the battery was so. This picture changed in the lat-1960s when the Johns Hopkins Un-sity Applied Physics Laboratory proposed a rechargink concept based on electronagnetic transmission through the intact skin. Rechargeoble batteries of the type used in satellites could solve the pacemaker short life problem

In 1973 Pacesetter Systems, Inc. of Sylmar. California, working with the Appled Physics Laboratory and the Medical Institutions of the Johns satellites. Joday, an ever more ad-vanced battery based on dithum elec-trochemistry is used. This has excep-tionally high energy densities and a very low self-discharge rate. Pacemaker technology had another, advance in 1979 when a programmable unit was introduced. Pacesetter Sys-

tems developed Programahth, a sys-tem with two-way communications capability based on technologies

de whiped by NASA to send coded in: be tabled by ANAM to send coded by structions to unmanned satellites. The Programatic system allows a physician to computencet with a patients pacemaker by means of wireless te-lemetry signals. Where earlier pacemakers delivered a fixed type of sumulus once implanted, the Pro-miniation system can be "fixed type of summities system can be "fixed type." stimulus once implanted, the iffoe-gramalth system can be "fine-tured" to meet each patient's individual needs. As many as six heart stimulat-ing functions; for example, pulse rate. amplitude, and wolth, can be adjusted as necessary. When reprogramming is complete, the system sends back a copy of the new settings from which a permanent record can be made. Recent technology developments by

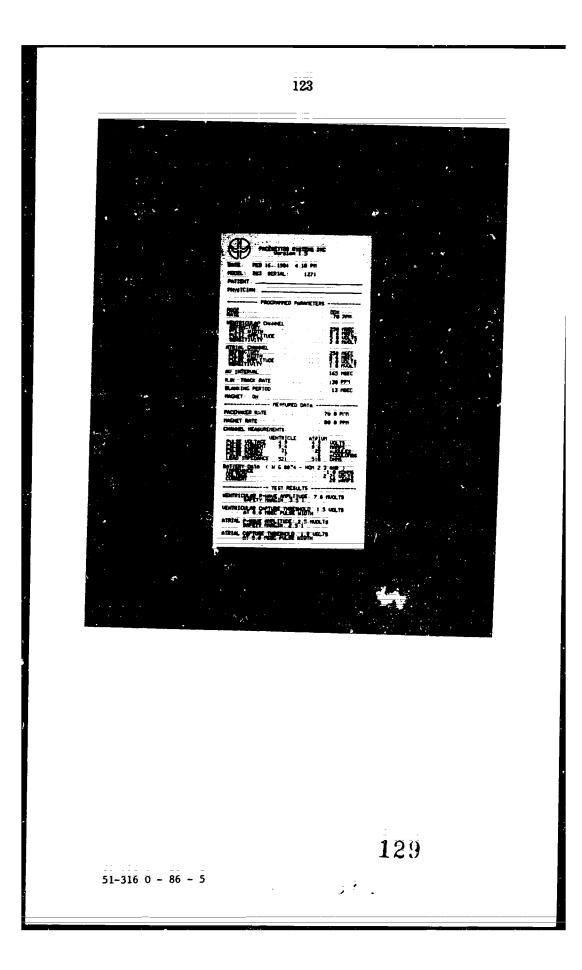
Pacesetter Systems have been di-rected toward an Advanced Function. Pacer, which offers an implantable de-vice smaller than any Programalish unit and incorporates substantially in-creased programming capability. This system is capable of sensing and stimulating either or both chambers of the heart and offers both better control ... over and monitoring of heart function.

The Advanced Function Pacemaker II 283 by Pacesetter Systems, Inc. features 14 programmable parameters, is 10mm across, and weighs 50 grams.

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# Cardiology Mannequin

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The evaluation of cardiovascular dis-ease releas heavily on the physician's examination: The bedside findings-from this examination allow initial dia-noses among a variety of heart condi-tions and guide the use of complex lab-oratory procedures. The development of effective diagnositi skills, however, requires a physician first to see pa-tients with the full spectrum of heart disease at various stages in develop-ment. Second, the examination skills must be practiced routinely and re-petitively. To achieve this with actual patients is difficult and expensive. The Cardiology Patient Simulator. "Hai vei," capable of simulator, a wide range of heart conditions, represents -const effective means of meeting these training objectives. training objectives.

training objectives. The cardiology manoequin is capable of simulating vertually unlimited cardiac disease states. Synchronized buliteral arteral (carotid, biachal, radial, and femoral) and jugular veinous pulsa-tions, precordal movements, r.spra-tion, blood pressure, and auscultation

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in the four classic acoustic areas ar-exactly simulated. Complex acoustic events vary with respiration when ap-propriate. Side, programs display back-ground data ior each disease state to increase the realism and effectiveness of transme.

ground data for each disease state to increase the realism and effectiveness of training. The Cardiology Patient Simulator program has been guided by Dr. Mi-chael S. Gordon, Professor of Cardiol-ogy at the University of Mamin (Flor-ida) School of Medicine. Physicians and scientistis from other medical cen-ters, including the J. niversity of Anzo-na. Duke-University, of Marin (Flor-ida) School of Medicine. Physicians and scientistis from other medical cen-ters, and university of Marin (Flor-ida) School of Medicine. Physicians and School of Medicine. Physicians and School of Medicine. Physicians and Diversity of Plonda. Georgetown University, the Maxin Clinic, and the University of Nebraska, as well as the National Heart. Lung and Blood Institute have-participated, in the privation of the presentation of play technology for the presentation of raining materials, also participated. Harvev is becoming in accepted in-structional system. An evaluation un-der the auspress of the National Heart.

Lung and Bl sod-Institute tound-that students who trained with this system scored higher on tests of cardiology knowledge and showed improved performance when examining actual patients.

other educational purposes. The pro-cuction of the current model (third generation) is being done through the University of Miami in Florida.

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# Advanced Defibrillator Monitoring System

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Victums of heart attacks require nume-idate and proper care. If cardiac arrest occurs when no one else is present, it is faial. The prospects for recovery are good, however, if treatment is given prompily and circulation main-tiffer d'unil the victur eaches a hosp-tal. If the attack occurs when the pa-bent is in a hospital, prospecti-are-even better. If cardiac arrest 1, caused by ventricular fibrillation, the h-ari-beat often can be restored with a ue-fibrillatiot, an apparatus that briefly passes an electric current through the passes an electric current through the heart.

The definitiation sends an electric shock to the heart var wo metal plates postuored properly on the chest wall. This method uf restarting a stopped heart minus a netward process in which impulses from the right atrium spread through the heart in the normal beating pattern of the heart. Once the definitiator has impused a normal pattern usually will be sustained by the heart. For it to be successful, however, the

defibrillator must be readily accessible

defbrillator must be ready accessible and put into immediatenese. The advanced defbrillator monitor-ing system is light-weight, portable and wasy to operate. It combines the defbrillator contacts (haddles) with a microprocessor-based monitoring sys-tem tu display both treatment and pa-bent information. The advanced de-fibrillator monitoring system is an outgrow to dia a earlier NASA project known as the Physician's Black Bag, a portable monitoring irratinet nun di-veloped for the Johnson Space Center by Telecare, Inc., known following ac-quisition as Narco Bo-Systems, m Houston, Texas.

The advanced defibrillator monitor-ing system is designed principally for use in a hospital environment. It incor-porates sealed membrane key-switch controls in a work station layout. Each energency operating step is indexed in numerical sequence for quick appli-cation, even with inexperienced users. There is a built-in annotating records r and clock for complete documentation

of its use in a fibriliation event. This system, although designed for hospital appacation, now is being con-indered as part of a privicity life sup-port module for possible application aboard future space shuttle flights. As the trypclation of Space Shuttle -trymmenabers becomes more diverses the possibility of a cardiac episode -must be considered. Appropriate treat-ment equipment must be available as part of the on-board medical system.

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Human Tissue Stimulator

Neuromuscular differuities. In particu-lar the problem of claronic facta, scient, on be helped by electrical stimulation of nerve and muscle rissue. Chroni-pain from arthotis, rheunatism, and other disorders affects at least ten-percent of the population. Several thousand of these obtain regular relief through electrical stimularism proce-dures, Devices in present use, how-evet, require an enternal power source ever, require an external power source and a transmittine coil taped to the skin-twenty-four hours a day. A device of this type is uncomfortable, inconve-

of this type is uncomfortable, inconve-ment, and generally unreliable, often with a greater than ninety percent an-nual failure rate. Processetter Systems, Inc., of Syl-mar, California, working with the Ap-phied Physics Laboratory of The Johns Hopkins University, has developed the Human Tassue Stimulator. Tais is an implantable device offering a solution for most of the problems found with earlier stimulation systems. The new earlier stimulation systems. The new device is based on technology devel-oped at NASA Goddard Space Flight

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carmum battery, theme is an com-mand systems technologies derived from those used with the satellite and reduced to micronomiature propor-tons. The implantable element is the size of a deck of carms.

The first two stimulator units to be implanted were quite successful. In The first were quite successful. In one, a Datient with severe nucleutary nextment duscreters from multiple scienciss achieved complete control, over the tremors. In the second, a pa-tient who suffered exclusing pain from a wrise injury incurred in a fail re-ported immediate relief from the pain. Based on the success of these trials. Pacesetter Systems is moving to com-mercial production. The field of electrostimulation is ad-vancing to encompass complex neu-tological disorders. Pacesetter Sys-tems now has developed the implantable Neuroith 6CL as a promis-ing device for the treatment of the

spasticity of cerebral Salsy and for the suppression of er legico segures. The deure has been shown to be sale and effective in over one hundred ceref cal nais, satents. The next phase will be the development of (a); protrammable neuropa.erg.sdustible through mero-processor technology to the changing needs of the individual patient.

The Pacesetter Neuropacer with its pro-

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### AutoMicrobic System (AMS)

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Any is novation that offers reduced hospital stay time is a welcome ad-vance in lealth care service because of the potential for saving money for both the patient z. 1 the hospital. One such the patient z. 1 the hospital. One such the string innovation, based on acro-space technology, is an automated sys-tem used by hospital laboratories to detect and identify microorganisms that cause infection. It has the addi-transi capability to test these organ-isms to determine which freatment. would be most effective in eradicating

would be must effective in eradicating them. Vice's Aut. Microbi-System (AMS) is the product or years of research and development of y A'Connell Douglas. Corpornion. The project originated in a NASA-sponsored study aimed at de veloping a f.'.'y automated microbial detection and identification system for the spore program. AMS is now com-me -- ily available through Vice's Sys-tems, Inc., Haselwood, Missouri, a McDownell Douglas subsidiary. ---The traditional method of testing for harmful organisms or pathogens re-

harmful organisms or pathogens re-

quires several step: First, specimens of body fluid-urines i. r example-or

quires several step: First, specmens of body fluid-curne, 1: recumple—or swabs from suffected areas of the \_\_\_\_\_\_ body—turnat, for example—are pre-jared in cultures. These cultures are incu-bated for two 1:0 three days and stud-ied for cell growth. Firom such study microbios, Next, the cultures are incu-bated for two 1:0 three days and stud-ied for cell growth. Firom such study microbiologists then can determine the presence of disease producing organ-sisms and identify the path-gens. The AMS does the same p-1 quick-et. Specimens from satistics are pri-pared in culture in rainstance of form. Over 30 tests can 1:- done simultane-ously on the same microrigation in a bit approximately the size of a playing card. During an incubating cycle in the AMS, an electro-optical scamer stud-ies each kit once an 1 our. Changes in cell growth are monitored and analyzed b- con suter. The AMS automatically reports its findings after sufficient data are collected. This information is printed and displayed on a CRT acceen.

The AutoMicrobic System enables, the microbiology laboratory to furnish guidelines to a patient's doctor for anti-microbial therapy the day after a spec-ium is collected. This amounts to a time saving of 50 to 80 percent over standard laboratory methods. The system ago uninimues human error reduces technician time, and increases laboratory output. J of the AMS can. laboratory output, for the AMS can handle up to 240 patient specimens at one time. Of greatest importance to the patient is shorter stay in the hospi-tal due to faster analysis of the infec-tion and earlier treatment.

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# Lixiscope

Aerospace technology has led to the

Aerospace technology has led to the development of a portable X-ray mage intensifier called 1 biscope which promises to be useful in a number of applications in medical and dental fluo-roscopy and intensifier assisted radiog-raphy, making it possible to use a weak radiation source and potentially reducing the dosage to the patient and radiologist. Such a combined radiation nource and image intensifier is so cor-part that for certain fluorescope ex-aminations a truly portable system can be brought to the homes of bedradden and handcapped patients. The Lesiscope—which stands for Low Intensity X-ray Imaging SCOPE—evolved out of the ra-diation received is extremely low As-tronomers sometimes want to observe objects is fordiar to allo and phonoton of radia.ion at a time. In the laboratory of NASAS Goddard Space Fight Cen-ter, scientists developed an image in-tensity device that capitalized both on the high efficiency of existing rare-Eart. phosphor screens (which detect and convert X-rays mito visible .get1) and the high visible-light gain of cer-

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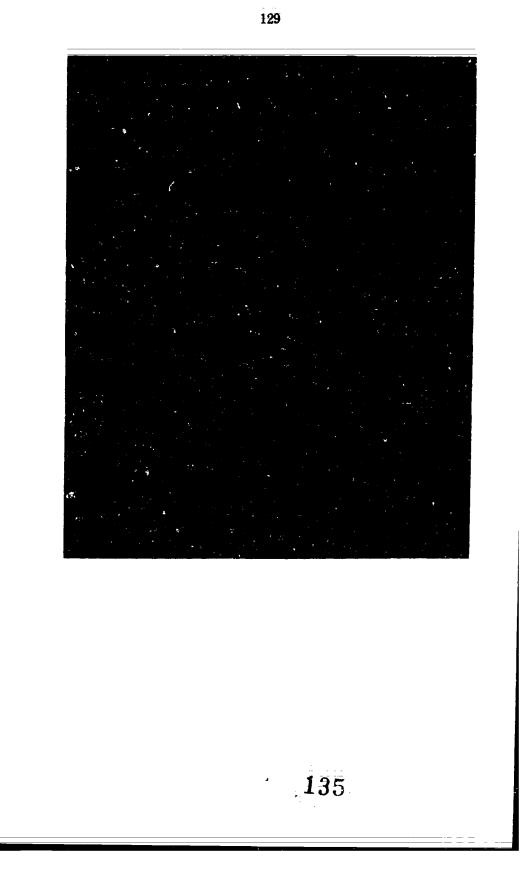
tain right vision image intensalers in

tan night vision image intensitiers in amplying the resulting high. Because the energy range of X-rays used in medical diagnostics is similar to the energy range of celestial X-ray object, such a low-intensity X-ray imaging system is also well suited for some medical applications. The original Luciscope uses a tiny rodosetive source is its supply of X-rays. Indign if a nearly pocket size system. However, radioactive sources are unable to supply the ideal energy. Intensity, or spectral distribution of X-rays in some applications. For such cases a ministure battery-operated X-ray generator has been developed re-cently at NASA's Goddard Space Plaght Genter. With the X-ray gener-ator, the energy, intensity and spectral distribution of X-rays can be adjusted at will. Therefore, in addition to radio-etime anti-cent with the X-ray gener-

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Space Stat Blood Analyzers

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Regulation of blood electrolytes is cru-Regulation of blood electrolytics is cru-cial for well benir. High blood pres-sure, dehydration, urne loss, dan-thea, kidney, fahrei, diabetic oma and certan types of bran injury all affect sodium levels. Potassium levels can be cruical since abnormal amounts can cause disturbances in the cardiocasci-tic persons, and mucha waterne. cause disturbances in the cardio-asct-lar, nervous, and muscle, systems... fonic calcium regulation is needed for blood coagulation, nerve junction and normal skoletal and cardiac muscle contraction. As part of a program to develo, techniques for monitornit. electrolytes of astronauts on long multis. NASA contracted with ORION Research of Cambridge. Massachu-setts, to produce compact analyzers. The traditional method of electrolite measurement at the unit require flammable circle with out no ne-used on space flights. ORION solved the problem by developing electrode-

based devices which operated well un-der. pace conduons. Included among the variety of bleec testing instriments brought about by space research are electrode-based electrolyte analyzers, notably sodium potassium and ionic calcium analyzers. As a spin-off of that early, work, ORION manifactured two dev. Jest hat simplified electrolyte analyzers is that simplified electrolyte analyzers is that calcium analyzer is still being dis-tributed by ORION, but its companion sodium/potassium analyzers, called Space Stat-30, was replaced in 1982 57 Model 1020 Model 1020 has increased the level of automatosi in the sodium/potassium measurement through increased use of microcomputers. With virtualls no-training, almost anjone ca i.t. nanaly ses on the instrument. There are no knobs or dials to turn—all operations based devices which operated well un-

can be mitiated with a push of one of three buttons (YES, NO, 2). Only 160 microliters of whole blood are required for a complete analysis. Results are displayed in less than one minute. The instrument fits in a foot of space and is portable. In addition to being used in traditional chincal labora-tiones and surgicat mons. Model 11:20 is making sodiumpotassum analyses routine in doctors' offices, small labo-ratories, ambulances and mobile mili-tary vetucles.

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Space-Stat Model 1020 Blood Analysis System.



Aseptic Fluid Transfer System

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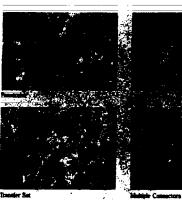
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The Aseptic Fluid Transfer System was invented at the NASA Jet Propul-sion Laboratory in 1974. It was guided through the technology transfer pro-cess and now is kensed to the Health Care Group Laboratories, Inc., of Lib-ertyville, Illinois. The transfer system uses coo-tainers made of two kinds of plastics that melt at different temperatures. Two layers of Dolyvnyi Choirde, which fuses under relatively low-heat, en-close a Liber of a more heat resistant pussic in a design allowing the con-tiguous regions of the two packs to form a common wall. When heat of 200°C is applied with a heat-sealer, the connectors are effectively fused, the joining area is sterilized, and an open-ing is introduced which allows blood to dow from one heag to another. Thus linking process takes one minute. Any bacteria present on the outer walls of Many flud transfer processes must be accomplished without contamnation. The purity of liquids is a special concern during the transfer of fluids into the human body. At this time, transfer systems used by blood banks do not ensure sterility. For this reason, the Food and Drug Administration has nided that blood which is frozen and stored, once thaved, must be transfer system uses to concern the sterilization of spaceraftic before launch to the moon and to other planets. Heat-selide plastic films are used to maintain a sterile environment during last-minute repairs and adjustments planets. Heat-selide plastic films are used to furnistin a design allowing the conceptions are effectively low-feat of the two packs to form a common wall. When beat of the two packs to form a common wall. When beat of the consectively low-feat of the specific planets is a design allowing the concisions are effectively low. This same ischerent buring last-minute repairs and adjustments planets is a sterilized, and an opening is introduced which allows blood to now from one bag to another. Thus linking process takes one minute. Any bacteria present on the outer walls of

test containers are killed during the

text containers are killed during the husing process. The ase-par-fluid transfer system is simple, inexpensive, durable, capible of ensuring sterility, and does not damage red blood cens or blood joint-ponents during the transfer process. The system appears suitable h to wide array of medical fluid processing functions, including intravenous and di-alysis procedures.

Aseptic fluid transfer system guarantees blood stenlity during blood bank transfer processes.







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### Chromosome Analysis

The nucleus of a living cell contains a number of thread-like bodes called chromostones. Each chromosome, in turn, is made up of genes which coutain the "blueprint" of information that transmits breefdary, characteristics of the animal or plant from generation to generation. Researchers use this celular information to study the genetics of cells and organisms. Medical clinicians use at to diagnosic faild even prevent genetic abnormalities in humans. But to be useful to these biomedical professionals, the information about chromosomes contained in a cell must be organized in a structured way. One important organization form is the karyotype i. Cataloging of the arrangement of chromosomes, by type, that occur in a cell. The preparation of a largotype by standard methods from a photograph of the chromosomes within a cell is a technician several days to comtaine.

plete. To speed up the preparation of human karyotypes, scientists and engineers at NASAS Jet Propulsion Laboratory developed an Automated Light Microscope System (ALMS) that will

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automatically, rapidly and accurately scan a chromosyme, specimen to measure and elassity the chromosymes present. The system uses diptal, teomputer-aided) unage processing technology derived from research and development that JPL has carned out in the past in support of NASA automated missions that returned mages of Mars, Jupiter, Saturn and other bodies of the solar system. To be economically (easible for use in a hospital or clinic, an automated chromosome, andlysis system must, consist of two parts: a device that automatically, routinely and quickly scans chromosomes; and another device that automatically, routinely and guickly prepares chromosome apec:

To be economically (easible for use in a hospital or clinic, an automated chromosome analysis system must, consist of two parts: a device that automatically, routinely and quickly ... scans chromosomes; and another device that auromatically, routinely and quickly prepares chromosome specmens for the scanner to use. JPL soientists have device system with their developme. To the State of Hoge National Medical Center in Duarts, California, where its biologists developed the second device: a machine that auronatically prepares chromosome specimens to be scanned. Using the ALMS technique, an opeffator with no special training can perform a karyotyping in 7–16 innutes, depending on the type of specimen. The system is now being used expenmentally at the Prentiss Women's Hospital in Chacato to obtain karyotypes of chumosomes obtained from pregnant women through arminocentesis. The potential time and cost savings oblamable by means of this automated technique are clearly great. However, the economic stimbling block to the actual chuical use of an automated, chumosome analysis system is the large number of samples needed to keep the machine operating most of the time. If a large-scale, centralized clinical laboratory to conduct automated chronosome analysis is ever established, the JPL system represents a technology that can be easily updated and put to immediate use.

Homogeneously stained, normal human male karyotype d.: ernaned by computer.





## **Muscle Biopsy**

Skeletal nuscles act to more the skel-etal structure of the human body and to mantan posture against the pull of gravity. Generally speaking, there are two types of skeletal muscle fiber. "Fast twitch" fibers contract rapedly but time easily. They predominate in muscles for which sudden exertion is often required, such as calf muscles. "Skow twitch" fibers contract skowly... but time less easily. They are most pre-dominant in muscles requiring en-durance, such as back muscles. About 15 years ago, a simple stain-ing technique was discovered which enables the two types of muscle fibers to be distinguished under a micro-scope. In cross section, muscle fibers from a biopsy sample form a mosaic pattern of light and dark shapes, Skow fibers are dark. Skeletal muscles act to move the skel-

bers are tight in color, while fast fibers are tark. The ATPase-staining technique en-abled physicians to diagnose both the type and severity of neuronuscular disease by being able to measure dif-ferential change in slow and fast fibers. There was, however, a serious prob-lem. The analysis made by a physician looking through an optical microscope

at stained niuscle fibers was subjective and of limited accuracy. A more quan-titative and precise analysis method was required.

bilding and provide a market in the uncer-sion Laboratory, became involved in the automated analysis of muscle tissue, while studying the observed loss of muscle bulk by humans and au-mais during space fight. Using a digital market processing technique to analyze the muscles of rais that had been in space for 18.5 days abord the USSR Biosatellites, Cosmos 936 and Cosmos 1129, JPE investigators, along with re-searchers from the University of Southern California, confirmed that there is indeed a reduction in both the there is indeed a reduction in both the size and weight of slow and fast muscle fibers.

The JPL-developed system uses a The PL-developed system uses a computer to add in carrying out rapid, accurate analysis of muscle samples. The device can measure the area, den-sity, circumference, and intensity of stain of a fiber in about 20 seconds. An stain or a noer in about as seconds, run advanced, version developed by MASA's Applications Engineering Pro-gram and the Musclar Dystrophy As-sociation is in use at the University of

California at Los Angeles for basic as In basic research, the device will ad-dress questions such as: What is the nature of normal muscle? What hap-

pens to an athlete's muscles as he-trans? What happens to the muscles of a patient confined to prolonged peri-ods of bed rest?

ods of bed resi? In clinical research, the device will address questions such as: What takes place with muscles during privinged paralysis? Can an early dagnosis be made and progress mea-und nine treatment of such neuromuscular dis-cases as emistional mission.

treatment of such neuromuscular dis-eases as mysathenia gravis, muscular dystrophy, and amoytrophic lateral scienciss (ALS)? If these questions can be answered successfully, the digital image-process-ing technique could become a routine tool in the diagnosis, treatment, and evaluation of neuromuscular disease.

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Muscle spectruen statued to show the mo-saic justern of light and dark shapes repre-senting slow-and fast-twitch muscle fibers in cross section.



### Ultrasound Imaging

The cardiovascular system, a network of arteries, veins, and capillanes with the heart serving as the central pump, distributes essential nutrients to cells and removes waste products. Its mi-portance is underlined by the fact that about one-half of all deaths in the U.S.

about one-half of all deaths in the U.S. each year are due to failures of cardio-vascular system components. One of the more common problems of the cardiovascular system is athero-aclerosis, a progressive build-up of fat-ty and calcificate deposits within ar-teries. Because this condition narrows the actions: it service demonstra blood teries. Because this condition narrows the artery, it partly obstructs blood flow and therefore causes an increase in blood pressure. Knowing the condi-tion of a patient's arteries, and being able to track changes in their condition over time, is of prime importance to a physician. This procedure involves in-jecting an X-ray-opaque material into the patient and then taking an X-ray-photograph of the artery. Although an-giography ab been used notimely for giography has been used routinely for years, it has significant drawbacks. It uses ionizing radiation; it is invasive (requiring injection of the material into the arteries): and it is not suitable for

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exact measurement of arterial block-

exact measurement of arternal block-age. The invention some yrars ago of the ultrasonic scamer—a device using very high-frequency scound waves to probe and visualize internal body-structures—was greeted with enthus-asm. It is a risk-free technique requir-ing no invasive procedures and no ion-izing radiation. In addition, it is less expensive than other medical imaging procedures. However, acardy ultrasonic. expensive data ourse medicar inaging procedures. However, early ultrasonic scanners did not provide very high res-olition and contained algorithcant "noise."

"nose." For more than a decade, scientists at NASA's jet Propulsion Laboratory have been attempting to improve the use of ultrasound as a diagnostic tool in medicine. Conventional ultrasonic in medicine. Conventional ultrasonic instruments are of the pulse-echo. Type. They transmit a pulse and then "issten" for a seturn from the target. JPL's researchers realized that this on-off characteristic was the source of the current technology limitations. Ac-cordingly, they developed an ultrasonic instrument that could do both at once. This "swept-frequency," time-delay spectroscopy instrument, or TDS, is capable of producing images with significantly higher resolution and a bet-ter signal-to-noise ratio than the ear-tier technique. The JPL-TDS ultrasonic scanner is

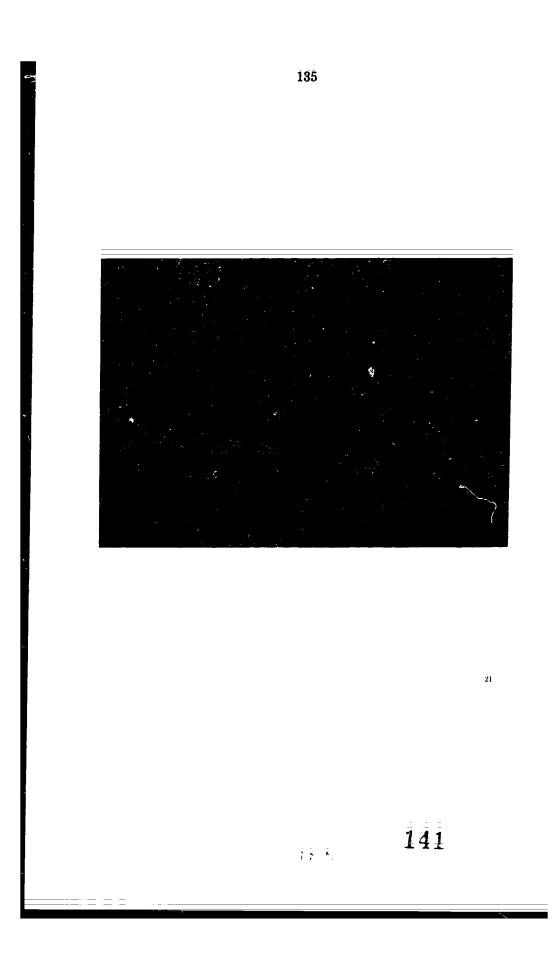
being used in a study at the Depart-ment of Cardiology. University of Southern California School of Medecine, to determine whether an ultra-sonic scanner can monitor the some scanner can monitor the ... development of the slight, suble atheroscierotic changes. The study in-volves 85 men who have their shallow-lying carotid (head and neck) arteries scanned five times, with an interval of a month between scans. Several hun-dred baseline ultrasonic scans now have been completed. With the improvements brought

with the improvements brought about by work at IPL, ultrasonic scan-ning now complements other "high-tech" medical maging (echnologies : such as computer-assisted tomography (CAT) and nuclear magnetic resonance (NMR). But whereas the TDS ultra-sonic scanner costs about \$50,000, CAT and MMP machines cost around some scanner costs about \$20,000. CAT and NMS machines cost around \$1.5 million--a major cost savings. With these advantages in view, further improvements to the TDS technology are now the subject of a grant to JPL from the National Institutes of Health.

Operation of Ultrasonic Time-Delay-Spec-trometer Scanner developed at JPL.









Eyetracker and Stabilized Laser Photocoagulator

Problems in which the return of the eye becomes detached or fifts away from its septorting structures are treated by laser photocoagulation. The focused energy of a laser beam "hums", a small part of the return and causes it to fuse to the rear of the eye creating a permanent point of attach-ment. There are two problems, how-ever, which firm the usefulness of the photocoagulation technique. First, a contact lens is placed over the eye of the patient which produces astignatic distortion with different-angles of beam incidence which, in turn, causes the shape of the burn area to vary with retinal location. Second, involuntary eye movements make it difficult to achieve the desired accuracy in locat-Problems in which the retina of the

achieve the desired accuracy in locatachieve the desired accuracy in locat-ing the burn site. The recently devel-oped eye tracker and stabilized laser photocoagulator offer promise for each of these problems. — The National Aeronautics and Space Administration in 1965 began support of studies of the visual accommodation system. These efforts, with additional

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support from the National Eye Insti-Support thim the National Eye insta-tute of the National Institutes on -Health, allowed SNI International to uvent and develop the Dual-Purking-Image (DPI) evertacker. This system works by tracking a pair of reflections from the from surfaces of the eye using invisible infrared light which op-enter though a dicknow moreous

from the front surfaces of the eye using missible infrared light scholo-erates through a dichroic mirror. There is no requirement for a contact letts. Accuracy is as good as, if not better than, that privided by the con-tact lens method. The Eye Research Institute of Bos-ton has developical alser congulator. system which can focus a laser beam onto the retina with no attachments to the patient's eye. In 1981, the laser congulator and the DP1 eyetracker were successfully merged into one, system and tested as part of an effort with the NASA Ames Research C en-ter. The objectives were to (1) config-ure the laser input system so that the eyetracker output signals might steer the beam and (2) merge the two in-struments mechanically so that they

did not interfere with cach other. Initial trains with an end of the second sec power laser source to be used in reti-nal repair procedures with human patients.

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Control of limbs is a special problem Control of links is a spectra problem for a chick wity cerebral palsy. The child's movements are weak, poorly coordinated, and jerky due to poor muscular control. Walking can be helped, however, through the prescrip-tion of physical therapy for individual like muscles. leg muscles.

leg muscles. In order to prescribe a specialized program of therapy, it is necessary to-messure a child's precise walking pat-tern. In the past, the child was con-nected by means of a bundle of wres to a recorder and a display to measure specific muscle movements. It was found that turnin proteints dues useful. Special muscle movements in was found that young patients follow more multited by the awkward tangle of training wires and the electrodes ait. tached to the body. This made it diffi-cult to obtain clear and consistent readings of their movement batterins. --An orthopedic researcher at the --Diddren's Vicenizal as Stational Dialogical to Plan.

- An orthopedic researcher at the Children's Hospital at Stanford in Palo Atto. Califorma, learned of the body sensors developed for the space pro-gram and contacted the NASA Arnes Research Center for assistance. Arnes

engineers, drawing on their experi ence with electronic systems used to monitor the movements of astronauts during space flight, developed a bioduring space flight, developed a bio-telementy system to measure the gat of cerebral palsy vertimes. The mua-ture transducers were affixed directly over the muscle groups being studied, with impulses then sent by wire to a smail transmitter wern around the pa-tient's waist. The transmitter relayed the signals to a receiver in another room where the data was recorded. While this was a significant improve-ment over earber techniques, prob-lems remained. The bett package con-taining the transmitter caused concern in the child and changed his gait. Also, the wire pickups and the signal mixing at the transmitter caused considerable electrone noise.

electronic noise. L-M Electronics, of Daly City, California, again working with the NASA Ames Research Center, recently developed a new gait analysis system with refinements which correct the earlier problems. This is a multi-chan-

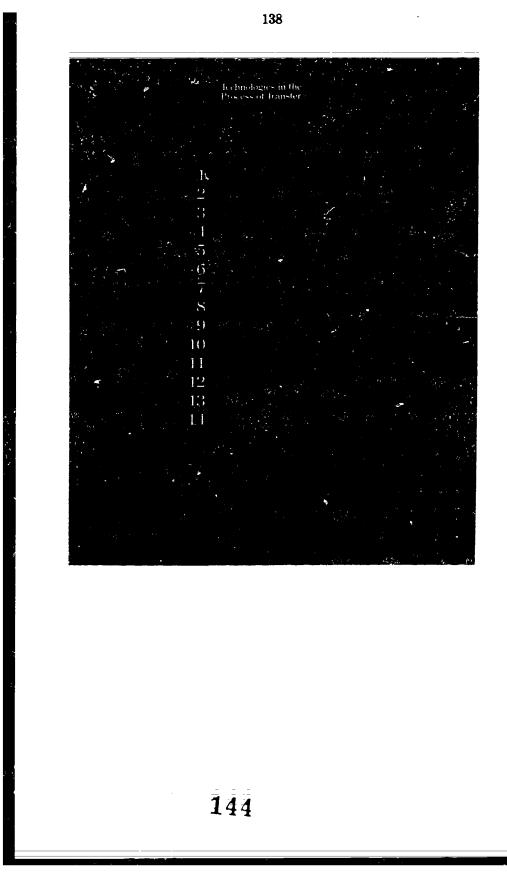
rel transmussion system with eight in-duxidual crystal-controlled transmit-ters, each operating on a different frequency. The belt package and all wires leading from sensors thus are removed. Each transmitter is pos-tioned at the torin of instruct. In our tioned at the point of interest. In one \_ application, each foot had a transmitter that sent information on four points of that seen information on four parts of contact, showing exactly what part of the foot was touching the ground. At the same line, three additional trans-mitters were affixed to each leg mus-cle group. These would transmit the electromyogram (muscle firing) of the particular muscle that was used in syn-

erans. Administrator, a civian huspital, and two universities with gait analysis centers for use in physical therapy programs.

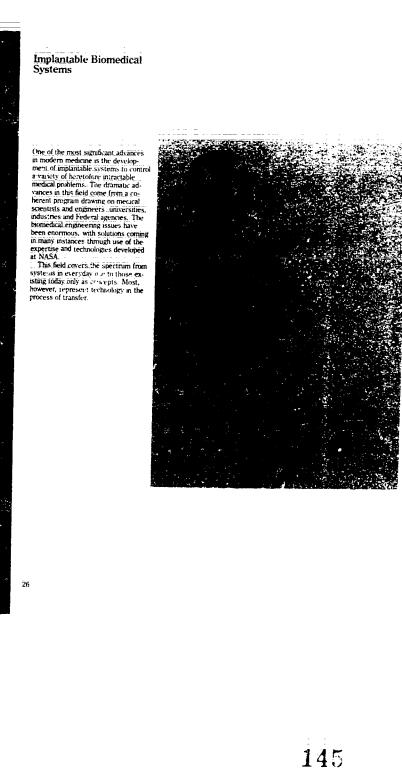
Placement of leg transmitters in the ad-vanced grat analysis system.

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Programmable Implantable Medication System

The traditional administration of drugs The transformat administration 4 ordes for method reasons, 50 who they injection. In many instances, these proceedures do not produce optimum, results. There are a number of drugs which achieve desired effectiveness only when delivered to the blood. only when delivered to the blood stream at a constant rate. A one-time dose, either orally or by injection, pro-vides a high level of the drug in the blood immediately after adramstia-tion, with a gradual decline thereafter. For many conditions, such as treat-ment of heart irregularities, neither the high initial level nor the subse-quent kow level is desirable. The peak-and-valley effect works against the purpose of the medication. The history of amplanted drug deliv-ery systems can be traced to 1937 when implanted hormone preparations were tested with livestock. The devel-opment of programmable delivery sys-tems, suitable for human application. is a recent event. While such a system will aid in management of many disstream at a constant rate. A one-time

will aid in management of many dis-cases, the thrust at this time is toward better control of diabetes. One million diabetics in the United States depend on daily insuln hyections to help con-trol blood sugar levels. Medical scien-

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tists believe that more reliable control of these blood sugar levels would du-manush the medence of the many com-plications associated with diabetes. In

pleations associated with diabetes. In addition, it would improve an individu-al's lifestyle bir enrivorus the require-ment for 2 to 4 insidu interviews dady. A Triggammable-Implantable Medi-cation System (PIMS) has been devel-oped by the Appleel Physics Usborato-ry, Johns Hopkins (L. versity, and the Technology Unitization Office, NASA Goddard Space Flight Center, Pacesetter Systems, Inc., Sylmar, Califorma: and Parker-Hanufin Bio-medical Products Division, Irvine, Califorma. — The implanted element in PIMS is the Implantable Programmable Infu-

the Implantable Programmable Infu-sion Pump (IPIP). An external unit programs the IPIP after implantation Automatis of tell and telemetry systems. A physician can construct a basal med-ication delivery schedule, which repeats within a period of 24 hours. In addi-tion, up to six different supplementary schedules can be programmed to be delivered more minimat of the actions delivered upon request of the patient. - The microminiaturized hybrid cr-cuitry used for the pump system as... well as the programming unit is hased

on NASA technology. The command and relemetry systems draw on tech-rologe used with small astronomy sat-ellites. Pärker-Hannifin, the organiza-tion which developed the mainturized four controls used for metering nu-trents into the scal samples in the Mars Value galacerth-provide the numaturized pump for CIMS. This pump is capable of metering methods ion in precise. dosses—about a mil-both of a liter at a time. Animal studies have been conducted to verify the system's efficacy in the treatment of diabetes. To date, four IPPs have been implointed in diabetic dises. Results demonstrate the ability of PIMS to normalize plasma glucose on NASA technology. The command

levels.\_\_\_\_\_\_ At the completion of clinical testing

active completion of clinical resing and acceptance for human use. Pacesetter Systems, Inc. and Parker-Hannidin plan to manufacture and mar-ket the Programmable Implantable Medication System:



Automatic Implantable Defibrillator

Over one melion Americans suffer heart attacks each year. Approximate-ly half of these survive the attack, but roughly 50,004-of this group die workin one year, mostly from x-einfricular, fibrilation. When it can be apolited in tim c, electric shock defibrilation is generally successful in restoring a nor-mal bear pattern to the heart. Untoru-natch, most of those who die each nately, nost of those who deceath year from a fibriliation episode are away from a hospital, where they could

receive proper treatment. The Automatic Implantable De-fibrillator (AID) offers a solution to this problem by implanting within-the this problem by implanting within the bodies of persons at risk a sensing, system to detect the onset of fibrila-tion or other potentials fatal arrevite-mus and to automatically dedicer; bala-anced electric pulse to restore the beert to a normal rhythm. Work for , the development of AID-1 began under the direction of Dr. M. Miroski of Kal-timore's Snai Hospital and the Johns Hopkins, School of Mechany, All de-wees nanafacured by Hare Systems hopmus school in device and Arto de-vices manufactured by Inter Systems, Inc., have been implanted in 238 human patients at 20 medical centers. Of these 238 patients, 70 have had a total

of 205 spontaneous arthrithmic epi-sides in which normal heart rhythm was restored by the implanted AID de-nee. The annual death rate for this se-nes of patients was reduced to only 4.6 percent from typical rates of 30 to 66 percent. Work is being conducted at this time toward an improved Automatic Im-plantiable DefionIlator System (AID-ID). This work is being conducted at the energy work is being conducted at the high center with it - Applied Physics Laboratory, working in conjunction with INTEC of Pittsburgh. Pennsylva-na.

na. Technology from the space program Is being applied toward three objectives. The first is to redesign as feasible the current AID using principles and components whose capabilities and reliabilities have been validated by use in spacecraft. The second objective is to develop

In elsecono cojective is to nevelop an esternal recorder capable of mon-toring and recording the patient's ECG al any time, when the patient's heart grees into fibrillation. A spacecraft-type, low power, solid state digital memory could be used to obtain an 80

second recording of the first de-fibrillator episode in a particular time penod. This would also provide a pa-tienti with an indication that a defibrilla-tion shock was admanstered. The third objective of AID-II is to greatly increase its capability. The im-proved AID-will provide a demand

proved AID will provide a demand pacer. Lucition to restore normal rhythm to an asystolic heart, an auto-matic test sequencer and low-battery voltage detector, programmability al-lowing adjustment by the doctor, carly wartuing of an unpending defibrillation episode, and a four functor, internal event ECG recor fer. The AID-II con-cept offers very sophisticated and ad-vanced support for individuals suffer-ing from heart problems.

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#### Liquid Cooled Garments

The NASA Aries Research Center de-vide more efficient and effective heat removal for astronauta wearing space suits. Water-pertused "panels" were designed which can be positioned over major muscle areas to remove excess body heat. The panels are constructed of two layers of unetlane-coated nyka which is heat sealed to form integral channels to direct the flow of cooling water. The panels are connected to each other and sewn inside a close fit-ing garment which is then connected to a pumping/cooling unit by inlet/out-let tubing. This panel construction pro-vides a close, comfortable fit to the body and promotes effective heat re-moval.

There are many medical applications for a system which provides partal or total body cooling or warmung. The Ames system also is used in various medical research programs. These programs include studies of total body thermal control in cancer therapy and neonatal warming and cooling during surgery. Partitional body cooling has been effective in several areas: head cooling to reduce hair loss during of spinal cord injury patients during hot weather, tor-so cooling of patients who cannot per-spire, and cooling of limbs of patients with a rare superheating problem. The cooling vest illustrates further development of cooling garment tech-nology. The construction of the vest is

unque in that it incorporates a third in-termediate layer between the two out-er urethane-coated nylon layers. This third layer is made of a synthetic mate-nal which is woven and heat sealed to form integral corrugated channels which are essentially noncompressible and thus insure water, passage even when the garment is compressed, such as when learning against the back of a seat or under heavy loads. The simple design ard construction of this garment provides reduced manufactur-ing costs for medical applications.

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Vascular Access Device

Advanced procedures in medical tech-nology, which offer such dramatic hope for heart disease, kidney disease and other affictions require access to the body. With some, electrical connec-tions must be made. In other in-stances, the blood must be drawn. Lemporarily from the body for treat-ment. In all cases, an invasive connec-tor is required.

ment. In all cases, an invasive connec-tor is required. Any invasive system carnes with it certain problems. If a simple puncture is used, there is post-treatment bleed-ing, tissue swelling, and the formation of brunsed areas. If a permanent con-nector is implainted, there is a high risk of infection and rejection by the body. The challenge is to develop a permanently implanted conjector with biocompatibility—one which can be used for a long period with no atten-dant complications. Pure cortion is one of the most bio-compatible substances known. How-

compatible substances known. How-ever, most forms are not strong enough for extended use. High

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strength forms of carbon, designed in-tally for space capsule heat shields, were studied, under XASA support, at the Rancho Los Arugos Hospital in Downey, California, Mitre au carbon was found to meet the requirement for bacompatibility, ito be light weight and appropriate strength. The preparation of percutaneous through the slend connectors is as in-portant as the selection of materials. The NASA Lewis Research Center-has been working with Applied Med-cal Technology, Inc., to use non-beam sputtering techniques developed in the NASA Election Propulsion Program to texture percutaneous connectors with NASA Electron Propulsion Program to texture perculaneous commercions with a regular array of micropillars (small raised points). These inhibit tassue dowingrowth and subsequent rejection of the connector. American Bentley, a subsidiary of American Bentley, a subsidiary of American Hospital Supply Corpora-tion, now offers a Vascular Access System using a vitreous carbon im-plant which is virtually non-reactive

with tissue, blood of chemicals. The implant does not miterfere with routine patient activities and provides an air-and moisture seal between treat-ments. Patients requiring chronic di-alysis procedures aire afforded consid-erable convenence since treatment may be given either at home or at a medical facility.

Positioning of bioCarbon\* vascular access implant.





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#### **Prosthetic Urinary** Sphincter

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Urmary incontinence drastically affects a sufferer's ability to lead a normal life. In addition to the inconvenience, ex-ternal collection devices leave a con-stant residual urine in the urethra and bladder, where it serves as a medium plegics, who are permanently aconti-nent, kidney failure from bladder infections is the most frequent cause of o ah

of ach\_\_\_\_\_\_\_Aerospace technology has been applied to the drivelopment of a simple, reliable prosthetic urinary sphincter control system to enable urinary incontrol system to enable urinary m-continent patients to achieve external voluntary control of blader function. This program started when Dr. Wil-liam G. Moutgomery, a researcher, treating paraplegics at Bowman Gray School of Medicine at Wake Forest. University, saw the need for a simple but reliable valve device that could be surgically implanted and easily con-ery contacted NANA Technology Appleations Evan at the Research Trangle histitute in North Carolini. A project then was started through the Marshall Space Flight Center with a key feature being the adjustion of the kw pressure, zero k ikage, high relia-bility valves used on the Viking Space-craft.

office or signed to not not over any female patients, contains a two-cham-ber inflatable, occlusive cuf, placed around the wethera, a self-sealing stor-age system, a check valve mechanism, and a valve fluid reservoir. The sphine-

ter system is implanted so that the ter system is implanted so that the value bub assembly is a cressible by nanual pressure through the skin. The cut applies pressure to occlude the urefura and mantain continence. The pressure can be released for voiding, then restored by manual manipulation of decisions.

Clinical trials of the prosthetic arm-ary sphincter are scheduled to begin in early 1985. When commercially availearly 1960. When continent any ada-able, this system will offer two unpor-tant advantages over earlier devices. Earst, its samplicity promises to reduce the surgical complexity of the implan-tation procedure. Second, the high rate of device malfunction with existing dimension of the due to when when devices, often due to valve tailure, should be dramatically improved

Se Prosthen, Unnary Sphincter

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**Ocular** Screening System

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Early detection and care of visual ab-normalities 'n school children is most important. An economical, highly reb-able outlar screening system has been developed to detect eye problems in children through a photometric anal-sis of retinal reflexes.

as or retrail relieves. The Generated Retrial Reflex Image System photorefractor is capable (f testing the human visual system for refractive error and defects in the retu-na or interior chamber and for ob-etherities in the semiclified of the semi-

of a direct photograph of a subject's. eyes, taken in a dark rown to facilitate pupil dilation. The color retinal reflex images then are analyzed by experts to determine eye problems. The project started when an opti-thalmologist in Huntsville, Alabania, contacted the Marshall Space Flight Center Terimology Uritization. Office to request a technical evaluation and as-

Sex Male VA Uncorrected 5t1 70/200 ы 20/200

Photograph made with Generated Retinal Reflex Image System.

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sistance in developing a photorefractor device. The resulting system, devel-oped with the assistance of a small-business. Electro Option Instruments, does safe, low-cost sciencing for am-blyopia (dimness of sight) and other eye diseases, especially for children too young to communicate. Independent tests conducted by the Smith-Kettlewell Eye Research Foundation in San Francisco graded the accuracy of a

San Frant isco graded the accuracy of a prototy c system is capable of detecting eye anomalies such as httperopa, myona astigmatism, strabele of detecting eye anomalies, such as httperopa, myona astigmatism, strateging and the substructions. It was used mitially in a mass screening, of students at the Alabama School for the Deaf and subsequently by a Huntsville Lions Chub in a screening of 1,835 kindergatten and first grade students. Five hundred and seven were found to have abnormal researchers also are testing a solect group of 441 students with learning. group of 441 students with learning disabilities to determine possible rela-tionships between these problems and eyr abnormalities. Of these students,

255 were found to have abnormal retinal reflexes. The ocular street, ng system is an

The ocular scree, no system is an effective measurement acvice which is geonomical, portable, and no suvas-ive. It is a promising technique for large-scale screening or field of the de-tect visual publicity of the screen the system was explored to the screen the system was explored to the screen mercially available in the screen through the screen the screen the screen th small business firm in .....

Visual anomaly patterns.

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#### Speech Autocuer

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The successful development of a wearable, real-time speech perception aid has the potential to improve the economic status and quality of life for the 1.8 million deal people in the United States. Research has been completed which demonstrates that, deal people can perceive sneach acrossing to the status of status

United States: Research has been-completed which demonstrates that... deaf people can perceive speech accu-rately through a prosthesis based on Cued Speech. Called the Autocuer, the speech analysing prosthesis pre-sents automatically derived visual cues in real time to a wearable eyeglass dis-play which, in combination with lig-reading, enables accurate speech per-ception by deaf people. The Autocuer projec, is a four-way collaboration between Research Tri-angle Institute (speech analysis, hard-ware and software design). Gallaudet Collaboration between Research Tri-ing, field test). NASA Goddard Spare Flight Center (proje-t coordination, technical consultation), and Telesenso-ry Systems, Inc. (labrication of field test units, commercialization)...NASA and the Veterans Administration pro-vided support for the work.

forts of NASA in developing comple-mentary metal oxide silicon (CMOS) low-power electronics for space mis-sions, work began in 1979 to develop a low-power, wearable microcomputer, to adequately analyze connected speech for successful automated cumg. The last two of the large scale inte-grated circuits needed by the Auto-cuer for producing accurate real-time. speech analysis in a wearable package have now been incorporated into the design and are being verified to meet project requirements. When this step is completed, the design will be re-leased to Telesensory Systems, Inc., of (labrication of 24 units for use in the field test. Schedilled to began in 1985 and last one year in duration, the field test will

works in the real-world speech en-





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### **Hip Joint** Biotelemetry

Over: 100.000 total hip replacement operations are performed each year in the United States. Unfortunately, a number of these do not have lasting success. X-ray endence of femoral component houseness in excess of 20 percent has been noted or exercise percent has been noted in reports from the Mayo Clinic in 1978 and from UCLA in 1979. Failure reports indicate that prosthetic losisening-may be tound in up to 24 percent of older patents in as hitle as seven years, and in up to 54 percent affect only five years in pa-tions of implant breakage, cement fracture, sike [14] koseming, and com-ponent wear are directly related to the transmission of force agrees this work potenti wear are unrecity related to the transmission of force across the joint. With younger patients who will have greater performance expectations from their replacement joint, we may expect increasing rates of failure due to the increased transmission of force across the upper

across the joint. The estimation of joint forces in-volves calculations based upon mathe-matical idealizations of joint geomeaccuracy of such calculations is not known since dynamic effects due to the musculature can only be estimated.

The NASA Jet Propulsion Laborato-The NSSA Jet Propulsion Laborato-ty, ni-scoperation with the Bomickian-k's Section of the Division of Ortho-pedic Surgery at UCLA, in 1977, began the development of a prototype ho-tclemetry package to be scaled within a total hip replacement implant. This system will give in riso data as a pa-tient fores about his of her daily activi-tion. Dombit transformed and a scale in the schemetry barreformed and a scale in the schemetric schemetric transformed and a scale in the schemetric schemetric transformed and schemetric schemetric schemetric schemetric transformed and schemetric schem

usin poes about no or net cany activi-ties, thereby prividing engineering data not previously available for the improvement of hip joint design. The experience of PL with man-alumzed remotely, con rolled space fe-lemetry systems has resulted in a during environment activity. Activity of the lemetry systems has resulted in a and use i relations, for tonical space fe-lemetry systems has resulted in a design overcoming many of the -difficulties previously encountered in powering implants. Rather than using batteries or wires through the skin, most of which are at best awkward, the JPL design relies on induced power. With this technogue, the patient needs only to wear a cuff, much like that used to take blood pressure read-ings, around his thigh. Power is trans-mitted from coils of wire in the cuff to an antenna built into the hig point im-plant. Date 6 mistrain gauge sensors within the serve in are read out (bough the same induction system. Thus data can be collected over months or years, with no diacomfort to the patient. At all times, the implant will function in a

all times, the implant will function in a rormal manner. Juata from the completed system will provide the first in revolveding in-formation from a total high replace-ment. Even if only one patient implan-tation is achieved, the information will be invaluable. Direct measurement of high force with walking aics, casts, and modified gait patterns will give, a rela-tive measure of the effect veness of these techniques. Validat on of mathe-matical models will be pussible. These data-will be of value in understanding the mechanical forces responsible for the mechanical forces responsible for prosthetic loosening and fracture and will also show wear patterns on internal components such as the acetabular

The components such as the acetabular cip. Work is proceeding at this time on engineering models for actual implant. This effort, funded by the Veterans. Administration, pending Government approval for use in human subjects. will result in data describing forces on human hip joints by 1986. This infor-mation will be invaluable for the im-provement of future hip joint systems.

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#### Versatile Portable Speech Prosthesis (VPSP)

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The number of people in the United States with speech impairment is est-mated at about two million, or about one percent of the total population. As many as one-half of these, up to one many as one-nail or unese. Up to one --malion, are believed to have serous or disa Yang speech impairment which re-quites the use of some type of com-munication aid, or speech prosthesis. While there are a number of communi-cation aids with visual and printed out-puts, a speech aid provides faster and more afficient communication, essent

speaking people designed to be placed on a wheelchair and powered from a wheelchair battery. The versatility of the VPSP allows it to accommodate a variety of input devices including sin-gle switch, multiple switch, joy stick, or other keyboard controls which

so outcome and a second controls which in a physically limited people have the abili-ty to use. It speaks with a synthetic voice for people unable to speak with

their own voice. The VPSP employs a microcomput-er with a phoneme speech synthesizer and a specially designed television screen. The user composes speech and phrases from a "starter vocabu-lary" in the microcomputer's memory as they are displayed on the matrix-board of the television screen. After, selecting a message, it is entered by manipulating a control switch which ùmanipulating a control switch which il-luminates the words or phrases one wishes to say. The microprocessor then activates the speech synthesizer device which speaks the message aloud. The users also can develop... their own messages and store them in the computer for later use. In chincial trials, all users feil that the VFSP was a met being the them. The measage a great help to them. The message construction time varied from one to three words per minute with the one-switch version to ten words per min-ute with a keyboard, using single-fin-



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were based on extensive psycho-linguistic human factors research con-ducted by the Man-Machine Integra-tion Branch of the NASA Arnes Research Center, This research mitaily was directed at applying synthe-sized speech in airplane cockpits as an effective means of warning pilots of dangerous situations.

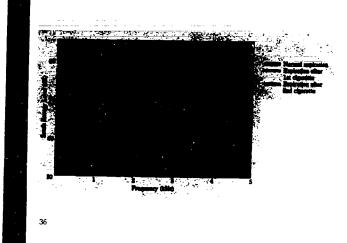
dangerous situations. The Versatile Portable Speech Pros-thesis has been successfully tested as a prool-ol-concept system and is avail-able for commercial development. Although designed as a wheelchair-mounted system, it can be used in other situations to aid persons not capable of speaking.

Non-Invasive Lung Diagnosis

# The prognosis for many forms of pul-monary disease is improved with early detection, accurate diagnosis, and the immediate initiation of an appropriate program of therapy. Disabiling pulmo-nary illnesses may develop as a result of occupational and environmental fac-tors, pulmonary vascular pathology, cystic fibrosis, asthma, or cigarette amoking. Management of these ill-nesses requires new methods to innesses requires new methods to in-sure early detection. Research in aeroacoustics con-ducted at NASA's Langley Research

Center has provided a basis for a theo-ry of the origin of human respiratory. sounds derived from the motion of vor-tices in the human hung. The nature of a given pulmonary ilhess should cause a distinct change in a pattern of air-flow through different regions within the lung. The developmental work in pulmonary acoustics and the validation of this theory using lung models has been accomplished by the "Theoretical Acoustics Branch, NASA Langley Re-search Center, and the Medical Col-lege of Virginia. This work include:

the development of a technique of suf-ficient sensitivity to record and analyze human respuratory sounds as these, sounds are changed by minimal lung dysfunction. B&K Instruments, Inc., of Cleve-land, Ohio, is supporting this project with engineering consultation and equipment, belleving it has potential commercial value as a diagnostic sys-tem. It predicts a marker for the system in employee industrial check-up centers as well as in hospitals.





bonding it to the right type of anti-

body. The most exciting part of this process from a medical standpoint is that microspheres can be filled with a vari-

microspheres can be filled with a variety of substances which are mietelinto the cell. This produces the cell "labeling" effect. Depending on the substance used, the cell can be labeled in different ways for different purposes. Fo, example, if the microspheres are filled with a radioactive substance, specific cells can be identified and counted by means of the radioactivity. they absorb. Similarly, labeing with a fluorescent substance will

coactivity, they absorb. Similarly, labeling with a fluorescent substance will permit both identification and separation of the labeled cells, using a special cell-sorting instrument. Imparting a impretic field to the microspheres

provides another way to separate labeled cells from non-labeled cells-

beled cells from non-labeled cells. For treating disease, the microspheres can be filled with a drug that can alter or destroy the specific cell to which a microsphere attaches itsef. Thus, the microsphere-antibody combination (called an immunomicrosphere) becomes a "smart bullet" tageted at the diseased cell. This tech-

#### Microspheres

All living tissue is made up of individual building blocks called cells. In medical research, it is important to be able to identify, examine or spharate different types of cells. But the techniques for doing so have always been time consuming and inexact. Faster and more versatile techniques would not only, benefit research, but would also have potential application in the diagnosis and treatment of diseases. Scientists at NASA's lef Propulsion Laboratory have developed a novel cell-labeling technique for a variety of such applications.

The technique is based on the preparation of microspheres. Imy hubbles made from synthetic polymers, that can be chemically bonded to antibodies, special molecules, produced by the bodys immune system. In turn, the antibodies are able to seek out,

the antibodies are able to seek out, recognize, and art.Ach themselves to molecules called antigens found on the surface of specific cells. In the process, the antibody brings the microsphere along with it. Because each, antibody will attach only to a specific type of antigen, the microsphere can be directed to a certain kind of cell by

tique has already been tested successfully in the laboratory for treating cancer (c.ls.

cer ccis. In a 1983 clinical procedure in London, physicians removed ten percent of the bone, marrow of a patient suffering from neuroblastoma. The removed bone marrow was treated with magnetic immunomicrospheres, and imagnetic field was applied to separate the magnetic, healthy cells. The healthy, bone marrow was then replaced in the patient. Since that time, about 20 young people with neunoblastoma have been ureated using this procedure. Significant improvement has been noted in most of the patients. Has of microspheres has orear med.

patients. Use of microsoberts has great medical porential. With further development, the work begun by JPL may lead to cancer therapies that are more effective than existing radiation and chemotherapy. for example, and lack their debilitating side-effects.

Due-t immunological labeling of living cells with microspheres covalently coupled to antibodies.

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#### UNISTIK

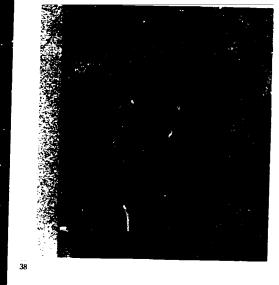
Driving an automobile is a complex perceptual-motor activity requiring use of all four extremities. For a hand-capped person, this activity is difficult in on impossible. In more instances, independent transportation is not achievable for the severely hand-capped and represents a real harmer to their leading productive lives. The National Aeronautics and Space Administration. Ithrough its Technology Unitation with the Veterans Administra-tion, is managing a program to use Lu-air. Rower Vehicle technology from the Apollo Program to ad in the develop-ment of a control system which will enable severely handicapped people to drive a conventional motor vehicle. During the Apollo missions in the

1970s. astronauts drive the Lunar Rover using one hand to accelerate. brake, and steer as they explored the surface of the moon. The UNISTIK uses a two-axis joystuck to control electric motors which position the con-trols of a standard motor vehicle. Mov-ing the stack forward depresses the ac-celerator pedal, rearward depresses the brake pedal, while left or nght, movements um the steering wheel in the appropriate direction. The system uses a "dy-by-wine" type of control used in spacecraft rather than the conven-tiona direct coupling of control to actu-ate.

ator. The design of the driver's control system is based on a human factors analysis of the control capabilities and

Initiations of quadriplegics who have suffered lesions of the spinal cord at the fifth cervical verticebrae. Inputs to the design study were nade by a quadriplegic and several patients at the Crais, Rehabilitation Hospital in In-glew-ad, Colorado, Jóinson Engineer-ng, corporation, Hormerly Nelson and Johnson Engineering, Inc.), the firm, which has worked with NASA and the VA to develop this system has tested a prototype UNISTIK in a 1981 Ford Yan. The Van has been successfully driven by several quadriplegics. This is a major size forward in opening the normal world to the severely handi-capped. capped.

UNISTIK being used for control of the





**Computer-Enhanced** Angiography

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The value of this technique less in its. capacity for making long-term compar-isons and in its accuracy. In clinical -studies, such as those at USC, it can measure small changes in lessons iden-ticed in progressive angiograms taken over-intervals of time. This computer-aided method also aboves a precision error of only about four percent, as compared to about 25 percent for the visual inspection method. Because angiograms involve an in-vasive procedure, with some nisk to the patient and the use of ionizing radia-tion, the computer-lifed, image-analy-sis technique developed at JPL must compete with presently developing non-invasive techniques, such as nu-clear magnetic resonance and ultra-sound, which are apparently nisk-free The value of this technique bes in its.

and which use non-innuming radiation. However, there are types of examina-tions that cannot be performed as well with altrasound (for example) as with angiography. In addition, this tech-inque offers much finer unage resolu-tion than even the improved eltrasound instrument developed at JPL. Perhaps the most promismo approach, how-ever, will be to use these same basic computer-image analysis pricedures in conjunction with the JPL ultrasound device. The technology described here is being evaluated through continuing chineal trials. Through extensive pub-lication of the results achieved thus far, computer-inhanced angiography is expected to come into increasingly wider use.

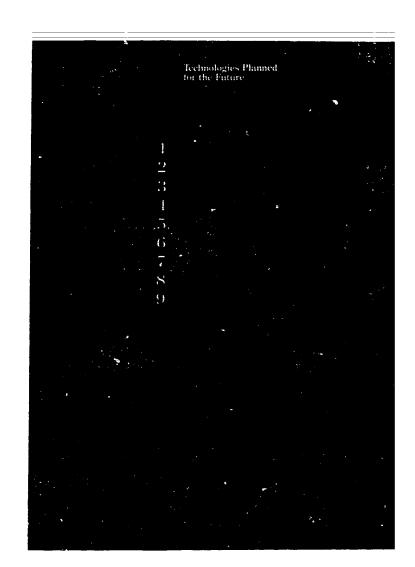




Computer-determined angiogram of a fermoral artery showing the edges of the arternal harmen foutline of tark area. (hare vertical lines estimate the cardine of the normal (pre-diseased) atternal lunen.

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Hydrocephalus Shunt

Hydrocephalus is an excressive ac-cumulation of fluid within the natural cavities of the brain. It is a condition in which the cerebral ventricles enlarge abnormally when the pressure of the cerebrospinal fluid rises. This is a re-sult of some impairment of the normal circulation or reabsorption of the cere-brospinal fluid. In children, approx-inately 8.000 cases occur each year as a result of a cleft spine birth defect. There may be as many as another 3.000 cases occur each year as a result of a cleft spine birth defect. There may be as many as another 3.000 cases occur each year as a result of a cleft spine birth defect.

area with congenital neural tube de-fects, traumi, infection and tumors... Treatment of hydrocephalus consists of the surgidal insertion of a device to divert cerebrospinal fluid from the brain to another part of the body.... While these dramage devices, called hydrocephalus shunts, have reduced mortality and other conseminences as: mortality and other consequences as-sociated with this condition, there are

a number of problems. An et imated 50 percent of hydrocephalus patients require at least one reoperation to re-place or repart a malfunctioning shunt. Obstruction of either the ventreular or distal cätheter is the major cause of ... shunt failure. The obstruction itself re-sults from an accumulation of body results. tissue

tissue. In 1981. NASA asked the Bio-medical Applications, Team of the Re-search Triangle Institute to determin-il NASA technology could be success-fully applied to the development of an improved hydrocephalus shunt. It was determined that technology developed in NASA's Ion Propulsion Engine Pro-gram might be used to perforate. gram might be used to periorate small-diameter catheters. A multi-end-ed mlet catheter, with hundreds of tiny inlets formed by ion-etching tech-niques, could minimize the blockage Problem and reduce the incidence of shunt failure. The small holes would — inhibit tissue ingrowth and the inulti-

inhebit tissue ingrowth and the inulti-pletty of holes, would reduce the possi-bitity of blockage. A team consisting of scientists from the Ion Beam Applications Section. MASA Lewis Research Center: the Jet Propulsion Laboratory: the University of California ai Irvine: and the Pudenz-Schulte Medical Research Corporation are working on the improvement pro-gram, Pudenz-Schulte is developing an animal model for evaluation of the Lewis infoitype shufts and will con-duct bench tests for shunt flow stud-ies. At this time, the JPI, team has successfully formed 15-micron holes in a teflon shunt, an encouraging step to-ward a successful new design.



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Sensor Actuated Medication Systems (SAMS)

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Hypertension, or high blood pressure, is a signat problem for the Ameri-can workforce. In the civilian, non-in-stitutional population between 25 and 74 years of age, there are over 16 mil-bion people classified as having definite hypertension. These individuals, rep-resenting 14 percent of the workforce, are at serious risk for heart attack and other diseases. In 1980, the deaths of over 32,000 Americans were attributed either to hypertension of hypertensive heart disease. In addition to these deaths, many more Americans devel-oped churoic heart conditions, suffered stroles of developed kidney disease. Hypertension is a disease of griat eco-nomic and social consequence for this nation.

nomic and social consequence for this nation. The National Heart, Lung, and Biod Institute, in a five-yetr pro-gram, found that death rates from hy-pertension could be reduced by 17 percent through a continuous and in-

tensive drug treatment program. Clinical experience, however, shows that it is difficult to maintain such a 

With this system, the medication is continuously available and is adminis-tered in direct response to the needs of the body. This represents closed-loop control of hypertension through a sensor actuated microprocessor con-trolled medication infusion system. In order to achieve the highest relia-bility, the SAMS development effort is using struceralit-type microminatur-ized hybrid circuitry and programming technology used on the Small Astron-omy Satellite and other spacecraft. The program schedule calls for clinical trials to be completed within the next five years. The resulting system will do much to alleviate a major medical problem in America.

Implanted portion of SAMS system.







System for the Measurement and Control of Hypertension (SYMCOH)

The optimum procedure for controlling hypertension would be one which contimuously monitors the blood pressure level and which can correct undesirable increases without the use of medication. Work conducted with NASA support indicates such a system may be feasible using the technology now being developed. The system concept is based on use of bioleedback pricedures.

a based of use of noteedback process — Biofeedback is defined as a process in which a person learns to influence. or control physiological responses not normally under voluntary control. It is a type of self-regulation in which one, learns to control activity normally mediated by the autonomic nervous system. The physiological responses most frequently used in bioleedback are. heart rate, skin temperature, blood pressure, and peripheral blood flow. Hypertension appears to be an appropriate candidate for bioleedback.

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The implantable system developed far admunistration of medication for hypertension control (Sensor Actuated Medication S) stem [SAMS]) can be modified, in principle, to accomplish the same control through a biolecedback process. The System for the Measurement and Control of Hypertension (SYMCOH) includes an implanted module for sensing and recording blood pressure, which provides at: alarm signal if programmed levels are exceeded. This signal serves as the basis for bioleedback control of blood pressure. The bioleedback can be by subcutaneous electrical stimulation or by an audiotone whose frequency or pulse rate is proportional to blood pressure. This signal, which indicates both the occurrence and magnitude of a blood pressure mcrease, triggers the biofeedback response which in turn serves to reduce blood pressire. The SYMCOH development pro-

gram will proceed in much the same manner as SAMS. The Goddard Space Flight Center will provide overall management guidance, with the Appled Physics Laboratory of the Johns Hopkins University performing the systems engineering application and development. The first evaluations of the SYMCOH system will be conducted at the Johns Hopkins Hospital. As with SAMS, clinical trials should be completed within the next five years. These trials will validate the operation of the implanted system and its controlling software. Additionally, they will allow the development of efficient techniques for teaching an individual the bioletaback skills necessary for this system to be successful.

Implanted portion of SYMCOH system.





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#### **Corneal Topography**

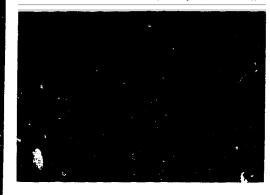
Aerospace technology used to mea-sure precisely the mirror surface of the space telescope is being applied to the development of an instrument that

the development of an instrument that will accurately may the cornea. This instrument, called the Corneal Optical Topographical Scan System (COTSS), unes a laser beam to scan the eye to obtain information required to deter-mine the precise shape of the cornea. New surgical techniques for the treatment of human eye cornea disor-ders depend on accurate measure-ments of the shape of the outer sur-face of the cornea. An example is radial keristicary in which eight to six-teen radial cuts are made in the outer layer of the cornea to cause the sur-face to flatten and reduce myopia. A Agence to flatten and reduce myopia. A face to flatten and reduce myopia. A very accurate mapping of the cornea is needed to establish the pattern of the cuts and to determine if the cornea is healing property. Another application is in cornea

transplants, where the surgeon need-to have quick measures to determine it the sutures are unformly stretching, the new comea Damage from trauma such as cuts, burns, and punctures also requires quick dagnosis and accu-rate measurements of the measure. rate measurements of the extent of the damage. The advent of faster and more accu-

The advent of faster and more accu-rate measurement technques will even improve the fitting of contact tenses. Instruments now in use by ophthalmic surgeons do not provide the required accuracy of the necessary high speed, real-time rate of data collection. - Engineers at the NASA Marshall Space Flight Center developed an im-tal prototype of the Corneal Optical Topographical Scan System. As the laser beam on this instrument scans the cornea, radiant energy that the eyer reflects from the laser beam is measured and processed in a special purpose computer, Within a few äcc-

onds after the events scanned, a de-tailed topographical representation of the comeans displayed on a citior tele-vision monitor. This can be used im-mediately by the physican or, if he re-guires quantitative data for use to a tens presemption, the data stored in the nDecial purpose computer can be analyzed and the results printed in hard conju-



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Nuclear Magnetic Resonance (NMR) Imagery

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The traditional means of examining mternal body systems has been through use of X-ray magery based on the dif-ferential absorption of X-rays by body systems of different density. Routine systems of different density. Routine X-ray images, however, do not dis-criminate well among overlapping structures. Computerized tomography (CT scarning), in which a number of images are reconstructed mathemati-cally to yold cross sectional views of selected body regions, provides great by improved information. Although the informator is very useful scarning images sell do Lay provide information concurring the functional or phys-iological state of metrial organs, bariological state of internal organs, par-licularly if pathological lesions exist which have X-ray absorption proper-

which have X-ray absorption proper-ties similar to surrounding tissoe. Also, there is a measure of risk m using extensive X-ray procedures. Nuclear magnetic resonance (NMR) imaging is a new technique for obtain-ing cross-sectional pictures within the body without use of oin ring radiation. NMR procedures are based on findings

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in the 1920's that many atomic nuclei have an inherent property of rotation which, ince nuclei are electrically charged, generates a small magnetic field. Nuclei with an odd number of nubed. ryder with an our number of nu-cleans (protons or neutrons) produce this magnetic effect. Hydrogen nuclei are excellent for these purposes, a for-turious event for mediane, since hy-drogten nuclei predomnate within the human body. In nuclear magnetic resonance, a magnetic field is proseed to a sample.

magnetic field is imposed on a sample in order to orient the nuclei in a direc-tion parallel to the applied magnetic 

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density and relaxation times (T<sub>1</sub> and T<sub>2</sub>) that are in registration for multiple sections through an orkin or body re-norm of interest. This is analogous to satellite images which include c. a sets based on measures of visible light, near infrared, and far infrared energy. Advanced make processing systems for the analysis of satellite energy. Advanced make processing systems for the analysis of satellite data are being adapted for purposes of combining the different data sets in NMR imaging may be especially useful in identifying malignancies and decretative disease of various kinds. The soft tissue contrast is inheritify superior to that of X-ray techniques. NMR is a new medical digmostic tool which is a new medical diagnostic tool which has great potential for solving medical problems having no current solution.







The return of nuclei to so original oriental for also is characterized by two principal relaxation takes at paid 1. These are the measures use on image production.





#### Self-Injurious Behavior Inhibiting System (SIBIS)

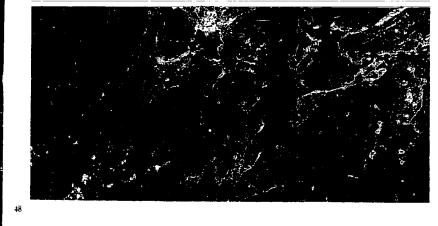
Children diagnosed as severely retarded, autistic, or scharophrenk frequently show a dramatic from of psychopathology termed self-njurnous behavior (SIB). Eight to fourteen ... percent of retarded institutionalized persons suffer this problem. The behavior can take many forms, with striking one's head against a wall a typical example. If uncontrolled, the behavior-can produce severe injures. blindnesis, and possibly even death... The obsessive and repetitive character of SIB bars all possibility for intellectual and social development.

ical example. If uncontrolled, the behavior can produce severe injuries, bindness, and possible veen death... The obsessive and repetitive character of SIB bars all possibility for intellectual and social development. Many procedures have been used for the control of self-injurious behavior. The principal method is restraint, which offers no therapeutic benefit ... Drugs can be effective but must be administered in such doses that all activity is curtaied. Behavioral modification procedures offer-a real measure of hope but, in general, operate too gradually for practical use with severely retarded children. The most successful procedure involves the use of aversive electrical stimulation (shock) triggered

د. الأ by an act of self-injurious behavior. Such simulation suppresses the behavior almost immediately. The pridlem here is that existing equipment for administering the stimulation requires an another person to be present to arefy the aversive shock. The equipment it self is large, cumeliable.

event is detected through an acceleroneter signal, the sensor electronics will transmit a coided signal to the stimulation module. Upon recepts of the cer rect coided message the stimulation module will produce the appropriate aversive stimulation to the patient's arm. The system also will incorporate an event recorder to study the patient's behavior when using the device.

device. The advantages of SIBIS are many, It operates automatically and does not significantly restrict a patient's activities. The mervention of another pers in is not required. Finally, it offers hole: for recovery and allows the social devicement of a child to continue.





#### Helicopter Medevac

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Helicopters have played, and are proreacopters have haven, and are pro-jected to play, important roles in such public service activities as concretency medical service (EMS), search and rescie, has eith coment and public safett and disaster roled. In emergen-ty medical service alone, studies show that in 1980 the are fail death rate dije to account theman is a context than C) interval service above, studies show that it. 1984 the air ail death rate die to accelent trauma was greater than 100 (0K) of - C ais. Trauma is estimated to cost U.S. society some 887 billion annually according to Department of Transportation. In attistus. With prompt, on the secret treatment and rapid transport to shock trauma centers, it is estimated to a substantial reduction in death and a substantial re

ing the public sector. The studies

ink the public sector. The studies, show that the nearesterm technology development needs for various publi-service vehicles are very similar and are reflected in those for EMS-helicop-ters. This 1981 EMS Workshop com-ledge that special action was needed to develop more effective EMS heli-copters. It was recommended that NASA serve to bring the involved par-ties together to better define system needs and pursue the helicopter tech-nology developments required. Webeles used for public service mis-sions have histonically been developed by the Department of Defense for mi-tary applications and have been ut-tary applications and have been ut-tary applications and have been ut-liated in the civil public service, the studies and workshops recom-mended that vehicles be specifically designed to meet the civil public ser-vice user requirements. —Recognizing this growing need, the NASA Technology. Unitation. Division and the NASA Ames Research Center are sponsoring an effort to identify those technologies that, if property ap-

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to develop special focus projects that address these equipment needs.







Medical Measurement With Ultrasonics

Ultrasora, technology, using sound waves just above the limits of human hearing, uncreasingly, is employed in ... new medical procedures: An ultrasone pulse: tytelly at a frequency of 10 to 20 MH; is a annitted into the body from a charged transducer. The emritted pulse quees through a coupling path, serving as a delay line to separate ultrasonic data from high frequer cy electromagnetic signals, before entering the skin to be characterized. As the pulse moves through the tissue, echo reflections are recorded. These echo patterns charge as the signal is reflected from a different type uftissue. With ultrasone, a resolution of approximately 0.1 mm can be acheved in set. tissue.

#### Ultrasound Determination of Burn Depth

The treatment of burn injuries is a major medical care problem. Each year, approximately seventy, thousand pactients in the United States receive intensive care for burns. Recovery canbe significantly side in the treatment received. Full the mess burns, those in which the entred dimude early removal of net. I missile and arrive duent skin graffing. This minumizes the risk of infection, the major cause of death in burn victums. However, graffing is not the optimum procedure when there is only partial tissue destruction. Unfortunately, clinical judge ments of burn depth lased on surface appearance and factile sensation are unreliable and impretise. The appropriateness of treatment requires an accurate method of determining the exset depth of a bern injury.

curate method of determining the exset depth of a born injury. A physicist at the NASA Langley – Research Center developed a concept for determining skin burn denth using ultrasound. He noted that the acoustical impedances of burned dermis, yiable dermis, and subcutaneous fat differ sufficiently to detect the interface between burned tissue and the underlying unburned tissue. With this measurement system, an early determination could be made of born depth, allowing immediate excision of fullthickness burns and consequent reduction in mortality, leading to a nore rapid and complete rehabilitation of the ration.

patient. — The Technology Utilization Officer at the Langley Research Center requested the assistance of the Regeneration of the Research Triangle Institute Bionedical — Seations Team in an evaluation of the ultrasoure burn measurement systen. A team of medical clinicians has been assembled for this evaluation. The U.S. Anno Instatute of Surgeal Research was selected as the prime v collaborator. Approximately 225 seroously burned patients are admitted to this facility annually. Clinical trials here will examine the effectiveness of this measurement system and determine appropriate procedures for its use before the system is released to industry for marketing.

#### Ultrasonic Temperature Measurement in Concer Therapy

Incasturement in Center Therapy Localized applications of heat (hypertherma) has been dery-mstrated to be effective in destrivant, malignant tumor cells while leaving aromal cells intact. The destruction of malignant cells are curs because these cells have an madequate blood supply and are unable to conduct away much of the applied\_\_\_\_ heat. Microwave energy typically is used to provide the hyperthermia to atment.

The treatment of cancer with hypertherma requires the temperature to be maintained within a narrow range of 43.10 44°C over a period of time, perhaps an hour or more. If the temperature falls, tithe cell destination ovcurs; if it ness, normal basic







destruction results. The success of hy-

destruction results. The success of hy-perthermia as a cancer treatment has been limited to date due, to pior tech-niques for monitoring temperature at the tunior site. Ultrassiund, however, has the potential for providing long: term accurate temperature monitoring with mainwin risk to the patient. A technique, based on research in Ultrasonics at the NASA Langiev Re-search Center, may allow continuous monitoring of hyperthermia. This pro-cedure uses an ultrasound probe sys-tem to monitor, at brief intervals, the inclusion of hyperthermia. This pro-cedure uses an ultrasound probe sys-tem to monitor, at brief intervals, the inclusion of a sharp meltiong point within the temperature range of interest. These contrast with natural body fat which is a complex maxime, with no... These contrast with natural body fat swhich is a comblex nixture with no... sharply defined me<sup>4</sup>ting point. Before treatment, the lipids are placed by in-jection in a tugh paty-my very close to the tumor. This pattern there is a scanned by ultrasound periodically dur-ing the hyperthermia therapy. As lipid masses change from a solid to aliquid state, the ultrasound exploration changes correspondingly. Thus, at any even tume during therapy a scan with changes correspondingly. Thus, at any given time during therapy, a scan with ultrasonics will show which of the lipids are in the solid state and, which are in the liquid state. The heat source then can be adjusted to maintain close

control over the temperature at the hyperthermia site. ....The lipid masses are biocompatible and car remain in a patient for several weeks until naturally absorbed. They the several weeks until naturally absorbed. also can undergo multiple changes in state back and forth from solid to liquid, before they become dispersed. They are thus available as temperature indicators during several sessions of

liyperthermia. The NASA Langley Research Center is coordinating the evaluation of the ultrasonic temperature monitoring effort. Tests to determine the ability of the system to measure phase changes in embedded indicator lipid beads are ongoing.

### Intracranial Pressure Measurement with Ultrasound

Investigators at the Medical College of Virginia are working with NASA's Langley Research Center to explore the feasibility of utilizing ultrasound the feasibility of utilizing ultrasound technology to evaluate traumatic head upuries. Measurement of intracranal pressure. (ICP) is important in the management of the head injured pa-tient. Currently, ICP is usually mea-sured through direct placement of the cannula-in the lateral ventricle of the Ferms. The remains in solubility action brain. The cannula is coupled exter

nally to a conventional strain gauge This invasive procedure has a number of disadvantages, including the risk of infection. A non-invasive technique for ICP measurement available a contro-bution to the improved nanagement of the bead injured patient. Scientists at NASA's Langley Re-search Center postulate that a change in intracranal pressure will effect a

in intracramal pressure will effect a systemic change in ussue acoustical properties. It may be possible to measure these shifts in acoustical proper-ties by non-invasive measurement at the skull using ultrasound. The shifts the skull using ultrasound. The shifts in acoustical properties could then be correlated with changes in ICP, itsus providing the physician with a non-in-vasive techn. "e for monitoring head injuries. The pulse-doppler technique proposed by the NASA scientists for measuring the alterations of acousteral properties and radial stress of the skull properties and radial stress of the skull was developed initially for non-des-structive testing of aerospace compo-nents. nents.

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#### **Functional Electrical** Stimulation

The classic demonstration of muscle The classic demonstration of muscle contraction in response to electrical stimulation was done by the Italian physician Galvani in approximately... 1790. At that time therest centered on describing the time stological charac-teristics of nerve and muscle fiber. Since then, attention has shifted to practical uses for electrical stimulation techniques. ...One of the first biomestical applica-tions of functional electrical stimulation begin in the early 1960 is a program.

bons of functional electrical standards begain in the carly. 1960s in a program to control peroneal palsy, frequently cailed "drop foot." In this program, functional dorsiflexion (foot lift) was obtained by means of currents gener-sted by a portable electrical stimulator. Appropriate muscles were stimulator. area by a portable electrical sumulator. Approvate muscles write simulated by electricities placed ag must be exter-nal surface of the leg. At a later time, an implantable version if the device was used. —The success of the perioneal stim-ulator led to consideration of a multi-

channel device which would control more than one paralyzed muscle. A ... multi-channel system could be used in the support and rehabilitation of cases where full loss of limb function was involved. The Veterans Administration Medi-

Inc. Veterans Administration Medi-cal Center In Cleveland, (Mas) in coop-eration with Case-Western Reserve University, has been working or a functional electrical stimulation system for the lower extremules. They have demonstrated that a computer-con-tended multi-channel accomputer-conconsistance that a computer-con-trolled multi-channel externally mounted stimulator can be used to make a lower-lumb parapiegic stand and even walk a few steps. This repre-sents a significant advance in the reha-bilitation of cases with spinal cord in-vulcement volvement.

The current stimulation system con-sists of a rather cumbersome combina-tion of a backpack control box, surface electrodes, force shoes, crutches and a mare of wires. The next logical step

in the development of stimulation tech-nology is to produce a simplified con-trol system which can be implanted in a patient. The National Aeronautics and Space Administration is collaborat-ing with the Veterans Administration Relativity of the Veterans Administration Reserve University to develop an im-proved implantable device (MANA)s providing packaging technical and electronics reliability (collaringh, taken from spacefarth develop and providing packaging technicals and electronics reliability (collaringh, taken from spacefarth develop a standardized implantable stimulation that can be used by researchers in many investigations of functional electrical stimuli, ion on firms, miscles and joint. The tim-range goal of this projet in its of allow lower-limb paraplegics to stand reliably and to have a limited walking capability. in the development of stimulation tech-

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Mr. MARTINEZ: Mr. Bartlett.

Mr. BARTLETT. Thank you, Mr. Chairman.

Mr. Gillam, what is NASA's budget for this area, the area of uti-

Lization, and how\_much of that budget is used for disability devices? Mr. GILLAM, Mr. Bartlett, the specific budget that we have for applications—I can give you the figures on that in just a second here—are funds that NASA leverages, so there is no real measure of the activity for NASA in this area. By leverage I mean we usually obtain a certain amount of funds from other Government agencies to work in this area, such as the agencies that have testified earlier this morning, the Veterans' Administration; and other agencies.

In fiscal year 1985, NASA has, in terms of the Applications Engineering Program, about \$2 million that it is expending on applications engineering specifically. We have additional funds in our budget for the information dissemination processes.

Mr. LARTLETT. An additional budget for dissemination?

Mr. GILLAM. Dissemination of information about NASA's technology in specific projects such as the development of the wheelchair and other projects like that. We have about \$2 million. We get additional funds in from other Government agencies. These funds are also leveraged against investments on the point of the private sector.

Mr. BARTLETT. How much coordination do you have with other governmental agencies? Do you have enough, or do you need more? For example, the National Institute of Handicapped Research?

Mr. GILLAM. We have an extensive amount of coordination with those agencies. Generally I might say that it is the interest of these other agencies in specific activities that stimulates NASA's putting up funds or participating in activities for the development of these kinds of things.

Mr. BARTLETT. What improvements can be made—first, one other question. Of the examples that you cite in your testimony, is this a comprehensive list or is this merely a set of examples?

Mr. GILLAM. It is merely a set of examples. It is not comprehensive list. We, in NASA, are in a rather unusual position in this regard. That is, we don't establish the requirements, we don't decide on which areas might have the greatest promise and greatest potential. We leave to the agencies those kinds of determinations. What we do is try to provide solutions within the realm of our technological capabilities to the problems that those agencies present us with. We enter into joint programs with them for the development of those solutions using NASA-developed technology. Mr. BARTLETT. Do you work directly with the disabled persons or

do you work with the agencies?

Mr. GILLAM. We work with the agencies. In some few instances we may work directly with the disabled persons, where there is not an intermediary agency, but that is extremely rare.

Mr. BARTLETT. And you think that working with the agencies is the more productive?

Mr. GILLAM. Definitely, because they have the expertise in the areas where we don't have the expertise. We have the expertise in the technology and how it might be applied, but they have the ex-

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pertise in the needs and in the requirements of the community, the disabled community.

Mr. BARTLETT. What kind of relationship do you have with industry that may want to use some of the devices you have developed and then market them?

Mr. GILLAM. The \$2 million that I was talking about is NASA investment in the actual building of a prototype device such as a wheclchair. The industry will put in funds. Generally, the ratio of funds, Government-to-industry funds on NASA applications activity is about 75 percent industry funding, 25 percent NASA funding. So the \$2 million is not really representative of the level of NASA activity in these areas.

We work very closely with the pr' ate sector in the development of a prototype. The funding that put in is for the development of prototype devices such as the sector in the development ed as a viable commercial product, and then it is up to the private sector to produce and to market and to sell the product.

Mr. BARTLETT. Jo you have any working relationship specifically with insurance companies?

Mr. GILLAM. No, we do not.

Mr. BARTLETT. Thank you, Mr. Chairman.

Mr. MARTINEZ. Thank you, Mr. Bertlett.

You said that the funding ratio for NASA's portion of that \$2 million in any particular project is 75 percent from industry, 25 percent from NASA.

Mr. GILLAM. That is the average for our whole program. In addition, the Technology Utilization Program goes beyond the bioengineering and the rehabilitation program. It is across the whole spectrum of possibilities.

Mr. MARTINEZ. The 25 percent that you put in, is this more in the way of technical expertise, engineering advice and design?

Mr. GILLAM, No, that is in addition to the \$2 million of cash that we will put into investment.

Mr. MARTINEZ. So the \$2 million is actually for part of the construction?

Mr. GILLAM. Yes, that is right. We put our technical expertise and we don't have an exact method of charging off how much NASA research went into composite structures which developed the technology which resulted in the chair. So we don't have a way of extracting how much of an investment NASA has in that, but we had a direct investment in the chair, in the development of the prototype chair itself.

Mr. MARTINEZ Along the same lines, could you describe for us the process by which various agencies and organizations work together to produce the autocuer, I believe you called it, the pair of glasses?

Mr. GILLAM. The Office of Commercial Programs is rather new and this process has been going on within NASA since 1971, but my understanding of the process is that the need is usually determined by one of the other agencies charged with this responsibility of dealing in this area. The requirements are established. They then contact NASA. NASA goes through its technical data base to see if it has technology available that has already been developed.



In some cases, it looks at what technology needs to be developed in order to try to solve the problems at hand.

If NASA has technology available in its data base that can provide the solutions, then we work out an arrangement with that other Government agency and with a private sector firm to build the prototype, such as the chair.

Mr. MARTINEZ. The magazine you provided for us says that the field tests were begun in 1985. Have those field tests----

Mr. GILLAL. On the autocuer?

Mr. MARTINEZ. Yes.

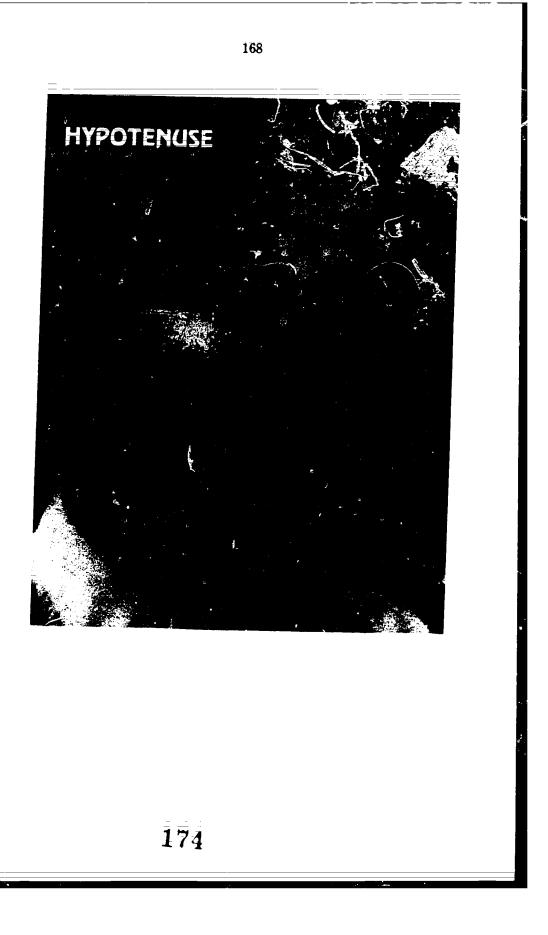
Mr. GILLAM. Yes; they have. I have a special brochure on autocuer that I will make available to you.

Mr. MARTINEZ. Would you, please, for the record, and we will make that available to members who want it?

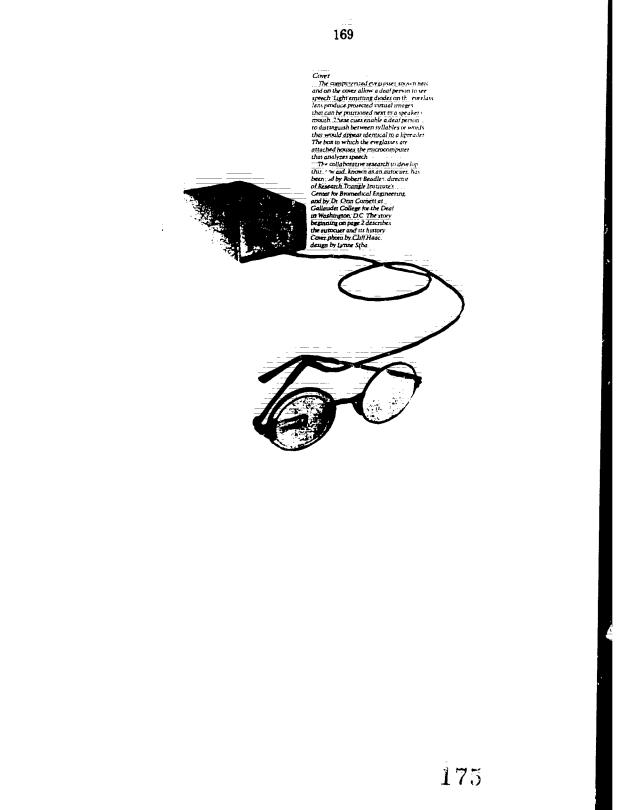
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Mr. GILLAM. Right. It is a complete brochure on it.

[The brochure follows:]

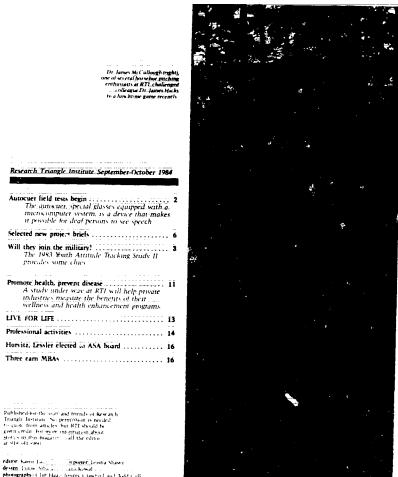












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## Autocuer · Field · Tests · Begin

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vecial glasses equipped with a microcomputer The autocuc system, is a device that makes it possible for deaf persons to see speech.

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The display rtual images rr to see curs shown at the and cight photo: optics produce via t allow the wears ones sh top of p



The microscomputer convert speech into electron is writhols which are related to light emission docks, [EDS1abonbundien the exclass traines — seet ing the LED magnities and projects v. agos These visual symbols, or cues variable pro-ing and with environ warms the glasses so they appear is used ing speakers mouth.

the speaker's mission The circle produced is the anti-circ an designed horizon to the ambiguity from liperading. They are and source the ambiguity from liperading. They are and source to the Coment deviced in 1990. Cured speech successful hand symbols in classifies different possible for a deal person to disrignation between which is on works that appear used in the addition of the source of the between the source of the traditional and the source of the between the source of the traditional and the source of the likeling of the source of the source of the source of the plenement do used speech source of the the of the source of the likeling of the source of the source of the the source of the source of the likeling of the source of the source of the source of the source of the likeling of the source of the source of the source of the source of the likeling of the source of the source of the source of the source of the likeling of the source of the source of the source of the source of the likeling of the source of the s

Defension of the constraint of the start in presention is sup-plemented by coord speech was not the of starts and a con-be identified. The combination of the 'ssemethics' - lipreading and coordination of the starts and the start in the start intrough version along. "We find all search intrough version along 'we find all search of the displater when these learned also at the technique in 1970. Elena which had beyond ear sine, then the search of the start inter the start in the technique in 1970. Elena which had beyond ear sine, the technique in 1970. Elena which had beyond ear sine, the technique in 1970. Elena which had beyond ear sine, the constraint of the start the time. However, it scattered and the technique in the start in the start is a start the new method but they were also away of the limitations. A swith sum include the datt person who with some and speech encommunicate casels only without the schedures used speech.

The Beadles began lock in the two ways to over other this that bears that separates the deathorized on the heating and speaking world. After some prefin-mary is ward, by red to world be possible to develop a wearable device that conditions to thornally acadese

Robert Beadles and his daughter Elena

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hinteen Var Las Robert leadles bean werk in advice that could diastically change the lows of the structured two million dial persons in the Unit of States, one of whom is his sharkitter. Liena, The autoxice, a pair of to compare frace develapses that serve as an adio lipitating has now mached its final stage of development. Development of the come com-which is scheduled to begin near spring. It fail uses well, the aniscen could be come com-mencially available in low, and well well the tability of the fabricated brows in a year of trild resting which is scheduled to begin near spring. It fail uses well, the aniscen could be come com-mencial langing ends. The autoxice water concerved in the late 1968 by Dy One Compet at Gallaudet College in Washington DC. However a termaned only a come privation beging of the array with Mr. Bealles on growth the been randed by the National Institute of Neuri-terna Administrative Disoulers and stink. The Variana Administrative Disoulers and stinks the Ventras Administrative and business the Ventras Administration and by Callaudet. In its present form the autoxice weight along a fight and comparises on the secone privates the ventum Administrative and business the second and business than a private to the the discourter of private the second and business than a second the origination of the second and business than a second the origination of the second and single second and business than a second the origination of the second as the second and second private strugging and a second theory second and the second second second second and the second second second second second second second second second and the second secon

must somputer system to analyze speech received in the misrophone located on the everylass trames.



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the 11 of a cliat <u>appear</u> cleat Art. Line autocoure produces wirt an above playing splay (that can vaned next to a speaker's mouth 192 the ambiguities adme

Person wave and automatically preduce valual cues. In carly 1971 Mr. Beadles, and Jr. Linnes, Biown, now an RTI vice pre-subart, mer with Dr. Cornert had cuss the preental of the unviruncent Mr. Breadles also been thunking about acting about the constraints of the technical experise to develop at the develop the tacked the technical experise to develop at the tacked the technical experises and expert to develop the time means before between Gallauder and RTI to de-wing the autocuer of the autocuer and computerized speech mathematical and prevention with the thetechnology mereded to design the autocuer of the autocuer melode. Dr. Nicheel MCCanner, who unspring the new autocuer display. This Russiewich, who developed individues the dure that methed on its analoge learning the autocuer. This Russiewich, who developed out the autocuer and packaged the tirst wearable unit, and Warren horts methed on its analoge learning the Musical com-tor the autocuer and be during the autocuer. The states who unspring the new autocuer display. The mathematical who the states and the autocuer and packaged the tirst wearable unit, and Warren horts methed on its analoge learning and advantion and former RTI staff member Devey Lawon

"When we starte workung on the autocuer, we thought it would take about five years to develop" Mr Beadles said

Beedles and However once work on the device began, they were divisioned two obtactes in their path analysis was not ask as along as we needed it to be: Mr Readles and "The other, more serious limitation was that the type of microprocessor we needed was unavailable" The first ourside hinding for the aurouver was a two year contract awarded in 1973 from the Nation

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Babwert Basellan, who hands hTT's offert to develop the annecest, resublished a set of the early versions of the actorney broadbased.

# Authough advances in electronics and computer technology computed during the funding full, two-key compenents needed for the autocure were still continued on part 4

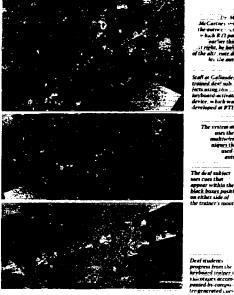
"... we believe the present occuracy rate of 70 percent is adequate for understanding speech."

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not available. One was a high-speed CMDS (completementary metal oxide offenni microprocessor and the other was a single clug audio (literibaria). In 1990 Mr. Beal's steerided to alandon temperature of the second steering of the second steering process is he had hoped to microprocess is he had hoped to microprocess bench and hoped to microprocess bench available in the steering steering steering of the second because begins of an elevation of the second because begins o

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The deal subject sees cores that appear within the black boxes positi on either side of the trainer's mout

unit for the hours between recharging." We Beades stud "Theodes melesisming the autor user amund the filter hank RTT result has have spent the parts test they hank RTT result has have spent the parts test they and analyzer a speech handwas software. The present: Mi-caddes stud, "filterin percent of the sub-groups are moursed and the other 15 percent are missing. "With more time and mores the autor user save areas can and probably will be increased the added filter whethere the present are unsaving." "With more time and mores the autor user save areas can and probably will be increased the added filter whethere the present areas users are a sub-statistic and the other 15 percent areas the added filter whethere the present areas areas and a soft of the advance is the index statistic and existing the advance is the problement of the advance is the advance of the advance is the problement will work in their order and the other 15 percent are uncertained whether more areas to provide its of the advance is the advance of the advance is the problement will work in their order and the advection of the advance is the advance of the advance is the problement of the advance is the advance of the advance is the advance is the statistic time of the advance is the advance is the statistic time advance in the collate would be emphasized in the advance is the statistic time the statistic time the word checolate would be emphasized at the statistic time of the statistic time."

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The speech analysis program used to the autocure has evolved gradually over the past decade. During the time it was tested and used is dear students at callander

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Dr. Orin Co

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Under the direction of Dr Cornert, over 100 stu-dents have bee, stained on perfectly sized subcotapes to use cues like the ones produced by the autocuer These students were. Benshow videosteps movined by the speech analysis prostant under study— ...There imprenetission was use if an OF Cornert and his staft evaluated the result sind possed them under the Beadler, the and it is colleagues then worked to climinate any problems that were iden-tified.

alog the second second

In the meantime, fift researchers will continue to work at improving the speech analysis software, and Gallaudet will select and pretrain 18 subjects for the field test

The subject with server and pretrain to deter children who have a good knowledge of the spoken language. Isds who have grown upuang manually used speech? Mi Beadles said "The other half will be ablics, primar, ill weterans who became do "ster learning spech and language. All tas benessing wet



Varren Jachem, shown above in his laboratory; worked on the autocuer's unalog electronics and designed its power supply.

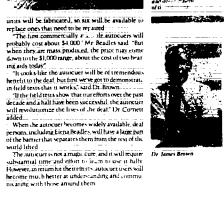
system He de circuitry.

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Latry McMaster nop left) helped de-velop the speech analysis software for the autocure. Peul Kizakes ich (left) hold sithe autocure's microcomputer system-He designed its digital



Black Vilson was one a the early contributes to the carly contributes and draw scarper of the



De James Brown



# Selected new project briefs

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Verenas' Health Survey Under a new contrast swith the Centers to Disease Control, RTI has beyout phase one and a writ singer an month relephone survey of 43000 mells who wrold in the enderstanding of the U.S. Arms at various pars on the mod 1985-71 interconvery will object, anthrantical about externing the Source with a strength and the object, anthrantical about externing the Source with a strength and the site site and the million dates. The source with active million dates. The and investigations in the held. Mishell Harves Schon and It "Doed Meeres as senior managers

More Veterane' Health This may her smaller, but still screable, Sto millioni Altmonth sources to so one under contract to the Veterans Ad-munistation Senant waters in the val-gest. Dr. Rechard Kulls and also ad-legrous will focus on the prevaluate and includence of positraumist, stress dissider among Vetrame et a veteran-and on the effects that it and other pss chalogical problems have hadjoin set tractors to RT are abut Netrins. Asso-ctates, the "Which Sill perform the lead interviews, and the Center for Social Research at the Cost of the veteran-tion of the effects and the sources of the social Research at the Cost Ontoerset ot New York.

# Recreation In a one-sear priority tar difficulty of the Architecture Bill International (Dr. Coefficient Management of Minner Section) and the Section of the Section analyses of the benefity and control to recreation tessure desclopment

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# NASA Director research for NASA is under was both an RTI and in Hampt ny. Yu Rinu an RTI and in Hampt ny. Yu Rinu an RTI sextensor robinering other care the NASA Langles Research Critice A RTI sextensor robinering hads hour tasks, operations are not heads hour tasks, operations are not safety in tasks and the second second reliable tasks and the second second second reliable tasks and the first and the second between NASA and the First and Drug Administration. At Hampton, com point scientisc Patteria Natel's long term without the time tampton action for the second second second second science and head the first and the first function has received new hunding flaund white an RTI have an De month varta at rosupport their work in data at set wars acceleration and height system design

Premature Infants High frequency ventilation among premature infants is the subject of a new 30 month collaborative clinical 1 allow which RTI will act as data cour-dinating center under senior statisti-cian DY Vijava Rao

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Marine Lab	Antimicrobial Use	queney device technology

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Marine Lab Dr. Robert Stallings, a chemical en gener, is developing conyent extraction processes for the Dake University Ma Inc Laberatory and Aquanutics, Inc. There of Retired Persons

## Smoke Condensate

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# WILLTHEY JOIN THE MILITARY?





Dr. Robert Brey

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## THE 1983 YOUTH ATTITUDE TRACKING STUDY II PROVIDES SOME CLUES.



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events on the plans of young

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Stephenie Person, Jan Wheelen and Dr. Rachard Kuller

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gram for their employees 'And all signs indicate that corporate involvement in disease prevention and

program works best in a specific type of corporate en simples of

But a stud- now under way will provide guidelines to help managers conduct, accurate evaluations of their consumer scaliness programs Revention and the content on Health Promotion in Research and Development at the Univer-

A set of the lin Science Center at Lower in word, and DA operated the composition in word, and DA operated the constant percent by the ship the S.S.Hog. The nurse words is known by the statistic transmission of the ship the S.S.Hog. The nurse words is known by the statistic transmission of the statistic of the statistic of the statistic transmission of the statistic statistic of the statistic statistic of the statistic of the statistic of the statistic statistic of the sta

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The products of the current value, especially the bealtaries Monopoly, will be define a many of the barry of the second second second second the methods and materials that employees can use to design and evaluate them own programs. It will ally contain an analysis of the data collected a timerrent, ton and companyon sites, which are being evaluated sparts the current protect. At interpreting uses as ployees will have the option of participating in a available at comparison sites. The data will allow program directors to compare continued in port 19.

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Promote Health control of the page 11)

One company that has already been selected to One company that has already been selected to pursistante in the atudy is Southern New England Rephane One or two additional companies that are relating to that some form of health enhancement purgan during the coming year, as a Southern New England Blephone, will also be selected to the properties of the selected in the selected is the selected in the selected in the selected is the selected in the selected in the selected in the selected is the selected in the selected in

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850? Dr. Harrwell and "Of course the actual number who will volumeer to take part in the study will be much lower. We hole to have about 600 perions in the intervention group and an equal number in the com-At the study sites where treatment programs are

At the study sites where treatment programs are othered, volunteens will be recruited from those who using up to participate. They will be given a 30 minute, on site health screen test. Measurements recorded will include the belly, weight and blood pressure. Value, teers will also be given an exercise step test, and a blood test, and they will be asked to complete a life wird questionnaire. The same tests and questionnaires will be donin screed to volunteen at the comparison it. At bedrifte incremention and comparison: "widtare will also be collectived from employer rec." It health insurance carrier records and through nonesponse surveys. The latter refers to questionnaires due house to persons at the ther type of it: "who do not the one to participate in the health screen offered by their em-ployer

# About one year after the programs have been in operation, the data collection procedures will be n

operation, the data collection procedure swill be in presed. The ensects scarn well "net-or-able to compare the intervention and comparison general in a number of ways. Their randysis will show how bealt in chance ment programs affect several factors, including about tersion. Unrever, duability and worker's compen-sation, bealth service expenditures, health insurance claims settivity = "society", health autometers and knowledge, bealt, attrude, and be'rets, mothality and premature in "nality attrude", social the work enjoynament, life, its data ge'r smoking satus), his metric data (e'r, nin, afr, satur), and pringram parise justion and compliance. In addition to the Lectuation Monograph, the

programs are defined as activities designed to help people control high blood pressure, stop smoking lose weight, exercise more and manage stress.

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LIVE KOS LIFE. That is the trademark of the comprehensive mellit pointion program the behavior & Johnson Fanais of Companies offers steemplayees. The trade of Companies of the planary goals. The trade is the gave behavior is being intermediates the opportunity of beyong the healthoust employees in the world. The second ex-ternation of the second externation of the second exto contain their illness care and other operating

b) Constant unit that the degree to which LIVE For --Trodetermine the degree to which LIVE For UEE aboves its guids and to measure its join effectiveness, behavior & Johnson executives united to Research Francis Instrume to the indivision KTI researchers conduct to above inge-study of Johnson & Johnson ergel wers working at stressen/Jeel to paracipate in LIVE FOR LIFE. This same health data was collected from the conduct usils one ond you ways after the rese. . -

same health data was collected from it ualsyone out low years attern the pro-Sites where kinnson 8 Johns, it the LNF FOCULE program as The study design used by R<sup>+</sup> FOR EUL involution words by R<sup>+</sup> FOR EUL involution for the UNE out approgram. As a resul-using the same design in us, or a methodology for exclusi-at other companies.

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5. S. D. LVE FOR LIFE the prometing of the transmission of the set of the transmission of the set of the se

results of ... us study will be presented in other ways One : ... these will be an overview and analysis of the usesings used in exclusion the effectiveness and effic icence of workplace health on hancement programs. Also 2 sents of using papers based on study results will be written by researchers at RTL at Pracer 14 OPF and at the University of Texas. Some of the tentative subjects include.

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Send control or comparison information needs to program sand information needs to program monitoring.
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# Professional activities

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Vignus Polytechnic Institute and will be al RTID'ra vezi. "The lournal of the America" --- ni ranz «ivocaron har published a report or "Neighborhood Design and Cranze bi Immer RTI accologio Di Sephanie Genebieg and Dr. William Pohe of the UNC Charel Hill department of caro and regional Diamitiz, The New Explored Journal of Medi care has published "Election Proposal on Mycoardial Indiget Size on Amily by Dr. Robert Roberts of the Baylar Col-lege of Medicane and I do countors, in-cluding RTI medical sessions director Parker, and vice president Dr. Kensech Parker, and Dr. Colla Pite are the say field, and Dr. Colla Pite are the

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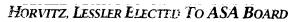
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Dr Judith Lessler



Ted Williams, Niloen Hust and Dr. Robert Hubba

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ard a Hunt, a senior analyse in the Center for Com First Applications holds a BA, in mathematics and English from Merdulfi College and a mater's in mathematics and statistics from NC State Univer-aity, where she has completed most of the course atty, where she has completed most of the course arry, where she has completed most of the coarse work towards softenate in mathematics, MS-Lunt waron, of all students in the MDA programmable named a logital schedular to recognize of a safety achievement and leadership. So hasbeen it RTI arrise 196° and is currently co-scithoring are grown for the NNCUES satisfysing recet MS-Hunt safe working with a project team on the Training Decisions System project for the US-Arr function.

Office of Personnel specialise. Ted Williams sound RT in 1971 as a chemist. The testology laboratory Three years laws, be startherers in in the Personnel Office Now he overnees RTTs health insurance cover are and Affirmative Action Program. Mr Williams earned his BS is assence e Jusaries with a manor in obernary fr in UNC Chape Hill At Duck he was class represent one and served on a com-mitter recommending releaves and curror ulum charges in the M BA program. Sensor recards hour approximation of the Bern Hub-bard has worked on a number of projects and com-ing to RTT 10 years ago. Since 1977 he has been associate proved director for the trasument nucleon progective early (TDPS) for the National instruse on Drug Abuse. Clamently the target provide interna-tic work has included a surfy of undurter assagging to onlike follow upstudy to that project Undergan error work has included as and/of undurter assagging to entitle follow upstudy to that project in device assagging to entitle follow upstudy to that project the labora and the solution as under the impact of Lieboh and thing abuse intermed has been received has been chard tree or bas by an eyeb heap than the University an 's ifth D in test of the projective follow thin the University in Mich gan

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ices. — Thangle Institute is a nor tor profit organization per soming research in many disciplines for government, industry and other cleares throughout the United States and abroad Cur rent research volume is more than 543 multion annually.

kTI was mcorporated at the end of 1958 by jour action of the University of North Carolina at Ch. (1 Hill, Duke University in Dutham, and North Carolina State University in Ashrah RTI is reparatively-operand affluer of the three achools with ma sen staff and facilities. Close working uses at many "wells are main staff and facilities. Close working uses at many "wells are main staff and facilities.

RTTs sulf of more than 900 occupies 391,000 square Net in 16 laboratory and office buildings on a campus of 180 acres in 10-...00 are Research Trangle Pr & comment oner Raleigh, Durbar and Charge Hull A septent, scatarston, the Research Trangle Foundation, promotes and developes the resource of the park, which is a locatine the size for some 60 office generationerial, urdnarnal and university-related research installations

RT research operations are organized int. units that i whilet basic and applied "search and prox." <u>Technical services</u> in the social, pastinical engineering, 4, usual, chemical and life sciences. Hypernus reports their scipitus.





Mr. MARTINFZ. You have been now; then, approximately 6 months into that field test. Do you have any report on how that is going?

Mr. GILLAM. I don't have one for you this morning. I can provide you one for the record.

Mr. MARTINEZ. Would you, please?

Mr. GILLAM. Yes.

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[The information follow ::]

#### THE AUTOCUER PROJECT

#### BACKGROUND

"ie "Autocuer" began in March 1979 with a feasibility study; software and hardware 'readboard cevelopment followed. A working breadboard and hardware was operating and under evaluation in March 1985, when progress halted due to reaccessment of the technological achievement and clarification of (1) the business partners requirements, and (2) continued funding from the Veteran's Administration.

#### CHARACTERISTICS

The visual display generates a cue in the form of virtual image in eyeglasses that can be read when the user focuses on objects from about 18 inches to infinity. Two battery powered prototype breadboards of the entire system are operational and initial tests show the system is performing in real time with adequate reserves of memory for software refinement. The breadboard measures 3 inches by 5 inches by 1 inch, and weighs about a tound including rechargeable batteries that provide 10 hours of continuous speech processing. Evaluation of performance and processing refinement is now needed.

#### TESTS

Preliminary tests with three women and three men reading five sentences spoken in a normal office environment, encompassing the spectrum of phonemic sounds achieved over 75 percent accuracy. This is viewed as preliminary to the user/field test which will be conducted in conjunction with NASA, the Vcteran's Administration, and a manufacturer.

The preparation of a test protocol for physical evaluation and perceptual evaluation with a variety of speakers and under background interference will be in sufficient detail so that any research group could conduct the evaluation.

Gallaudet College has been under a subcontract agreement to train and test subjects at the beginning, middle and end of the field tests. The training will be for about six months before the actual one year field trial. This will be a measure of how well the Autocuer performs for trained deaf populations.

#### COMMERCIALIZATION .

- As of May 29, 1985, under terms of the commercialization agreement, Telesensory Systems Incorporated withdraw its support for building the field test units and commercializing the Autocuer. This withdrawal is tied to business considerations and the agreed upon commitment to have the device commercialized without government subsidy. Telesensory did express a high regard for the system and its capability. The effort to secure a new commercialization partner is underway. To date, interest has been expressed by: (1) IBM. (2) Johnson and Johnson, (3) TRACOR, and (4) Lachmen Association.

The commercialization partner will design the unit for production, possibly reducing its size of the process. The VA and NASA will support the technology transfer and field test.

#### INSTITUTION/USER I:TEREST

Gallaudet College is the only liberal arts college for the deaf in the world and the largest single organization serving the deaf of all ages in the United States. Believing ir, the ultimate potential of the Autocuer, Gallaudet has in ested many years and hundreds of thousands of dollars in research and development of the Autocuer concept. The Veteran's Administration has a large number of hearing-impaired and

deaf patients for which it must administer help. The Autocuer is one project which can make possible a device that would be of great help to this population.

Mr. MARTINEZ. And what will happen after that evaluation is over? Let us say this thing is proven to be what it was expected to be. What is the next step?

Mr. GILLAM. The next step is for a commercial firm to take over the process and the procedure for the manufacture of it, and to put it onto the commercial market.

Mr. MARTINEZ. The chairman was concerned about there being enough of a market to entice a manufacturer to produce something, realizing that nobody really wants to produce anything they are going to lose money on. They want to make a profit on whatever endeavor they go into. In this particular area I would imagine that there would be a tremendous market for it.

Mr. GILLAM. Yes, I would think so. However, I was thinking that I might be asked a similar question when the previous questions were asked. NASA does not take a position in terms of the marketability of the product; that is a decision which we believe should be made by the private sector. Our mechanism for determining that the private sector is interested in such an activity is their willingness to make a contribution to the prototype. Their financial investment in such an endeavor tells us that they are very interested in and they are very serious about it. We do not review their market analyses; or their market studies; or the marketability, or the profitability of their activity. We are interested in getting the best technology transferred to the U.S. private sector across a broad spectrum; not just in the rehabilitation area.

Mr. MARTINEZ. That is just where there is a great need, and you help in providing the resolution to it?

Mr. GILLAM. Yes.

Mr. MARTINEZ. Very good. Thank you very much, Mr. Gillam, for appearing before us.

Mr. GILLAM. Thank you, sir.

Mr. MARTINEZ. Mr. Clyde Behney.

Mr. Behney is the manager of Health Programs, Office of Technology Assessment, representing the Office of Technology Assessment.

Please be seated. You may proceed with your testimony.

STATEMENT OF CLYDE J. BEHNEY, PROGRAM MANAGER FOR HEALTH, OFFICE OF TECHNOLOGY ASSESSMENT, CONGRESS OF THE UNITED STATES, REPRESENTING THE OFFICE OF TECHNOLOGY ASSESSMENT

Mr. BEHNEY. Thank you, Mr. Chairman.

--With-your permission, I will submit my whole statement for the record and just make some remarks here.

Mr. MARTINEZ. As the previous chairman said, I encourage it.

Mr. BEHNEY. The project that we completed in 1982 on "Technology and Handicapped People" was an effort to examine how technologies for disabilities are developed, evaluated, put in use, paid for, and 50 forth, and identifying the problems or missed opportunities related to that process.

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I would also like to submit a copy of the report's summary for the record.

Much of what you have heard so far this morning has been about technologies. It has not been about the system by which technologies arise and are paid for and are marketed and are used. I will go very quickly through here.

We found that aside from the fact there is an extremely small amount of money spent on research and development, and aside from the fact that the tradition of comprehensive user oriented strict criteria evaluation was not as strong as it could be. There is a big difference between a prototype and an acceptable usable technology, for example. That the problems in this area are not really ones of technology. We have heard example after example of new technologies, exciting technologies, and so forth. The problems are really for the most part social, political, economic, and I will summarize our conclusions in that area.

Reimbursement and financing are sometimes not adequate or efficient. For example, reimbursement may encourage purchase of inexpensive versions of devices such as wheelchairs even though increased replacement and repair expenses may outweigh the savings. This latter finding remains as true in 1985 as it did in 1982. It is not just for wheelchairs, that is a fairly common thing.

The reimbursement system, in fact, it was asked earlier about Medicare, there is a real problem in that the reimbursement system, at least from the Medicare and Medicaid side, is driven by medical criteria. In fact, it would be interesting to find out if the companies that are willing to put funds into the NASA programs are ones that are interested in more medical products rather than ones classically thought of as disability because the medical market, as you know, is some ways artificially supported whereas the disability market is much less so. So that the willingness to put up funds may be based on an expectation of future profit which is driven by the Federal Government.

We found that the goals of Federal policies are sometimes conflicting and ill-defined. Of course everybody finds that, but it is especially true in this area and I really think some attention could be paid to it. For example, the vocational rehabilitation system is oriented to employment and there are certain things that, if you want to put people to work, you have to take into account. But if you are simply interested in curing them or approaching them from a medical perspective, you don't worry about it. So you have devices being furnished from a rehabilitation perspective and you also have far larger programs providing devices, making decisions about devices, driving the market for devices from a medical perspective, and they can easily be in conflict.

Many of the Federal programs that provide or pay for technologies have strong civil rights aspects especially connected to employment, accessible housing, transportation to the work site, and so forth. Often, there is uncertainty regarding the philosophical and political basis of these programs. These turn out to be not just philosophical questions, but they turn out to be very important to how we decide to distribute resources. That is particularly important in terms of the capitalization question.



Similarly, there is confusion or inconsistency concerning the timeframe in which to judge the effects of spending on disabilities. Again the capitalization question.

Attention needs to be given to the inherent conflicts that are set up when the future savings resultings from expenditures by one capartment or type of agency-for example, rehabilitation servicesdo not accrue to that department or agency but instead result in relative gains for others, such as income maintenance or health insurance programs. Again the idea of capitalization. It is not just the timeframe, it is not just the philosophical, but it is the fact that competing Government agencies turn out to be winners and losers. Although that shouldn't be a factor in Government, it is a factor in Government, as you know.

Although these are findings from a study that we completed 3 years ago, everything that we have seen from our involvement with specific case studies and from keeping our hands in informally seem to indicate that these general problems, rather than the specifics of any one technology, remain true today.

I would also just like to quickly make some observations about some things that were said earlier. Concerning, for example, the idea that the investment will pay off handsomely. I think that the Government-needs to take into account the fact that with the way technology is going; with a population that the benefits are to be applied to probably growing; with the results of neonatal intensive care unit advances of a decade ago and 5 years ago showing themselves in terms of larger populations in the coming decades; and with the technologies that could be used to offset some of the expenses and provide some of the benefits and make independent living more possible, the communications and computer technology-relatively speaking, the prices are going down and the opportunities are rising. There are going to be biotechnology applications in the area. Those prices will after a time begin to be less expensive than some of the traditional types of approaches. So the equation gets better and better as time goes on. Thank you.

Mr. MARTINEZ. Thank you.

[The prepared statement of Clyde Behney follows:]



#### PREPARED STATEMENT OF CLUDE J. BEHNEY, PROGRAM MANAGEMENT FOR HEALTH, OFFICE OF TECHNOLOGY ASSESSMENT

Mr. Chairmen and Members of the Subcommittee:

I am Clyde J. Behney, the Health Program Manager of the Office of Technology Assessment. In addition. I was the project director for OTA's 1982 study, *Technology and Handicapped People*. I am pleased to appear before you to discuss some of the findings of that project. I will make a brief oral statement and, with your permission, submit my full statement for the record:

The study was requested by the Senate Committee on Labor and Human Resources. We were asked to examine how technologies for disabilities are developed, evaluated, and put into use, and then to identify any problems or missed opportunities related to that process: The study also identified policy options for Congressional consideration. Again with your permission I would like to submit a copy of the Report's summary for the record.

Since 1982: the Health Prögram has not been requested to conduct any other projects on disability and technology. We have, however, issued several specific case studies on disability technologies, such . as wheelchairs, communication devices, and we are about to release one on technologies for managing urinary incontinence. My testimony is



based on the findings of the 1982 study and additional information from the recent Work on specific technologies: In addition: the Biological Applications Program at OTA has conducted or is conducting studies of Technology and Aging, Diseases Causing Dementia, and on Long-Term Care; and a case study on technologies for deaf people.

The Federal Government is deeply involved in programs that affect the use of technologies for disabilities. Programs cover research and development, marketing, financing of technologies. civil rights and their enforcement, employment, transportation, health care, income maintenance, independent living, and many other aspects of life. Concerns have been raised about consistency of objectives, conflicting incentives, and lack of appropriate distribution of technologies.

Clearly, technology exerts a powerful influence over the lives of everyone, making life easier, more fulfilling, but sometimes more painful and frustrating. This statement is especially true for people with disabilities.

## WHAT DO WE MEAN BY IMPAIRMENTS, DISABILITIES, AND HANDICAPS?

Many people have modest impairments; and others are significantly; disabled in their ability to perform one or more important life functions. These limitations either are present from birth or occur from



injury; disease; or aging: whether an impairment becomes a disability depends on many things, including technology. Whether a disability becomes a handicap depends on the interaction of the disabled person with the physical and social environments surrounding that person, and many other factors. And, again, technology is one of those factors.

The term *impairment* refers to the physiological. anatomical or mental loss resulting from accident, disease, or congenital condition. Generally, an impairment results in a *disability* when a basic human function such as eating, hearing, seeing, speaking, or walking is limited. It results in a *hand:cap* when a disabled person comes into contact with a handicapping cocial or physical environment, such as an absence of accessible transportation to get to work.

Technology for disabled people plays the role of improving the compatibility between individuals and their environments. By making a distinction between "disability" and "handicap," DTA recognizes the necessity of studying both individuals and the environments in which they function. Cbylously, this is especially important in considering the issue of employment of disabled persons.

The key to appropriate development and use of technologies lies in finding a compromise between: 1) the needs, desires, and capabil- . ities of users and other relevant parties: and 2) the costs, risks, and benefits of technologies. Such compromise may be simple when, for

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ERIC Contrast Provided by ERIC example; deciding to prescribe on wear eyeglasses. However, some compromises may be far more complicated; for example, whether to consider a mycelectric limb.1 In such cases; an explicit framework for analying technical alternatives becomes very important.

Some technology; especially medical technology such as knee implants or eveglasses; can eliminate or reduce impairments and keep them from becoming disabilities. Other technologies are used extensively to prevent disabilities from becoming handicaps by, for example; making transportation systems and accommonations accessible. Disability technology may be complex; e.g.; a voice-activated nower wheelchair, or simple, e.g., special utensil attachments. Disability technology is used to facilitate education, to prepare disabled peop? for employment, to adapt job sites to the capabilities of disabled persons; and to create manageable home environments.

#### TECHNOLOGY AND DISABILITY: FINDINGS

The 1952 report noted that the U.S. Government spent about \$66 mi lion a year on R&D related to technologies for disabilities. However, the U.S. government also spent more than 500 times that amount--about \$36 billion--each year just to support the income of

A mydelectric arm, for example, is an artificial, electro-mechanical limb controlled by the individual through use of existing nerve endings at the place of attachment, usually the upper arm or shoulder.

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disabled people. Thus, its R&D expenditures in this area represent only 8.2 percent of its transfer payments. When other costs related to disability are included, such as health care, the percentage becomes even smaller.

Despite problems, disability-related R&D is characterized by innovation. Given sufficient funding and a: effective organization of efforts; the predicted "explosion" in relevant technologies could become reality. Advances in solid-state electronics, other communications and information developments, new alloys, micro-computer-aided movement (e.g., of artificial limbs), and biomedical knowledge; including biotechnology and neurochemistry; are already producing dramatic improvements as well as new possibilities. The future may see an acceleration of technological contributions. Some advances may have great value; others may turn out to be useless. Most important, though; is planning for and identifying the appropriate ways to evaluate, distribute, and use the breakthroughs.

Evaluation of technologies should be an integral part of the R&D and markiting process. For disability-related technologies, however, OTA found inadequate attention is being given to evaluation. This finding is especially true for criteria such as repairability, convenience, cost, consumer satisfaction, funding or reimpursement status and potential, and cost-effectiveness: Evaluation becomes particularly crucial in view of the possibility of a significant increase in

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the number of technological advances, such as in the area of communication devices or mobility aids. Unfortunately, this area of technology has not had a tradition of evaluation and remains today subject to very low funding for evaluation.

As of 1982, there were relatively few examples of successful Federal efforts to bring a product developed under a Federal R&D program to private manufacturers for mass marketing and distribution. The Veterans Administration; the National Aeronautics and Space Administration, and the National Institute of Handicapped Research are lead agencies for the successes that have occurred. The reasons for the lack of success include several that arise from the specific characteristics of the disability-related market: the disability population is ill-defined; the economic status of users is often far below the average; disability-related technologies often do not appear viable from a strictly "market" perspective, resulting in a lack of private interest in their production; product liability is often perceived by manufacturers to be a problem; and, especially, the systems for third party reimbursement of devices sometimes discourages the marketing of certain types of technologies.<sup>2</sup> in addition, many of the factors that hinder the successful commercial application of government-funded research in any technological area also apply in the disability area. For example, government support is often given for .





At the same time, it is important to point out that third party reimbursement, e.g., under Médicare, is also one of the largest sources of funds for disability technologies.

research and development of technologies that are complex and expensive; mak: g them less competitive in the marketplace. Also; the public patent status of government sponsored technologies can be a disincentive to their later commercial development.

The use of technologies by disabled people depends primarily, but certainly not entirely, on their eligibility for public and nonpublic programs that provide the devices and related services. This is partly because many disabled people have lower than average earnings and partly because the programs are the primary source of information on available technologies. Through their affiliation with these programs and services; users either receive devices and services directly; have them financed; or learn about them. The programs consist mainly of: 1) income maintenance; 2) health and medical care; 3) social services; 4) educational gervices; and 5) vocational rehabilitation and independent living.

OTA found that the current system of disability-related research. development, evaluation, diffusion, and use suffers from a number of significant weaknesses. The system could be capable of providing a great deal more service, even with existing levels of funds. For example, inadequate attention is being paid to the concept of approcriate technology; that is, finding a compromise fit between the device and the user. Analytical methods for determining and ittaining the proper match of technology and user need to be developed and applied

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over the lifetime of the disabled person. In addition, information on available technologies is ofter, fragmented, so that disabled persons; rehabilitation workers, insurance companies, and other individuals and groups may have difficulty locating needed data. Strengthened information dissemination is urgently needed.

#### CONCLUSIONS OF THE REPORT

The OTA Report's major conclusion was that *despite the existence* of numerous; important technical problems related to developing technologies, the more serious issues are economic and social ones. For example;

- \* Reimbursement and financing are sometimes not adequate or efficient. For example, reimbursement levels for durable medical equipment under Medicare and Medicard were found to be so low that many needed devices cannot even be purchased at those levels. Also, reimbursement may encourage Purchase of inexpensive versions of devices such as wheelchairs even though increased replacement and rebair expenses may outweigh the savings. This latter finding remains as true in 1985 as it did in 1982.
- \* The goals of Federal olicies are sometimes conflicting and ill-defined. For e.g. some programs (such as vocational renabilitation) are or red to employment and independent living; others (such as dedicare and Social Security programs) are governed by a "medical" orientation; other are a confusing mixture (e.g., the Veterans Administration). The two different outlooks result in confusing differences in eligibility; services; and use of technologies. An (artificial speech) communications device; e.g., might be paid for by an employment oriented programs but not by Medicare, on the grounds that it is not a "reasonable and necessary" part of medical care.



- \* Many of the Federal programs that provide or pay for technologies have strong cicil rights aspects (e.g., education, accessible housing and transportation). Diten, there is uncertainty regarding the philosophical and political basis of these programs. Are they efforts to compensate for past. inequity; or are they efforts to distribute resources on the basis of an equal; present; right to a satisfying quality of life? These basic uncertainties lead to uncertainty about how to implement the programs and about the specific ends to be sought through technology;
- Similarly, there may be confusion or inconsistency concerning the time frame in which to judge the effects of spending on disabilities (e.g., how do we balance the costs of employment-related programs that increase expenditures in the next few years against their potential cost savings in future years?
- \* Attention needs to be given to the inherent conflicts that are set up when the future savings resulting from expenditures by one Department or type of agency (e.g., rehabilitation services) do not accrue to that Department or agency but instead result in relative gains for others (such as income maintenance or health insurance programs).

Although we have not been directly involved in these areas over the past three years; I believe it is fair to say that these conclusions remain true today.

## WHAT ARE THE RESULTING POLICY ISSUES?

Providing disabled individuals with the advantages offered by technology requires the resolution of several policy issues. Federal policies on financing and R&D of technologies would be greatly improved if they encouraged criteria for devices such as rate of obsolescence, ease of maintenance; ease of actual procurement by the user.



and users' preferences. A disabled person might then have a better basis, for example, for selecting a manual wheelchair over a power wheelchair.

The 1982 OTA Report presented a series of *issue areas and related* options. I would be pleased to submit a copy of the issues and options chapter from the Report for the Record and mention to you only the issue areas that the options address. There are five overlapping issues:

- \* How can we improve the production, marketing, and distribution of technologies for disabled people?
- \* How can we increase, and make more effective, the involvement of disabled persons in analysis and decision making concerning the development and use of technologies?
- How can we make the process of developing and evaluating technologies more responsive to the needs of disabled people?
- \* How can we reduce the financial barriers to the use of these technologies?
- How can Federal policies help assure a well-trained and adequate supply of personnel in disability-related disciplines and services?



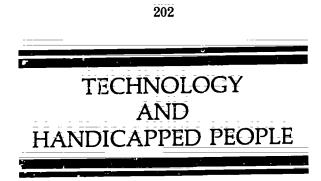
Each of these issues can be cast in terms that are directly relevant to the question of employment for disabled people. By devoting attention to a combination of the above issues, and by developing an approach that involves the private sector, disabled consumers, and government, we can do much to take advantage of technology's growing potential to enhance the lives of disabled people.

Thank you for inviting me; Mr. Chairman. I will be happy to answer any questions.



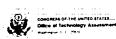






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# Summary



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The Technology Assessment Board approves the release of this report. The views expressed in this report are not necessarily those of the Board. OTA Advisory Council. or of individual members thereof.





## Foreword

Technology exerts a powerful influence over the lives of everyone, making life easier, more fulfilling, but sometimes more painful and frustrating. This statement is especially true for people with disabilities. The appropriate application of technologies to diminishing the limitations and exterding the capabilities of disabled and handicapped persons is one of the prime social and economic goals of public policy.

The Federal Government is deeply involved in programs that affect the development and use of technologies for disabilities. Congress and other institutions have become increasingly interested in questions of how well programs that directly or indirectly develop technologies and support their use have been performing.

The Senate Committee on Labor and Human Resources requested the Office of Technology Assessment (OTA) to conduct a study of technologies for handicapped individuals. This summary presents the major findings and policy options of the full assessment report. The full report examines the specific factors that affect the research and development, evaluation, diffusion and marketing, delivery, use, and financing of technologies directly related to disabled people.

The study was guided by an advisory panel, chaired by Dr. Daisy Tagliacozzo. In addition, a large number of consultants, contractors, and reviewers contributed significantly. We are grateful for their many contributions. However, the content is the responsibility of the Office and does not necessarily constitute convensus or endorsement by the advisory panel or by the Technology Assessment Board.

JOHN H. GIBBONS Director

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\*Until December 1981 \*\*From December 1981 #Until September 1981 #Until January 1982





Many people have significant limitations in their ability to perform one or more important life functions. These limitations either are present from birth or result from injury, disease, or aging. They often result in disability and, less often but still commonly, in handicaps. Whether a disability becomes a handicap depends on the interaction of the disabled person with the physical and social environments surrounding that person, and many other factors. Technology is one of those other factors. This report is about technology, handicaps, and the ways in which technology may be used to keep impairments from becoming disabilities and disabilities from becoming handicaps. It is about the governmental and social role in directing those technological processes. The report's major ronclusion is that despite the existence of important problems related to developing technologies, the more serious questions are social ones—of financing, of conflicting and illdefined goals, of hesitancy over the demands of distributive justice, and of isolated and uncoordinated programs.



"Ho credit: Barry Corbet. Courteey of North American Reineurance Con

Sports and physical activity are an important part of the lives of all peopla. Technologies, such as special wheelchairs or soundemiling baseballs, are often used to allow the fuller participation of disabled people. Mary Wilson, shown above, beliavat, that sports builds selfesteem and confidence, and improves attitudes toward and among disabled people



The influence of technology is felt in nearly every dimension of the lives of disabled people and in policies relating to disabilities. In some cases, technology is the cause of impairments, disabilities, and handicaps. Industrial accidents, adverse drug reactions, and automobile injuries illustrate this. In other instances, technology, especially medical technology, can eliminate or reduce impairments and keep them from becoming disabilities—e.g., knee implants and prescription eyeglasses. Furthermore, technology is used to facilitate. 'mainstreaming' in education, to prepare disabilities—e.g., knee imployment or reemployment and to adapt the tasks and physical sites of jubs to the capabilities of disabled persons, and to create a controllable physical home environment. It is also used extensively to prevent disabilities from becoming handicaps—e.g., by making transportation systems and accommodations accessible. Technology enters the lives of disabled people in ways that people without disabilities may consider mundane—e.g., in the form of special utensil attachments or uniformity of traffic light bulb placements. Yet even these uses of technology are far from mundane. They may fulfill important needs and, when applied appropriately, may make life easier, safer, and more fulfilling for disabled and nondisabled people

The state of technological capability in part determines what legislation and regulations are possible. It very clearly affects their implementation. Federal and State governments have created dozens, perhaps hundreds, of programs that relate to the "needs" of disabled persona. At the Federal level, with which this report is most concerned, there are programs (and agencies) for research, income maintenance, health care, education, transportation, housing, independent living, etc. It is important to understand the goals and operations of these programs, because not only are they affected by the state of technologies.

Increased attention is being focused on how to effectively and efficiently implement the laws and programs that are already in place rather than on the passage of additional laws or establishment of new programs. The volume, diversity, and often contradictory goals of many of the initiatives have tended to produce an administrative "gridlock," where movement of any kind, in any direction, is increasingly difficult.

The full report presents the results of a study requested by the Senate Committee on Labor a..d Human Resources. To support its broad responsibilities in the area of disabilities, the committee asked OTA to take a comprehensive look at the role played by technology in that area, identify technology-related problems, and suggest policy options for congressional consideration. The study concentrated on sp cific problems by examining the development and use of technology as a lifecycle process—a complex flow of ideas and technologie: from conception, through research and development (R&D), through diffusion (including marketing where appropriate), to delive.y and "se.



## STUDY BOUNDARIES

OTA uses a broad definition of technology: the practical application of organized bodies of knowledge. Such a definition covers both hardware and process technology. The present study, however, limits the definition of technologies so that the focus is on technologies that are intended for and applied to individuals. Broader technologies, such as transportation systems, are covered in this report only in the context of program and societal-level examination of costs and benefits.

The study's involvement in certain disabilities and handicaps was tempered by pragmatism. For example, OTA tried to avoid becoming too involved with medical issues that are not substantially related to technology and to the functional disabilities that stem from chronic illness. Similarly, the aging process often carries with it a gradual lessening of functional abilties in various areas: such disabilities are covered, but only as part of the central theme of disabilities.

Prevention of impairments, disabilities, and handicaps is covered only briefly. The issues involved in a full-scale inclusion of prevention technologies (e.g., highway safety technologies, prenatal acreening and diagnosis, diet) are of such magnitude that they deserve attention on their own. To illustrate some of the issues regarding prevention, a case study on passive restraint systems in automobiles is being issued separately as a background paper to the study.

## SUMMARY

What constitutes an impairment, a disability, or a handicap? OTA's approach to definitional issues begins with the idea that society defines, implicitly, a population of people with "typical" functional ability. In contrast, society defines those who cannot perform one or more life functions within the broad range of typical as "disabled" or "handicapped."

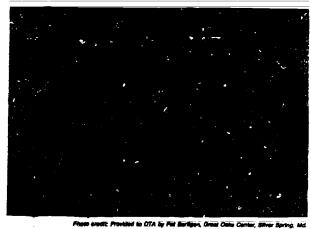
There are many possible definitions of the terms "handicap" and "disability." Definitions are important, because they affect the methods for identifying, and actual identification of, people in need of assistance. OTA found that it is most accurate to use the phrase "having a disability" in describing a person with some type of functional limitation, given no specific background (contextual) information. A "handicap" has to be specified within its environmental and personal contexts. Disabilities and handicaps arise from impairments, which are the physiological, anatomical, or mental losses or "abnormalities" resulting from accidents, diseases, or congenital conditions. Generally, an impairment results in a disability when a generic or basic human function such as eating, speaking, or walking is limited. It results in a handicap when the limitation is defined in a socially, environmentally, or personally specified context, such as the absence of accessible transportation to take disabled people to work.



Tech. ology for disabled people plays the role of improving the fit between individuals and their environments. By making a distinction between "disability" and "handicap," OTA is highlighting the necessity of studying both individuals and the environments in which they function.

Another critical issue, closely related to definitions, is that of demographics—the numbers and distribution of disabled or handicapped people. In large part because imp. irments and disabilities are not as objectively measurable as is desirable and because handicaps may change depending on their context, there is no dependable count of the number of disabled or handicapped persons. Nevertheless, considerable time is spent by researchers and various groups in making such estimates. Some of these estimates range as high as 45 million, including more than 10 million children. Typical lower range estimates are from 15 million to 25 million people.

Estimates of the number of people with disabilities are plagued by practical as well as conceptual problems. There is double counting of some people with more than one disability, underreporting of some disabilities (in part due to the stigma attached to being included on a list of disabled people), overcounting by organizations seeking to make a strong case for the extent of a particular disability, and incomplete counting of some disabled people, particularly those in institutions. A perhaps more important prob-



This photograph shows Pat Berliger essisting Danny Neylor in the use of a mercury head switch. The head switch activates be music on the tape recording when Danny holds his head in proper position. This training is used to give a person graster control over the use of muscles and nerves to position the head



lem with reported counts is that such counts usually do not take into account the severity of the functional impairment reported.

Basic to the development and use of appropriate technology are the procedures by which disabilities and indicaps are identified, goals for their amelioration established, and resources to meet the goals expended. The assessment and planning methods used under three Federal programs—worational rehabilitation services, services for developmentally disabled persons, and special education services—are examined in the report in terms of their potential use in management information systems. The analysis discusses their effectiveness and efficiency in alding or determining the appropriate use of resources for modifying handicapping and disabling conditions and for meeting the needs of actual participants.

#### Technology

One of the necessary conceptual bases for an examination of policies related to technology and disabled people is a framework of "appropriate application of technology."\*

A technology may be considered appropriate when its development and use: 1) are in reaction to or in anticipation of defined goals relating to problems or opportunitize in the disability area; 2) are compatible with resource constraints and occur in an efficient manner, and 3) result in desirable outcomes with acceptable negative consequences or risks to parties at interest.

The key to appropriate development and use of technologies lies in finding a compromise fit between: 1) the needs, cosines, and capabilities of users and other relevant partics; and 2) the costs, risks, and benefits of technologies. Analyzing such a compromise may be relatively straightforward when, for example, deciding to prescribe or wear eyeglasses. In a case in which the disability in question is of the type for which technologies such as an artificial, myoelectric limb are being considered, however, the compromise decision process becomes extremely complex, and a framework for analyzing alternatives becomes very important. Factors, such as explicitly stating the goals of the technology's use, that should be part of a policy approach to appropriate use are presented in the full report.

The disability-related research and development system includes both public and private organizations. Federal, State, and local governments; individuals; con-panies; universities; special interest associations; and a number of other actors. The people that the system is intended to assist possess a broad range of handicaps and disabilities of varying severity. The technologies that the system produces cover an even broader range, both in type (including devices and process technologies or services), in sophistication; and in purpose.



<sup>&</sup>lt;sup>7</sup>By "appropriate application of technology" OTA is not referring to the same concept as "intermediate technology" or "low capital technology". Instead, the term refers to an informed sensitivity as to the conditions under which any particular technology is appropriately developed and, especially, applied.

The Federal role in Jisability-related R&D has been steadily increasing in scope and magnitude, although it remains small in comparison to the number of people affected and the complexity of the research r. oblems involved. The organizations expending the greatest effort, as measured by the size of their relevant R&D budgets, are the National Institute of Handicapped Research (NIHR), the Veterans Administration (VA), the National Institutes of Health (NIH), and the Office of Special Education. The National Aeronautics and Space Administration (NASA) is also involved in this area as a result of technology trainfer efforts stemming from its primary mission, it collaborates with the above agencies to transfer new technologies evolving from its R&D base.

A recent survey conducted for NIHR found that the U.S. Government spends about \$66 million a year on R&D related to technologies for diaabilities. However, the U.S. Government also spends about \$36 billion a year to support the income of disabled people. Thus, its R&D expenditures in this area represent only 0.2 percent of its income transfer payments. By comparison, the Government's total health care R&D accounts for about 2 percent of its total health care costs.

Private sector involvement in R&D is difficult to characterize or quantify. The companies and organizations that conduct R&D range from multibillion dollar companies to small businesses to nonprofit organizations, associations, and disease-specific foundations. Often, these companies and organizations are the primary actors in the development, delivery, and purchase of new technologies for their constituent groups. The R&D funds used may come from the companies and organizations themselves or from the Federal Government. Debate continues to surround the issues of how much R&D is enough, who should do it, and who should benefit financially from the complex interaction of private, public, and nonprofit-sponsored research efforts.

Despite problems, disability-related R&D is characterized by innovation. Given sufficient funding and an effective organization of efforts, the predicted "explosion" in relevant technologies could become reality. Advances in solid-scate electronics, other communications/information developments, new shoys, microcomputer-aided movement (e.g., of artificial limbs), and biomedical knowledge, including neurochemistry, are already producing dramatic new possibilities. The future may see an acceleration of technological developments. Some advances (e.g., writing aids for physicall, disabled children) may have great value; others may turn out to be useless. Most important, though, is planning for and identifying the appropriate ways to evaluate, distribute; and use the breakthroughs.

Evaluation of technologies involves a broad spectrum of activities and a number of criteria. Safety, efficacy, feasibility, and profitability are the criteria often used first in evaluation efforts. Criteria that follow include effectiveness, reliability, cost, repairability, convenience, affordability, esthetics, consumer satisfaction, patent protection, legal impacts, liability, coerns, accessibility, economic impact, reimburgement status, social implica-





tions, cost effectiveness determinations, and ethical concerns. However, these important criteria are rarely, if ever, applied consistently to new technologies for disabled people in the public or the private sectors.

There is, however, no shortage of agencies, organizations, and universities interested in the various issues surrounding the evaluation of technologies. The level of the Federal effort in terms of money spent on evaluation efforts is impossible to determine fully. The lead agency in evaluation of technologies for disabled people is NIHR. Evaluation research supported by NIHR is conducted along with basic and applied research and technology development at the various NIHR-funded research centers. In theory, evaluation research is an integral part of the R&D process. In reality, it is often done only in an oversimplified fashion or with inadequate funding. NIHR does support some evaluation of devices produced outside of its research centers. However, the problem is that there are not enough of these activities. The Food and Drug Administration (FDA), the National Bureau of Standards (NBS), and NIH are three other agencies that focus on evaluation of technologies at the Federal level, but their efforts do not meet the evaluation needs in the area of technology for disabled or handicapped persons. The provate salso involved in the evaluation of technologies, particularly technologies that it develops or distributes.

OTA finds that the public-private sector partnership is inadequately designed to support fully useful evaluation efforts and that a coherent, adequately funded and focused program of evaluation is needed at all levels of diffusion and adoption -f technology for disabilities.

Such a finding is particularly crucial in view of the possibility of an increase in the number of technological advances becoming available—e.g., communications devicer and mobility aids.

Diffusion and market as of technologies for disabled people require quite different methods and information than the R&D and evaluation efforts. The public-private sector interrelationship is particularly complex. In the disability field, models of diffusion and marketing in the general health care system and of diffusion of innovations in the private sector – which are not necessarily complementary—are often at work simultaneously.

There are a number of successes in the diffusion and marketing of technologies that have been directly related to Federal ciforts to bring a product developed under a Federal R&D program to private manufacturers for mass marketing and distribution. VA; NASA; and NIHR are lead agencies for these successes. However, such successes appear to be the exceptions. There are a number of reasons: the disability market population is illdefined; the economic status of users is often far below the median; technologies often do not appear viable from a strictly "market" perspective, resulting in a lack of private interest in their production; product liability is often perceived by manufacturers to be a problem; and, especially, the systems for reinbursement of devices sometimes provide disincentives to the marketing of certain types of technologies. Two additional issues in this area are the problem of rapidly changing technology and the need to involve consumers to assure that marketing efforts are effective.



The use of technologies by disabled people appears to depend primarily, but certainly not entirely, on the public and nonpublic programs or which the individuals users are eligible. This is partly because many disabled people have lower than average earnings and partly because the variety of programs that exist are the primary source of information on available technologies. Through their affiliation with these programs and services, users either receive technologies directly, have them financed, or learn about them.

Although there are over 100 different Federal programs serving disabled people, the majority of public services are in the form of: 1) income maintenance, 2) health and medical care, 3) social services, 4) educational services, and 5) vocational rehabilitation and independent living. The greatest expenditures have been—and continue to be—for income maintenance, related transfer payments, and health and medical care.

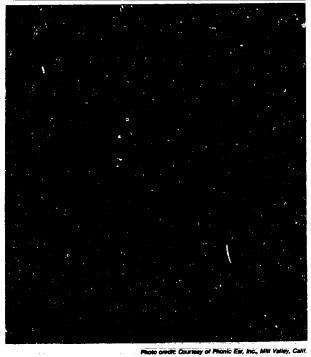
The major income maintenance programs are Social Security Disability Insurance, Supplemental Security Income, VA pensions for nonservice-connected disabilities, and VA compensation for service-connected disabilities. Individual beneficiaries of these programs receive cash payments with no restrictions on their use. The programs influence the use of technologies not only because they provide the funds to purchase the technolzgies, but also because they establish eligibility for health, medical, and vocational-related services and technologies.

The major publicly financed health and medical care programs serving disabled people include Medicare, Medicaid, and VA medical services. The use of technologies is significantly affected by the amount of funds provided by these programs, either to individuals or providers, by the methods ured to authorize payments, and by the organization of the provision of services. Folicy issues that affect eligible Medicare and Medicaid recipients include what technologies are covered and how are those decisions made, what types of professions and institutions are recognized as providers, what amount is reimbursed for the cost of covered services, what technologies are determined to be medically necessary, and what effects the Medicare and Medicaid programs on the type and location of services to disabled beneficiaries.

The prime social services programs that serve disabled persons are those authorized under title XX of the Social Security Act and the developmental disabilities program authorized under the Developmental Disabilities Assistance and Bill of Rights Act. Under these programs, a wide range of technolor ies are directly provided to disabled people. Thus, the major issue affr i g the delivery and use of technologies is the determination of eligibility to these programs (and currently, whether and in what form there program, and others will continue to exist).

The two largest education programs for disabled people are authorized under the Education for All Handicapped Children Act and the Vocational Education Act. If necessary for receipt of services under these programs, devices may be funded. The programs are more important, however, for





Aiding in preparing employment and carrying out job functions has always been one of the prime uses of technologies for disabilities. This photograph shows a woman using the Phonic Mirror Handivoice to communicate with her fellow workers. The Handivoice speaks the words which the person manually enters into it

preparing disabled people to use technologies and for providing information on what is available. The vocational rehabilitation and independent living programs authorized under the Rehabilitation Act directly provide technologies to eligible recipients for use in the workplace or to live outside of institutions (in the case of severely disabled individuals).

Although the availability of public funds in support of public policies has greatly shaped decisions in the private sector, nonprofit and for-profit private organizations are usually the actual providers of services under public programs. In addition, they provide services and funding not covered



by the public programs. Private insurance companies provide income maintenance, although the total amount is much less than what the public programs provide. Health and medical care are also provided: device technologies are funded using criteria similar to the public programs'.

Several issues, related to the public programs in general, affect the use of technologies by disabled people. The y include: 1) the degree to which services and funding are coordinated from program to program or are consistent from State (or region) to State (or region); 2) the effect, on coordination and consistency, of the methods (or determining eligibility; 3) the extent of the gaps in eligibility for services under public and nonpublic programs; 4) the degree to which maintaining rehalilitative device technologies is difficult or costly; 5) the degree to which consumers are effectively involved in services delivery; and 6) the shortage of rehabilitation providers.

OTA's examination of the current system of disability-related research, development, evaluation, diffusion, and use finds that the system suffers from a number of significant weaknesses. The system is, or could be, capable of a great deal more.

Information on available technologies is currently disseminated through publicly financed or publicly operated programs for disabled people. Information is often fragmented, since many of the programs cover discrete subject areas and are uncoordinated. Strengthened information dissemination in a coordinated fashion is urgently needed.

Providing disabled individuals with the advantages and opportunities provided by technologies requires the resolution of several policy issues. One issue is: What types of providers are most appropriate to match possible technologies with a potential user? That is, who shall be responsible, in cooperation with the user, for identifying possible technologies, selecting a technology, fitting it to the specific user, and training the user in its use?

#### **Resource Allocation**

The development and use of technologies for disabled persons are greatly tifected by available resources and the ways in which they are allocated. In fact, all decisions about the development and application of such technologies are ones of resource allocation. Efforts to improve resource allocation must take into account the incentives and controls currently operating on the development, evaluation, diffusion, and use of technologies. They must also examine the "fit" between the intentions of policymakers to assist disabled people (create opportunities for disabled people to help them. lives) and the actual actistance afforded by the available resources and the rules governing their allocation.

Effective resource allocation must take into account a number of current issues in the disability-related area. For example, to what degree should definitions of disability and handicap used in Federal programs focus on people's abilities as well as disabilities? An increased concentration on abities could lead to the expenditure of a greater proportion of resources to

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alter aspects of the environment that turn disabilities into handicaps. Another example of a current issue in resource allocation is the extent to which the Government should encourage and financially support independent living and the involvement of people with disabilities in pertinent actions such as evaluation of technologies or the determination of the types of personnel who will prescribe or fit technologies.

Other issues have to do with the types of outcomes sought in allocating resources, the degree to which society and other decisionmakers support the development and application of technologies to prevent disability, the influence of an increasingly aged population has on resource allocation, and the proper role and use of analytical techniques in allocation decisionmaking.

## **BRIEF POLICY OPTIONS**

A large number of factors affect the success of technological applications in the area of disabilities. OTA's policy is to provide Congress with a series of alternative actions and discussions of the possible consequences of implementing them. The options in the full report are organized by issue area. The following presents brief statements of the issue areas and related policy options. The options are not mutually exclusive.

## Production, Marketing, and Diffusion of Technologies

How can the Federal Government increase the probability that technologies will reach the people who need and desire them?

In as many cases as possible, commercial viability should be one of the goals sought in technology development. A critical issue is how to alter the currently inadequate state of marketing efforts and processes.

The production, marketing, and diffusion of technologies are most often private sector activities, and yet a number of factors work against that sector's willingness and ability to engage in them. R&D organizations have typically placed a low priority on production, marketing and diffusion activities. Also, the difficulty in projecting the markets for disability-related technologies increases the risks of a commercial venture, as do the often small populations in question. Many disabled individuals traditionally have had low average earnings or funds at their disposal. The reimbursement policies of the Federal Government and the States also contribute to the uncertainties of the marketplace for a firm considering the production of a technology.

OPTION 1A

Congress could amend current legislation to create a consistent and comprehensive set of fiscal and regulatory incentives encouraging private industry to invest in the production and marketing of disabilityrelated technologies.



Fiscal incentives are created by policies, such as taxation policy, to allow private investors and firms to make more reliable estimates of potential returns on investment. Regulatory incentives seek to accomplish the same objectives as fiscal incentives but do so through methods less directly connected to financial factors, including patent  $\sim d$  licensing policies. Another example would be changes in the penalties fill on compliance with Federal regulations regarding the hiring of disabled people or the provision of appropriate technologies to disabled people. This type of incentive would increase the demand and therefore the potential market for technologies.

One benefit of implementing this option is a potential increase in revenues to the Federal Government as a result of the larger corporate taxes paid by firms and the increased taxes paid by disabled people using technologies that allow them to lead more productive lives. On the cost side, revenues would be reduced by the amounts of any tax reductions embodied in the fiscal incentive structure. Yet Federal costs would be diminished by the reduction in funds spent on income transfer and health insurance payments: Also, a nonmonetary benefit of this option would be the increase in wellbeing of the disabled people who would benefit from receiving helpful technologies.

#### **OPTION 1B**

Congress could legislatively charter a private organization to provide marketing and production-related services to both the private and the vublic sectors.

Congress has occasionally granted an official charter to a nonprofit organization recognized to serve the public welfare. The initial funds for such an organization would come primarily from the nonpublic sector, with perhaps a small startup grant from the Government. After startup, however, it would be expected to operate on its own revenues.

The goal of the organization would be to provide technical assistance, analysis, and other services related to the production, marketing, and diffusion of disability-related technologies. Tasks performed in return for fees could include preparation of marketing surveys and strategies for private firms, and development and management of demographic and product data sets. The organization could also serve as a liaison between firms or Government agencies and ultimate consumers.

Two potential advantages of the proposed organization are that it is designed to carry out an important and currently inadequately performed function and that it is located ir. the nonpublic sector. Potential disadvantages lie in the possibility of conflict of interest and in the difficulty of the tasks assigned to the organization.

**OPTION 1C** 

Congress could establish a joint public-private corporation to provide marketing and production-related services to both the private and the public sectors.



This option would have similar goals to the previous one and seek to accomplish them through the same types of tasks. Instead of the legal authority of a private corporation with official recognition as in option 1B, though, this option would establish a quasi-governmental entity. Analogous organizations are the Overseas Private Investment Corporation, the Tennessee Valley Authority, and the Federal National Mortgage Association. In setting up any such organization, public interest services can be performed using primarily private funding and managerial techniques.

## OPTION 1D

Congress could mandate the collection of market-related demographic data by an interagency group led by the Bureau of the Cer.sus.

This option might reduce some of the uncertainty that accompanies the decision to develop or market a product by producing demographic data divided by types of functional limitations. It would also be useful to the public sector in setting research priorities and allocating funds for the applied engineering and diffusion stages of technology's lifecycie.

The cost of this option would vary considerably, depending on how extensively the current survey techniques and activities of the Bureau of the Census would have to be modified or expanded. It might be possible to create a mechanism whereby the private sector, including industry, advocacy groups, and foundations, could contribute funds to the effort. Another dimension along which costs would vary is the extent to which new data are collected as opposed to old data analyzed to provide new answers.

# Involvement of Disabled People and Other Consumers

How can policies and programs be designed to encourage or assure the effective involvement of disabled people and other consumers in the development and delivery of technologies? In addition to providing information, consumers should themselves be part of advisory and policymaking bodies to the maximum extent feasible.

In theory, assuring maximum effectiveness, efficiency, and relevance in the development and application of technologies requires the extensive involvement of those who will use the technologies —the consumers. In practice, there is relatively little involvement. There is no "correct" amount of consumer involvement, and there is no easy way to achieve effective involvement. Consumer involvement is frequently discussed, however, and everyone seems to believe in the concept, —yet few satisfactory schemes or actual actions to improve the situation exist.

### OPTION 2A

Congress could mandate formal consumer involvement in any or all Federal programs or federally funded programs related to the development and use of technologies.



Congress has already mandated consumer ('handicapped persons') involvement through several Federal laws. The individual planning processes required by several Federal laws, for example, art designed to involve disabled people or their parents or other repres. ttatives in decisions about education or rehabilitation. Under this option, Congress could expand the formal, statutorily based, requirements for the participation of disabled people in areas of policy c.velopment and program implementation, including setting research priorities, evaluating grant and contract proposals, evaluating reports of progress on existing grants and contracts, and reviewing technologies for inclusion in reimbursement and purchase lists.

In general, this option could involve a program-by-program review to determine which programs could use the various mechanisms for establishing or expanding consumer involvement. Consideration should be given wherever possible to the use of flexible mechanisms—e.g., combinations of advisory panels, staff hiring, and contracts with consumer groups—to make involvement as effective rs possible.

OPTION 2B

Congress could mandate an office of consumer involvement to munitor and provide assistance to other offices dealing with technologies, and Congress could encourage all relevant agencies to expand consumer involvement.

Instead of legislatively mandating consumer involvement in specific instances. Congress could clearly encourage various agencies to expand their consumer involvement activities through oversight hearings, committee reports, and other means. This option provides the advantage of flexibility--flexibility to change as conditions change over time and as data on the performance of involvement methods recome available.

The obvious disadvantage of this option relative to the previous one is the difficulty of gaining voluntary compliance by the agencies. Mandating the creation of an office of consumer involvement would be a step to lessen this disadvantage. The proposed office could coordinate, monitor, evaluate, provide technical assistance to, and report on the involvement of disabled people in Federal activities.

#### **OPTION 2C**

Congress could encourage agencies to increase consumer involvement activities.

If Congress wishes to signal a concern about the inadequate amount and quality of consumer involvement activities, it could do so through mechanisms less formal than legislation. These mechanisms include, as listed above, oversight hearings and records of hearings, and language in committee reports accompanying related legislation.

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Research, Development, and Evaluation of Technologies ISSUE 3

How can R&D activities be seganized and funded to produce knowledge, techniques, or devices that serve the needs of disabled people and relevant providers in accordance with the magnitude of various problem areas and opportunities? How can evaluation of present and emerging technologies be organized to provide consumers, providers, and policymakers with adequate information?

Funding for both R&D and evaluation is quite low in relation to the amount spent on transfer payments and other services. For evaluation, though, a perhaps equal problem is the lack of recognition given to the potential contribution of evaluation to decisions about the appropriate application of technologies. The organization and directions of R&D and evaluation also contribute to the inadequate number of useful technologies from these activities. The peer review systems in effect are not well organized. Inadequate attention is paid to what will happen to the results of R&D crice that stage is completed. The constraints and demands of marketing, production, and consumer acceptance and preferences continue to play a relatively small part in the R&D process, though that situation seems to be changing slowly.

OPTION 3A

Congress could mandate that consumers and production and marketing experts be represented on R&D panels and evaluation panels.

This option explicitly recognizes that considerable involvement of the people and organizations who will play a major role in the subsequent usefulness and diffusion of technologies should take place early in the processes of R&D and evaluation. Its implementation would require extensive thought on the most effective ways of avoiding tokenism and conflict-ofinterest situations for private industry. Yet many aspects of the R&D and evaluation processes are amenable to experienced consumer input. Consumers might inject a degree of reality to the setting of R&D goals and priorities; evaluation criteria might be set to more closely resemble the list of factors that lead to a technology's successful application.

Production and marketing experts could help the R&D process in several ways. For example, the simple presence of such people on panels could remind researchers and policymakers that the end result of R&D is supposed to be (in most caser) useful and cost-effective techniques and devices. Also, their experience and expertise would allow them to make suggestions relating to the evaluations that are necessary and the technological characteristics that should be sought.

Theoretically, no congressional actions are necessary for the adoption of this option. If Congress finds that it is a desirable option, however, and the executive branch agencies do not implement it on their own, Congress could amend relevant laws to mandate that R&D-related peer review and other advisory groups have such representation.



#### OPTION 3B

Congress could mandate demonstration projects for the awarding of "production stage" grants or contracts early in the R&D process.

The objective c: this option is to assist R&D efforts in the development of technologies that will be effective and will successfally reach their tracket. Small grants or contracts to non-profit or profit-seeking organizations to analyze the potential market and to develop plans for the efficient prodution and diffusion of specific technologies may help. This option is oriented to only a demonstration effort because of the many questions that exist concerning the effectiveness of such a mechanism.

One method of implementing the demonstration would be to select through a competitive process a firm that is interested in the marketing rights, for a specified time or are. for a particular technology. That firm would use the contract funds to examine the n ost efficient ways to produce the technology under development.

OPTION 3C

Congress could appropriate specific increased funds for evaluation of technologies.

This option addresses the relatively low level of funds and activities currently existing in the disability  $\simeq$ .a. Although economic realities naturally affect the viability of this option, it is important to remember that the current level of funding for evaluation is extremely low—yet the number of technologies being developed is increasing constantity and many are in need of evaluation. Some of these may produce dramatic effects, others may turn out to be useless, but most will produce benefit under certain conditions—i.e., when applied appropriately in relation to their costs and risks. An increased amount of funds will be needed to adequately assess these new technologies as well as existing ones.

#### OPTION 3D

Congress could conduct oversight hearings with the Department of Education to determine why the dissemination of information on technologics remains inadequate.

OTA finds that the amount, usefulness, and accessibility of information on the characteristics, availability, and performance of technologies are not meeting the needs of ucers or potential users. A partial explanation is that the National Rehabilitation Information Center is relatively new, and its ABLEDATA system is even newer. Also, these activities have not had significant amounts of funds appropriated.

Before any specific legislative actions are taken, a number of questions could be addressed in overright hearings. Such hearings could be designed to bring out more clearly the reasons for the current situation and the administrative reactions to that situation. An example of questions that could be explored in oversight is: Why have agencies, especially in the Departmert of Education, oriented their dissemination activities to professional research institutions and similar clients?





Theo credit Bury Corbst. Courtesy of Porth American Reinformance Corp. Imogene D'Ckey of Buff-Jo, Wyo., Uses a wheetchair for mobility. She and the chair ride on a Chair-5-Yecht of, for longer distances, a rampequipped van

### Financial Barriers to the Use of Technology

#### ISSUE 4

'low can imancial barriers to the acquisition of technologies by iisabled people be reduced, within reasonable constraints? Can the levels and distribution of available funding be made more appropriate in relation to the level of the problems addressed?

Imperfections in the structure of delivery systems need to be minimized. Inadequate and sometimes illogical criteria for reimbursement or payment for technologies should be reviewed and, where appropriate, changed.

Despite eligibility for the public and nonpublic programs that may pay for technologies to assist them to function more independently and productively, a number of disabled people are denied funding for particular technologies which are clearly appropriate. A primary reason for the denial of funding is that the technologies in question are no: strictly "medical" in nature and are therefore not considered "necessary." While most indigent disabled persons are eventually able to receive some assistance towards meeting their needs, acquisition of technologies in the period immediately following the onset of their impairment presents particular financial hardships. OPTICN  $\bar{4}\bar{A}$ 

Congress could establish a loan guarantee program with low interest financing (on an income-related sliding scale) to assist disabled people in device purchases.

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This option would reduce or eliminate financial barriers to acquiring devices for individuals who have the capability to generate the funds to pay for the devices but who do not have the resources for the initial capital outlay. These loans could assist in the purchases of devices which, in turn, would assist the individuals directly or indirectly to function independently, work, and pay back the loan.

Pursuit of this option would likely involve a minimum of Federal dollars. The program could be State-administered, as is the program of federally guaranteed student loans for higher education. The interest subsidies could be provided either by the Federal Government directly or by the lending institutions with tax incentives to do so. A significant implication of this option is the public-private partnership likely to occur if it were implemented.

#### OFTION 4B

Congress could conduct oversight hearings on ways to change criteria for reimbursement under the Federal health insurance programs with respect to technologies for disabled people.

Disabled people eligible for coverage under one of the Federal health insurance programs are often denied payment for technologies which are not considered strictly medical in nature, although the technologies would improve the independence and productivity of their lives. The legislation for the programs does not expressly prohibit payment for "nonmedical" technologies such as communication, education, and rehabilitative aids. Instead, nologies such as communication, education, and rehabilitative aids. Instead, the denials usually occur at the State or regional level through regulation. This way, funds may be saved in the short term, but in the long term, a greater amount of total funds is expended in, for example, income maintenance payments or institutionalization expenses.

Hearings on methods to change reimbursement criteria would focus attention on the need to consider the implications of policies in one area on other related areas. Theoretically, the hearings should provide alternative criteria for expanded r indursement and suggested regulatory changes to accomplish that objective which the Health Care Financing Administration and the States could then adopt. Congress could then hold oversight hearings at a later date to determine the effects of any adopted changes. OPTION 4C

Congress could conduct oversight hearings on methods to improve health insurance coverage for persons leaving employment as a result of disability.

The objective of this option is to reduce the financial barriers to the acquisition of technologies during the period immediately following termination from employment due to disability. Most people who leave employment lose health and medical insurance coverage formerly provided by their employers. Since health and medical insurance programs are a primary source of funding for technologies for disabled people. Congress could investigate ways to close these gaps and examine the resultant benefits and costs to society of any administrative action implemented.





One method that might be covered in oversight hearings is the provision of Medicare coverage during the 29-month period that individuals must wait for Federal Disability Insurance. Another method that might be covered is the provision of incentives to employers to provide health and medical insurance coverage to their terminated employees for 12 to 29 months fol-lowing termination for disability-related reasons. Unless changes in the criteria for reimbursement under the Federal health insurance programs are pursued as discussed under the previous option, there is likely to be an inefficient expenditure of dollars under any program arising from these hear-ings as long as appropriate technologies are not covered.

#### Personnel Issues

#### **ISSUE 5**

How can Federal policies assure an adequate number of well-trained personnel at all stages of the development and use of technologies? Systems for R&D as well as delivery of services should provide incentives for the cost-effective use of these personnel,

Although the actual number of professionals (disabled and nondisabled) working to develop and apply technologies to disabled people has increased dramatically over the last 40 years, there remains a shortage in a number of key areas. First, there are too few rehabilitation researchers and rehabilitation engineers. Second, there are too few allied health professionals, including physical and occupational therapists, orthotic and prosthetic technologists, speech therapists, and rehabilitation counselors. Although the size of these shortages is difficult to quantity, legislation such as the Education for All Handicapped Unildren Act; as amended, has served to increase the demand.

Finally, there is a shortage of rehabilitation physician specialists. Under the current reimbursement system, this shortage is a key one, because it is often the physician who must prescribe a technology for it to be funded. Yet the physician is not always the appropriate provider to prescribe the technology, particularly if the technology is not medical in nature. OPTION 5A

Congress could appropriate funds for the training of increased numbers of disability-related personnel, including rehabilitation engineers, re-habilitation medicine physician specialists, and allied health professionāts:

The objective of this option is to alleviate the shortage of providers. Schools eligible to receive the funds under this option would include schools of engineering with specific programs for rehabilitation engineering, medical schools that sponsor residency programs in rehabilitation medicine, and schools for allied health professionals. An alternative to training more rehabilitation medicine specialists is training physicians in other specialities to b.come "managers" of the rehabilitation of disabled clients.



**OPTION 5B** 

Congress could encourage volunteer participation in assisting disabled people by modifying tax incentives related to volunteer expenses and charitable contributions.

This option suggests the use of volunteers to perform some of the functions normally provided by professionais, to enhance the services provided by professionals, and to assist in implementing existing legislation that has, to date, not been appropriated enough funds for full implementation (e.g., the Education for All Handicapped Children Act). Although "volunteer participation" suggests that no compensation is provided, the incentive of reduced taxes is known as a relatively inexpensive method of providing compensation. This option assumes that the provision of such "compensation" will increase the supply of volunteers.

#### OPTION 5C

Congress could mandate the funding of demonstration projects to test reimbursement for technologies under Federal health insurance programs by the types of skills provided rather than by the types of providers.

This option is in response to OTA's finding that those providers who are permitted by the structure of delivery and reimbursement systems to prescribe technologies for disabled people may not always be the most appropriate ones to do so. In these instances, a client may not receive the proper assistance, or the skills of several providers (those able to prescribe and those unable to) may be employed at more expense and loss of efficiency than necessary or desirable. Another problem is that services necessary for the proper use of prescribed technologies are often not reimbursed under the Federal health, insurance programs (see option 4b) if they are not provided by a physician and are therefore not provided. A program of demonstration projects under the Medicare and Medicaid programs is proposed under this option in recognition of the untested status of this potentially helpful solution. Congress might want to limit the types of services eligible for the program in its authorization of the project.

NOTE: Copies of the full report "Technology and Handlcapped People" can be purchased from the Superintendent of Documenta, U.S. Government Printing Office, Washington, D.C. 20402.



## **General Information**

Information on the operation of OTA, the nature and status of ongoing assessments, or a list of available publications may be obtained by writing or calling:

Pt Communications Office Other of Technology Assessment U.S. Congress Washington, D.C 20510 (202) 226-2115

#### **Publications Available**

OTA Annual Report. — Details OTA's activities and stemmarizes reports published during the preceding year.

List of Publications.--Catalogs by subject area all of OTA's published reports with instructions on how to order them.

Press Releases.—Announces publication of reports, staff appointments, and other newsworthy activities.

OTA Brochure. - "What OTA Is, What OTA Does, How OTA Works."

Ongoing Assessments.-Contains brief descriptions of assessments presently under way with estimated dates of completion.

## **Contacts Within OTA**

(OTA offices are located at 600 Pennsylvania Avenue, S.E., Washington, D.C.)

Office of the Director	
Congressional and Institutional Relations	
Energy, Materials, and International Security Division	
Health and Life Sciences Division	
Science, Information, and Natural Resources Division	
Administration_Office	
Personnel Office	
Publications	224-8996

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Mr. MARTINEZ. Mr. Goodling, do you have any questions?

Mr. GOODLING. No, I have no questions.

Mr. MARTINEZ. I am trying to understand completely what you are saying about the conflict between the aspect of curing a person and providing help for him to get by with his Pythagorean injury or handicap. It seems to me that there would be in an area where there was a possibility of curing a person's handicap, but that there is another area where a person is permanently handicapped, whether through injury or at birth and that the technology that is being developed now would go a long way to assist that person. The more pertinent question is how do you fund this, and who funds this, and who is responsible for this?

Could you elaborate on that?

Mr. BEHNEY. The conflict I was speaking of is illustrated I think by the Medicare Program, which is medically driven. As far as I know, unless things have changed in the last 2 days or something, the reimbursement criteria are that a communications device such as this would probably not be paid for, whereas, if the Government R&D and private R&D apparatus created an artificial speech-generating organ that would theoretically take the place of a specific organ, that would be paid for. That would be much more expensive. It would raise great questions of resource allocation. It would be much tougher to get to people who have attendant risks and so forth. And it is way in the future probably.

So the medical orientation in that program, which is a big supplier of medical devices, makes it extremely difficult to get communications devices paid for. You don't want that attitude in an employment-oriented or a rehabilitation-services-oriented environment. And I don't think you have that environment as much, but the fact is that there is a large incidence of the Medicare Program and it is a big supplier of disability services and devices and so forth. And unless you somehow divorce an individual person from that and get them into the rehabilitation mainstream, you may miss out. They may not be able to pay for that. It takes a very sophisticated user, or advocate, or insurance company, or employer, or whatever, to work the system to get that device approved by Medicare.

Mr. MARTINEZ. There is no other program that now provides for these devices for that handicapped person?

Mr. BEHNEY. Well, I think, and I am not certain about this, over the past few years, but I think the person would have to be in and eligible for some type of rehabilitation training program or in some program like that that has a different orientation, perhaps the Veterans' Administration, and so forth, and then that might be supplied, or part of the Education for Children Act. But that is hit or miss. You are excluding a major source of devices.

Mr. MARTINEZ. You are of the opinion, then, that Medicare or Medicaid should be extended to cover some of these things?

Mr. BEHNEY. My personal opinion is that many of the reimbursement rules under the Medicare program, unless they are changing, have slightly counter-incentives to logic; yes.

Mr. MARTINEZ. Mr. Williams, do you have any questions?

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Mr. WILLIAMS. No questions.

Mr. MARTINEZ. Thank you very much for appearing before us and giving us the benefit of your expertise. We appreciate it.



Mr. MARTINEZ. The next two people are part of a panel. It is Nicholas Zill and Shelde. Simon. Mr. Nicholas Zill is president of Child Trends, Inc. Sheldon Simon is president, Rehabilitation Engineering Society of North America.

Mr. MARTINEZ. Would you please proceed?

## STATEMENT OF NICHOLAS ZILL, PH.D., PRESIDENT, CHILD TRENDS, INC.; AND SHELDON R. SIMON, M.D., PRESIDENT, RE-HABILITATION ENGINEERING SOCIETY OF NORTH AMERICA, REPRESENTING THE UNITED CEREBRAL PALSY ASSOCIA-TIONS, INC.

Mr. ZILL. We have heard a great deal this morning about the exciting technological developments and the research possibilities that might be used to train and assist individuals with sericus disabilities to become productive members of society. In trying to evaluate the applications of these technologies, it is natural to want to ask how many young people in the future will have handicaps that require this kind of assistance.

Unfortunately, the social science technology to make projections about specific groups of people in the future leaves a lot to be desired. Even the statistics on the current numbers of individuals with handicapping conditions are quite imperfect, and I would like to come back to that theme. It was raised in the questions earlier, and I think it is an important one.

There are, however, some general considerations that one can look at in determining whether the number of handicapped persons is increasing or decreasing and to get some rough idea of the magnitude of that change. Among the considerations are changes in the overall size of the child population in the coming decades; the life expectancy of people with disabilities and how that is changing; and then also changes that were just mentioned, namely, medical technology and social programs that are drastically changing the mortality rates of high-risk infants. I discuss these at some length in my written testimony, and let me try to summarize them briefly.

The first, and perhaps most important thing to realize is, though the size of the child population has been decreasing throughout the 1970's and the early part of the 1980's it is now——

Mr. WILLIAMS. You are referring to total size?

Mr. ZILL. Total size, right. It is now on the upswing. The Census Bureau is projecting 3.8 million births per year for the rest of this decade and early part of the 1990's, and between 3.7 and 3.5 thereafter. What that means is that the overall size; namely, children from 0 to 17, is going to increase from less than 63 million now to some 67 million by 1995. If we look at the school-aged population alone, which is ages 5 through 17, it is going to go from 44 million this year to over 45 million by 1990, then to 48 million by 1995, and nearly 50 million by the year 2000. We are going to have to reopen some of those schools that have been closed.

Unless the relative frequency of serious handicapping conditions changes dramatically in the next few years, then, we can anticipate simply on the size of population growth alone that we are





going to have more handicapped children to educate and to provide for, and that will be true for the remainder of the century.

A second thing that is not realized often enough is that there has been dramatic increases in the life expectancy of disabled persons. We know about the savings in the neonatal care wards, but there have also been increases after the handicapped individuals get past the first year of life. These increases have been true across the board, but they are particularly dramatic in the case of Downs syndrome. Forty years ago, an individual with Downs syndrome could be expected to live perhaps to 12 or 15 years of age. Today, the estimates are that the Downs syndrome individual has a life expectancy of perhaps 48 to perhaps 55 years. Indeed, so dramatic has been the change that there is growing concern about the number of Downs syndrome individuals who develop Alzheimer's disease in their later years.

There are a number of reasons for this increased survival. One is that we have better medical management of conditions like pneumonia and respiratory disease from which many handicapped individuals used to succumb, particularly Downs syndrome. I think an important general consideration is that disabled individuals are no longer relegated to the back wards of large institutions. They are getting better medical attention, better individual attention, and as a consequence, they are living longer.

This increased life expectancy has several important implications. Obviously, even if the incidence rate of a disability stays the same but the life expectancy goes up, the number of individuals with a handicap in the population is also likely to increase. Even if the incidence of a condition is going down, as seems to be the case with Downs syndrome, increases in life expectancy can offset that decline.

These increases in life expectancy make it all the more important to find ways to turn handicapped individuals into productive members of society. Because every year of additional life, if that is not achieved, means additional burden for the families of the individuals and for the taxpayers in general. If we look at figures such as \$85 a day to maintain some disabled individuals in State-run institutions, we are talking about each additional year of life costing \$31,000 per person.

On the other hand, the return on the research and training that will pay off in terms of a productive job will be that much greater with this increased life expectancy.

Those are two factors. The third factor is this lower death rates for high-risk infants. This is a bit more complex because the implications of this are arguable. I would like to just illustrate to you how dramatic the changes have been. Of the babies born in the United States in 1960 who weighed 1,500 grams, that is about 3 pounds, 4 ounces or less, only about 28 percent lived to see their first birthdays in 1960. In 1980, infants who were of similar low birth weight 52 percent were alive at age 1.

I have some recent figures from the State of Missouri for the most recent data. In 1984, in Missouri, 63 percent of those very low birth weight infants are surviving to age 1. So we have had a very dramatic improvement in the survival of high-risk individuals.



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There is no question that these infants have a greater risk of handicap and disability. In one study that was sponsored by the Robert Wood Johnson Foundation, for example, it was found that 39 percent of the infants who at birth weighed 1,500 grams or less, at age 1 had some kind of abnormality or developmental delay. That compared with 13 percent of normal birth weight. If we look only at severe defects, 12 percent of the very low birth weight infants had such severe problems compared to 2 percent of the normal birth weight.

On the other hand, it is important to realize that the majority of the low birth weight babies we are saving do not have such disabilities, at least as far as we can tell, at age 1. Furthermore, the majority, the vast majority of babies that have congenital abnormalities are of normal birth weight. Therefore the size of the increase that we are going to get by keeping high-risk babies alive is not as large as anticipated. I did some calculations applying the 1980 mortality rates and the change from 1960 to the 1980 birth numbers, I estimated that you would get an increase of about 3 percent in severely handicapped infants. Now that is about 2,000 more infants. It is not nothing and the economic cest of that is substantial, but on the other hand it is not the epidemic of handicapped individuals that is sometimes portrayed.

We should bear in mind also that the improvements in the neonatal technology have had a beneficial effect. We are doing a better job of handling things such as respiratory distress, of jaundice, picking up problems in the delivery very early on because of fetal monitoring—and these are probably having a beneficial effect in reducing the numbers of at least some kinds of handicaps.

I think to try to integrate and summarize what these various factors mean is that it is likely there will be increases in the numbers of seriously handicapped young people in the U.S. population between now and the end of the century. These increases will probably be more modest in scope than is sometimes feared. But I would hazard a guest that 10 years from now, in 1995, there will be about 6 million young people in the public schools who will be receiving various forms of special education assistance for handicapping conditions that range from mild to severe. I would also estimate that in the same year there will be a total of perhaps 1.3 to 2.7 million young people between the ages of 3 to 21 with handicaps severe enough to warrant the kinds of technological assistance that has been described here today.

Given the higher expectations that we have today for the quality of life of handicapped individuals, the economic implications of these increases will be far from trivial. On the other hand, the financial and the emotional payoffs from successful attempts to train handicapped persons for productive activity will also be sizable.

That concludes my prepared testimony. I would like to make one more remark with respect to the need for better statistics on childhood disability. The question was raised earlier to Secretary Will, and we really do not have good data. We don't have the data that will answer the kinds of questions, how many individuals do we have who need this and know about it or don't know about it and could make use it? I would very much like to see this committee at least attempt to mandate the National Institute for Handicapped

Research to carry out the kinds of sample surveys and studies that are needed to provide these kinds of data.

It is not an impossible task. We have some models within the Federal Government. We even have something called the national health and nutrition examination survey where individuals are actually given physical examinations and tests so that you can evaluate what they can and cannot do. These kinds of mechanisms have not been applied to the handicapped population to give us the data, the points over time to see how we are progressing and to see how many of these individuals are or are not making use of the technologies that are available. Thank you.

Mr. WILLIAMS. Thank you.

[The prepared statement of Nicholas Zill follows:]



PREPARED STATEMENT OF NICHOLAS ZILL, PH.D., CHILD TRENDS, INC.

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We have heard a great deal this morning about exciting technological developments and research possibilities that might be used to train and assist individuals with serious disabilities to become productive members of society. In trying to evaluate the applications of these technologies, it is natural to ask how many young people in the foreseeable future will have handicaps that require these kinds of assistance. Unfortunately, the social science technology that can be used to make estimates of the size of particular human groups at specific points in the future is far from perfect. Indeed, the statistics that are available concerning the current numbers of persons with specific handicapping conditions leave a great deal to be desired. There are, however, some general considerations that may be used to help determine whether the number of handicapped persons is increasing or decreasing and by roughly how much. Among these considerations are: changes in the overall size of the child population; changes in the life expectancy of disabled persons; changes in 1 fant mortality and morbidity that are being brought about by advances in medical technology and social programs. I have tried to summarize and evaluate some of these developments in the remarks that follow.

## Growing Size of the Child Population

The first and perhaps the most important thing to realize when trying to project the size of the handicapped child population into the future is that the total population of young people in this country, which decreased in size during the 1970s



and early 1980s, is now on the rise again. Although the average number of children borne by each woman remains low, there are now so many women in their childbearing years (as a result of the post-World War II baby boom), that the total number of children produced is increasing. The Census Bureau has projected that there will be approximately 3.8 million births per year for the rest of this decade and into the early 1990s, and between 3.7 and 3.5 million per year during the late 1990s. This means that the total child population (ages 0-17) will rise from less than 63 million this year to nearly 65 million in 1990, and more than 67 million by 1995. The school-aged population (ages 5-17) will go from about 44 million this year to over 45 million by 1990; to more than 48 million by 1995, and nearly 50 million by the year 2000. Thus, unless the relative frequency of most seriously handicapping conditions were to drop significantly in the near future, it seems likely on the basis of population growth alone that the absolute numbers of handicapped young people in the U.S. will increase for the remainder of the century.

## Increasing Life Expectancy of Disabled Persons

A second development that must be considered in trying to project the size of the population in need of rehabilitative services is that there have been significant increases in the life expectancy of individuals with serious handicaps. It is fairly well known that babies born in the 1980s with Down's syndrome, cerebral palsy, cystic fibrosis, and other disabling



conditions are much more likely to survive their first few hours, days, and months of life than children born with these conditions in previous decades. What is less widely realized is that today's handicapped children are also more likely to survive into young adulthood, middle age, and even beyond.

Increases in life expectancy have been true for a number of different disabling conditions, but the evidence is particularly dramatic in the case of Down's syndrome. Forty years ago, an individual with Down's syndrome could expect to live only to about 12-15 years of age on the average. Today, such an individual can expect to live into his iste forties to cid-fifties. Indeed, persons with Down's syndrome are living long enough so that there is now concern about the high proportions of them who develop Alzheimer's disease in their liter years.

There are a number of reasons for the increased survival of individuals with serious disabling conditions. Part of the story is better medical management of specific acute illnesses to which disabled individuals are susceptible. In the case of Down's syndrome, it is better treatment of pneumonia and other respiratory diseases that has made a difference. An important general change is that individuals with long-term disabilities are now less apt to be relegated to the back wards of large institutions and are more likely than in the past to receive adequate medical attention for their health problems.

There are several important implications of the trand toward longer life expectancies among disabled persons. To begin with,





if the incidence of a specific disability -- that is, the rate at which individuals are born with or otherwise develop the condition -- remains constant, but the life expectancy of victims of the disability goes up, then the prevalence of the disability will also go up. That is, there will be more people in the population at any given time who have the disability. Even if the incidence of a disability has decreased, as seems to be the case with Down's syndrome; increases in life expectancy may partially or completely offset the decline as far as prevalence is concerned.

Increases in the life expectancy of disabled young people make it all the more important to seek new and better ways to train these individuals to become economically productive members of society. If productivity is not achieved, each additional year of life means an extra year of economic burden for their families or for taxpayers in general. At the rate of \$85 a day, which is what it cost in 1982 to maintain a disabled individual in a state-run institution, the costs mount up at the rate of \$31,000 per year per person. On the other hand, if training and technological assistance make it possible for a disabled individual to become productive; then the economic return on the investment in research and training will be that much greater. In sum, the increases in life expectancy are likely to enlarge the number of handicapped young people in the population and make it more imperative to provide these young people with adequate training and assistance.





## Lower Death Rates for High Risk Infants

Another development that is sometimes thought to be increasing the number of handicapped persons in the U.S. population is the advent of neonatal intensive care units and other medical and social changes that have dramatically improved the survival chances of premature; low birthweight; and other high-risk infants. Modern medical technology is succeeding in preserving the lives of tiny infants who would almost certainly have perished had they been born a decade or two earlier. Here are some figures that show just how much change has occurred in this area: Of the babies born in the United States in 1960 who weighted 1,500 grams (3 lbs., 4 ounces) or less; only about 28 percent lived to see their first birthdays. Of the babies born in the U.S. in 1980 with similar very low birthweights, more than half -- 52 percent -- were still alive at age one. Although 15-to-date data are not available for the U.S. as a whole, Joseph Stockbauer of the Missouri Health Department has been good enough to provide me with some recent data from that State's vital statistics system. These data show that low birthweight mortality rates have continued to improve since 1980. For babies born weighing less than 1,500 grams in Missouri in 1984, 63 percent survived to age one.

Although nearly everyone would agree that preserving the lives of vulnerable infants is a good thing, a number of commentators have expressed concern that an unintended consequence of these advances may be a sharp rise in the number of young people with physical and mental deficiencies. There is

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disagreement among public health experts, however, over the issue of whether such a rise in handicap really is an inevitable sonsequence of the improvements in nechatal care.

There is no question but that children born with very low birthweights show a higher <u>rate</u> of physical defect and retarded development than children born at higher birthweights. For example, in one study of a random sample of one-year-old children in several different areas of the U.S., it was found that of those who weighed 1,500 grams or less at birth; 39 percent had some form of at least mild congenital abnormality or developmental delay at age one. Among children of normal birthweight (more than 2,500 grams), less than 13 percent were found to have some form of abnormality or significant delay. If we focus only on severe defects or delays, 12 percent of the very low birthweight children had such problems, compared with less than 2 percent of the normal birthweight children.

On the other hand, it is important to realize that the majority of very low birthweight children do not show congenital defects on developmental delays, at least not by age one. Moreover, the vast majority of children who do exhibit such defects and delays are born at normal birthweights. Thus, the potential increase in the number of handicapped children that might be produced by saving the lives of a high proportion of low birthweight infants is not as great as is often assumed. I have calculated, for example, that the changes in birthweight= specific mortality rates in the U.S. between 1960 and 1980 would, when applied to 1980 birth numbers, produce at worst a 3

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percent increase in the number of severely handicapped children. Now a 3 percent increase is not nothing. It represents about 2,000 more seriously handicapped children produced from one year's births. It is, however, a far cry from the epidemic of unintended disability that is sometimes envisioned as a necessary byproduct of the reduction in infant mortality.

A number of public health experts would question whether even the relatively modest increase in disability that I have just described is really taking place. They would argue that the improvement in meonatal technology is actually producing a net reduction in later handicap because difficulties that may arise during pregnancy and delivery are being picked up earlier and complications such as respiratory distress and jaundice in newborns are being treated more effectively. The avoidance of childhood disability that results from these advances more than offsets the increase in disability that comes from preserving the lives of more infants with congenital abnormalities, or so it is argued.

There are data that seem to support this contention. Regional surveys of one-year-olds sponsored by the Robert Wood Johnson Foundation and conducted by investigators from The Johns Hopkins School of Public Health in 1976 and 1978/79 found that the overall risk of congenital anomalies or developmental delay decrease significantly between the two surveys. On the other hand, the same studies found that the proportions of children with severe or moderate congenital anomalies or developmental





delay did not change over time. I believe that a prudent reading of these results does not rule out the possibility that the <u>number</u> of severely handicapped children may be increasing as more high-risk infants survive.

To reiterate and try to integrate the considerations discussed above: I project that there will be increases in the number of seriously handicapped young people in the U.S. population between now and the end of the century, but that these increases will be more modest in scope than is sometimes feared. For example, I would hazard a guess that ten years from now, in 1995 there will be about 6 million young people in the public schools who will be receiving various forms of special educational assistance for handicapping conditions that range from mild to severe. And I would estimate that in the same year there will be a total of perhaps 1.3 million to 2.7 million young people between the ages of 3 and 21 with handicaps severe enough to warrant use of the kinds of technological assistance that has been described here toda; ; Given the higher expectations that we have today for the quality of life of seriously handicapped persons, the economic implications of these increases will be far from trivial. On the other hand, the payoff from successful attempts to train handicapped persons for productive activity will also be sizable.





Mr. WILLIAMS. Dr. Simon?

Dr. SIMON. Thank you. Perhaps it is worth a moment to give you my background, and my presence here is for that reason. I am an orthopedic surgeon at Children's Hospital and associate professor of orthopedics at Harvard Medical School. My undergraduate background was in engineering, and after receiving my medical degree I received further training in rehabilitation, and for the last 12 years have been at Children's Hospital associated with both the clinical side of rehabilitation in the patients that I see, both on a childhood level and an adult level, as well as on the research side combining efforts with MIT and their rehabilitation engineering center.

My specific research has been on rait analysis and developing a mechanism by which we can evaluate the handicap person in terms of their movement. Prior to about 10 or 15 years ago we had no means by which of assessing in a ve. accurate way just how disabled people are and what mechanism. and what proper treatments might be for them.

The research that we have done over the last 10 years with regards specifically to cerebral palsy has shown some significant facts clinically that are of importance. Cerebral palsy is a disability of birth related to brain damage that affects the locomotor system, and with an inability to properly assess it a number of treatments have, if you will, been given as the best guess in terms of how best to improve their function. Notably, one of those, of course, is surgery. With the methods that I have described in my testimony about the evaluation of these children in terms of their walking; what we have found is that we can now predict to about an 80 percent level of how they are going to walk after a particular surgical procedure.

What we have found locally is that we can reduce the number of surgical procedures by 35 percent because, in many cases, they are not necessary. This is also true with the types of braces, so that it isn't a hit or miss game in terms of picking a brace that is most appropriate, finding out after \$500 to \$600 is spent that it is inappropriate and using another one. In this sense the idea of rehabilitation technology in assessing the patient has been a very important factor. This is only one of a variety of different types of research that has been going on and that has found its way to the marketplace, so to speak, in clinical practice in a variety of handicapping physical disabilities.

That to some degree is what a lot of the technology and research in the technology has been all about. Clearly that has improved over the years with the improvement in the technological advances such as in computer and electronic technology. Now the contention is that we have a lot of means available to us to both assess and properly treat individuals with physical handicaps that could allow them to get back into the workplace.

Some of them may cost a good deal of money in hard initial dollars. But many of them we can find by proper evaluations and are relatively small in price. For example, in Texas, they have estimated that the proper technology applied costs something in the neighborhood of less than \$1,000 to get somebody back to the marketplace and to work, and the benefit, therefore, in tax dollars both that the person pays as well as the savings for not being on disabil-



ity is enormous. There are several examples that I have given in the testimony, but I will for the sake of brevity not go into that. But I think it is important on both sides to realize that.

In fact, probably only about 30 percent really need a significant increase from that \$1,000 figure to put somebody back in the marketplace. Even then, if we consider, for example, a wheelchair for a handicapped person that is motorized and having need of a nonvocal device such as an onboard computer, we are talking about \$12,000 to \$14,000 that somebody then could be allowed to use for over 10 to 15 to 20 years that would be effective and allow them to work appropriately in many work settings.

The other fact about this is that industry is becoming more and more aware that it is not just to bring 'he person back to the marketplace, but to properly place him in that marketplace and allow these technological developments to be properly used. So in many ways we have the means by which we can bring people back and allow them to have a high quality of life.

The question becomes one of how best can we take this technology and the individual with their particular handicaps and combine them together in the most economical and proper way. There I think is one of the greatest difficulties we have; and that is, right now it needs a multifaceted team. But one aspect of the team that is not involved in the act is a rehabilitation engineer who can see what the technical difficulties of the individual are and match them with the appropriate equipment. Given to the orthotist or the prosthetist, given to a team of a physical therapist and a physician, there is still an individual missing.

The second problem that we have is in acquiring the funds for the individual. We have already heard about the difficulty in trying to find those funds in terms of where they are designated. Internal prosthesis, for example, to give just another example of a total knee replacement in an individual, is repayable by third-party billers. The technological advances to allow a person to walk from an external source, such as many of the new technologies can provide, is less easy to see in terms of how it can be obtained. With a great deal of effort by the individual, or the family, or the physician, or some other particular advocate it can be done, but it takes a great deal of effort and many people are not getting it in a lot of States because of the fact that it is just not easy to see.

The question that was raised before about the dissemination of information. It seems that the consumers are more aware of the things that are available, although there needs to be more work on this, but who to go to and how best to address it is one of the significant questions. Therein lies a great deal of the problem.

What I am saying basically is that a rehabilitation engineer is missing from the vocational rehabilitation, and the education to vocational rehabilitation and to a great deal of people is somewhat missing in this respect. Even though laws state that these things should be available to the handicapped, the laws are relatively loose and it is therefore difficult to try to implement them. So what we are suggesting is that certain recommendations be made to the rules and encouragement from this committee to amend them appropriately, and these are listed in my testimony between page 8 and page 12. I will just briefly go over those.

One. In section 7, paragraph 5, the law defines the term "evaluation of rehab potential." Many persons despite——

Mr. WILLIAMS. Mr. Simon, I don't want to be rude, and you are into a very important part of your testimony, and I know, too, that you came up here from Memphis. Let me ask you, though, because bells are about to ring here and we are going to have to go vote. Let me ask you to summarize your recommendations, which I commend you for delivering in such specificity, and that will give Mr. Bartlett and myself time to ask a couple of questions before the bell rings. That way we won't have to keep you all for another half hour waiting for us to return.

Dr. SIMON. All right. Well, in summary, I think they are listed there, so I won't reiterate them.

I think one of the most important points about this is that identifying in those laws basically that specific technological advances can have reimbursement, that the appropriate assessment be made for those through the efforts of incorporating rehab engineering into the system at the vocational rehab level.

I think I will stop there for the sake of brevity, because I think they are all listed in that sense.

[The prepared statement of Dr. Sheldon Simon follows:]



## PREPARED STATEMENT OF DR. SHELDON SIMON, DIRECTOR, GAIT ANALYSIS LABORATORY, HARVAR 9/MIT, ON BEHALF OF THE UNITED CEREBRAL PALSY ASSOCIATIONS, INC.

#### Introduction

Good Morning! My name is Sheldon Simon, MD., and I am testifying today on behalf of United Cerebral Palsy Associations, Inc. UCPA is a private, non-profit agency with 230 affiliates in 45 states concerned with meeting the needs of persons with cerebral palsy, and those with similar disabilities. In recent years, UCPA has become increasingly concerned about providing employment and Independent living opportunities for persons with cerebral palsy. Our testimony will outline how rehabilitation engineering can radically change the lives of persons with severe disabilities. We will also make recommendations for amendments to the Rehabilitation Act which would make it possible to provide greater employment and independent living opportunities for disabled persons. We appreciate the opportunity to present this testimony before the Subcommittee.

It is important for the Subcommittee to understand my professional background and why I am so committed to the concept of rehabilitation engineering. I am the Associate Professor of Orthopedic Surgery at Harvard Medical School, Director of the Gait Analysis Laboratory in the Harvard/MIT Rehabilitation Engineering Center as well as Orthopedic Director of the Cerebral Palsy Clinic at the Children's Hospital Medical Center in Boston. I received my undergraduate education at New York University College of Engineering and combined my engineering background with a medical speciality in orthopedic surgery and rehabilitation medicine. I am the current president of the Rehabilitation Engineering Society of Worth America.

By major research interests and in orthopedic biomechanics and rehabilitation engineering. I hav, been especially interested in the mechanics of neurological control and human locomotion. Por the past





five years; the Gait Analysis Laboratory has received a research grant from the UCP Research and Education Poundation to study the unique ambulation problems experienced by children and adults with cerebral palsy.

#### Description of the Gait Analysis Laboratory

cerebral Palsy is a disability which generally occurs before, during or shortly after birth and results in brain damage to the locomotor segments of the brain. Children and adults with cerebral palsy often experience difficulty in walking depending on the type and degree of their disabilities. Until recently, these children and adults have often been subjected to painful surgery only to find that the operation did not help their functional abilities and, in some cases; their ability to walk decreased after surgery. Also, in the past these children and adults have been fitted with costly braces which, in some cases, did not improve their conditions. The Gait Analysis Laboratroy seeks to methodically understand the individual's gait problem and thereby prescribe the correct treatment.

Gait Analysis combines the use of a number of infrared cameras. placed at differing angles to photograph the movements of the individual walking across supersensitive scales that distribute the force of the individual's gait in all major directions, and electromyography of a number of the major muscles involved in controlling the ankle, knee and hip joints of both lower extremities.

All of these variables are automatically fed into a computer which is programmed to produce photographs which can then be interpreted to provide a complete analysis of the gait of the individual. This analysis will guide the physician in providing suitable treatment for the individual, whether by orthopedic surgery, the use of orthopedic treatment, physical therapy, or other methods.



The work of the Boston Children's dospital Gait Analysis Laboratory over the past decade has led to a decrease of about 35% in the use of orthopedic surgery for the correction of lower extremity defects in children and adults with cerebral palsy. Purthermore, the experience has indicated an 80% positive predictive value of the gait analysis in terms of further treatment: The methodology being used is now being adapted towards whole-body movements, problems of the Opper extremities, and the evaluation of communicative devices and mobility alits such as mechanical and powered wheelchairs.

I have focused on the benefits of the Gait Analysis Laboratory for persons with cerebral Palsy, but the Lab can clearly help many other persons who experience walking and coordination difficulties.

This is one example of how rehabilitation engineering is being programmatically applied to enable Persons with disabilities to live more independently.

## Rehabilitation Engineering and How IE Changes the Lives of Consumers

Rehabilitation Engineering has been defined as the application of engineering to "improve the quality of life of the physically handicapped through a total approach to rehabilitation combining medicine, engineering, and related services." In addition, Rehabilitation Engineering means the provision of physical devices or the adaptation of the physical environment to enable physically handicapped persons to perform everyday activities in a workplace, in an educational setting, or in a home or other place of residence. UCPA believes that rehabilitation engineering holds the key to the future for persons with severe disabilities. Rehabilitation engineering can help young disabled professionals adapt their work sites so they can work more effectively. Such technology also can improve the productivity of persons with



cerebral palsy and mental retardation who are employed in a sheltered or supported work environment. Rehabilitation engineering can enable the nonverbal teenager with cerebral palsy to communicate and socialize with peers and family members. It can dramatically improve the employment potential of disabled persons and enable greater numbers of persons with disabilities to live independently.

How does this technology actually benefit the disabled person? Perhaps a few individual examples will enable the Subcommittee to understand its importance. A young ran disabled by cerebral palsy wanted to become a computer programmer. dis major difficulty was lack of control over his hands, arms and legs which prevented him from moving smoothly from one task to another. de had some coordination control if he sat with his legs crossed while working at the computer. However, in order for him to sit that way for long periods, it was necessary to lock his wheelchair in place. This was accomplished with caster locks from a local wheelchair supply house for about \$30. His employer obtained an automatic dialer from the telephone company at a minimal cost. These adaptations allowed this individual to be become successfully employed:

Another young man severely disabled by cerebral palsy had outstanding professional credentials but lacked dexterity to perform some of his professional tasks. He obtained a computer which has an "abtreviztion expansion mechanism," and he could type entire paragraphs by pushing only a few keys. This has enabled him to grow professionally and he has since consistently received promotions. In addition, his computer has helped him do post graduate work, and he will soon receive his Ph.D. His success has allowed him to buy a condominium and drive a car. This individual, once thought to be unemployable, has a bright future, thanks to rehabilitation engineering technology.



Let me give you one more specific example of the cost-effectiveness of successful rehabilitation engineering from the state of Indiana. Wenty-two year old Lisa, who has paraplegic cerebral palsy and was supported in part with Supplemental Security Income benefits was referred to a Rehabilitation Engineering Team to help her find employment. She became an administrative clerk, but five modifications were implemented by the Rehabilitation Engineering Team before she could succeed in her job:

- 1) her wheelchair seat was raised so she could reach copier buttons;
- 2) A new footrest was installed on her wheelchair so she could get closer to the copier;
- 3) a sheet of dycem was attached to her workspace to help Lisa open clear plastic report covers;
- 4) a reacher was secured to help her retrieve dropped items; and
- 5) a refrigerator basket was attached to her wheelchair so Lisa could carry papers.

Lisa has recently completed her on-the-job-training and received a raise. The cost of Lisa's success was \$1,422.00 for the Rehabilitation Engineering Team's interview, assessment, supplies, equipment and modifications. Money generated by her employment was a yearly salary of \$9,880.00 of which she pays \$2,753.40 in taxes. The decrease in SSI payments resulted in a saving to the federal government of \$3,900.00 per year. At this rate, it took Lisa just a little over eleven weeks to pay back the cost of her rehabilitation engineering services.

# Problems in Accessing Rehabilitation Engineering and Technology

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We have demonstrated that rehabilitation engineering and technology have the potential to radically change the lives of disabled persons. Research is being conducted in a variety of areas, but the benefits are



not reaching the consumer. Perhaps this gucte from the Wisconsin Division of Vocational Rehabilitation will help us understand the problem of accessing rehabilitation engineering:

"Rehabilitation Engineering as a profession is widely diverse. Partly because of the diversity of the needs and partly because it is in a conceptual stage. It covers a broad range of applications from wheelchairs to special monitoring systems, from accessibility to reading machines for the blind. Some areas are mature, long established with years of experience, some areas are developing, some barely past the concept stage, and some still in the conceptual stage."

UCPA believes that there are three approaches which can help apply rehabilitation engineering and technology to the worksite and/or home environment. First, the information must be disseminated. Much technology is available to help the consumer function more independently. The National Renabilitation Information Center administers the ABLEDATA system which lists more than 11,000 commercial aids and devices specifically designed to assist disabled persons. This system is one avenue of obtaining this critical information, but unfortunately, many professionals do not know of its existence, and it is too expensive for most consumers.

Second, professionals, parents and consumers can adapt available aids and devices to meet individual needs. Much "technology" can be obtained at the local Radio Shack store and can be readily adapted for use by the disabled child or adult. In fact, many parents of severely disabled children become "resident experts" in developing or adapting devices to meet the children's needs.



A third method of obtaining rehabilitation technology is to specifically construct aids, devices or equipment to meet the unique neers of the individual. Some "customized technology" may be complex and cristly. However, it has been estimated that approximately 65% of the rehabilitation engineering services required by persons with disabilities are low cost items which can be purchased easily. According to a report by the Texas Rehabilitation Commission prepared under a National Institute for Handicapped Research grant, 1,014 solutions to rehabilitation engineering problems over a three-year period averaged \$838.00 per solution.

If rehabilitation engineering and technology are to be maximally utilized by disabled Persons; the VR system must become more knowledgeable of the benefits of technology. While we have already cited examples of state VR agencies using rehabilitation engineering, there are many barriers to this process.

We believe that the local VR counselors <u>must</u> have a rehabilitation engineering resource at the state level to assist in understanding individual client needs. In Wisconsin, the VR agency has hired a rehabilitation engineer to advise and actively assist local VR counselors in applying rehabilitation engineering to their clientele. Also, this person offers consultation to clients, other rehabilitation professionals and potential employers. Through these efforts, as well as a document which serves as a "guide" to applying rehabilitation, we feel that the Wisconsin Division of Rehabilitation has made a significant contribution to the rehabilitation community.

Finally, VR must use rehabilitation engineering in <u>evaluating</u> the client's rehabilitation potential. Many persons with cerebral palsy may be reverely physically impaired, yet be bright and capable of handling a

number of employment opportunities. Often; because of the severity of their involvement, these persons are either told that they are "unemployable" of placed in positions far below their capabilities. Onless a client's potential is accurately evaluated with the use of technology; many persons we represent will either be turned away by the agency or "closed out" in sheltered employment earning far below the minimum wage.

### UCPA RECOMMENDATIONS

The problems of transferring the benefits of technology to the consumer are complex. We believe the solution requires a multi-faceted approach which must include the training of vocational rehabilitation professionals in how technology can be applied to enable persons with disabilities to live and work productively. While much fine research is being done by NIHR, UCPA recommends that we continue to search for new ways to apply rehabilitation engineering and technology to the lives of disabled persons.

With these goals in mind, UCPA makes the following specific recommendations for amendments to the Rehabilitation  $\lambda ct$ :

1) Sec. 7 (5) of the law defines the term "evaluation of rehabilitation potential." While this Section outlines the type of evaluation a client may have, <u>rightere</u> does the law require that the clients be assisted by rehibilitation engineering services or technological aids of devices as part of the evaluation process. Yet, many persons with detebral palsy are denied VR services simply because the application of rehabilitation engineering and technology was not considered. Thus we recommend that Section 7 (5) be amended to include the provision of rehabilitation engineering services to any individual with a severe handicap to assess and develop the individual's capacities to perform adequately in a work environment."

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- 2) Sec: 102 of the law outlines the Individualized Written Rehabilitation Program (IWRP). The IWRP defines the client's rehabilitation needs and a program of how these needs can best be met. The IWRP is a critical document because it often determines not only the services the client will receive, but ultimately the client's current and future employment potential. Without rehabilitation engineering services, many severely disabled clients will either be "unemployable" or will be employed at a job which is far below their abilities. Therefore we recommend that Sec 102 (b) be amended to include "a statement of the specific rehabilitation engineering services and long range rehabilitation goals for the individual."
- 3) Sec. 103 outlines the "Scope of Vocational Rehabilitation Services." While this section of the law may allow for the application of rehabilitation engineering services and technology, these services are not specified. While some state and local VR agencies (such as Wisconsin and Texas) are making rehabilitation engineering an integral part of the rehabilitation program, other states are not. UCPA recommends that Section 103 be amend. to include "rehabilitation engineering services designed to help individuais with a severe handicap increase their functional abilities and potential for self-sufficiency". UCPA believes that if Section 103 is amended to include rehabilitation engineering services these would be provided to greater numbers of severely disabled ser v ) could become more independent and productive. per.
- 4) Section 101 of the Act outlines requirements for state plans which are to be submitted to RSA every three years. These plans outline in

detail how the ACE Will be administered at the state level and how the state agency will serve disabled persons. UCPA recommends that Section IOI be amended to require that the state agency "describe how rehabilitation engineering services will be provided to assist an increasing number of persons with severe handicaps." Further we recommend that the state agency "he required to either establish an office of rehabilitation engineering and technology or enter into agreements with nonprofit agencies and organizations, including institutions of higher education to provide training, technical assistance, consultation, and services that will increase the application of rehabilitation engineering (ad technology to individuals with severe handicaps.\* We believe these additions to the state plan requirements will expand the availability of rehabilitation engineering services which in turn, will increase the employment and independent living potential of severely disabled persons. This provision is also likely to increase the number of "status 26" closures.

5) Section 304 of the Act calls for the training of rehabilitation professionals. Clearly, if rehabilitation engineering and technology is to have a long term impact on the VR system, we must train more professionals in this field. Such training must have two components: first, we must encourage more young engineers to enter this profession. This can only be done through extensive pre-service training.

Second, we must enabl. VR counselors and other rehabilitation professionals to become more aware of how technology can be applied to benefit persons with severe disabilities. UCPA urges that Section 304 (a) be amended to <u>assist in increasing the numbers of gualified</u>



personnel trained in providing rehabilitation engineering services.\* UCPA further recommends that Section 304 (b) be amended to include \*projects in rehabilitation engineering.\*

NIER has been at the forefront of fostering the growth of rehabilitation engineering research for the last several years. We applaud their efforts for they have paved the way for much success in this area. However, W, offer the following recommendations for amendments which we feel will enhance NIER's efforts.

- 1) Section 204 (p) (1) calls for the establishment of rehabilitation research and training centers. These centers provide training to students entering into the rehabilitation field and also encourage research into a variety of rehabilitation problems. UCPA recommends that Section 204 (b) (1) be amended to state that "the Centers be encouraged to provide training to assist individuals to more effectively utilize rehabilitation engineering services and focus on the application of technology and rehabilitation engineering to increase the vocational potential and the independent living skills of individuals with severe handicaps." It is our belief that this amendment will help close the gap between the recent achievements in research and their application to everyday rehabilitation problems."
- 2) Section 204 (b) (2) authorizes rehabilitation engineering centers (REC): These REC's have provided a wealth of information including the Gait Analysis Laboratory which I run. However, there is currently only one REC dealing solely with employment and independent living. While the current language in this section discusses the need for medical technology, it does not discuss the need for rehabilitation engineering as it relates to employment and independent living. UEPA strongly urges that Section 204 (b) (2) be

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amended to include on additional subpart (c) "to demonstrate innovative models for the delivery of cost-effective rehabilitation engineering services that promote the prompt utilization of engineering and other scientific research to assist in meeting the employment and independent living needs of individuals with severo handlicaps." OCPA urges that NLAR fund at least one REC under this new subpart (c).

- 3) Current law allows iffR to fund nimber of demonstration projects which put into practice important research developments. UCPA recommends that Section 204 have a new subparagraph 14 to • conduct model research and demonstration projects to expand the cost effective delivery of rehabilitation engineering services and the application of technology to meet the rehabilitation needs of individuals with severe handicaps.\*
- 4) Host projects funded by NIER are subject to a peer review system which allows "experts in the field" to rate various research projects for funding priorities. We have pointed out in our testimony that consumers must play a vital role in development of any technology which will ultimately change their lives. Therefore, we urge the Subcommittee to encourage NIER to routinely include persons with disability on these peer review panels.

### Conclusion

We are delighted to have been given the opportunity to testify below the Subcommittee on the impact of technology on the lives of individuals with severe handicaps. We hope that we have given you information which will assist you in the reauthorization of the Rehabilitation Act this next year. The application of technology and rehabilitation engineering to benefit persons with cerebral palsy and other severe disabilities has the potential to revolutionize the VR system. The amendments we have proposed today, if enacted into law will become a declaration of independence for thousands of Americans with Disabilities.

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Mr. WILLIAMS. Mr. Bartlett.

Mr. BARTLETT. Thank you, Mr. Chairman. I have about 3 hours' worth of questions and no doubt you would have several days' worth of answers, but let me try to hit them in order of priority. I very much appreciated your testimony, and particularly the specific recommendations for the R hab Act, which is essentially what this committee is looking for and it is very helpful for you to provide them.

My first question is on a related issue but not in your testimony, so let me ask you one that was not answered. That is on the legislation that you may be aware of that I introduced earlier this year, H.R. 2030, which would make section 1619 permanent requiring notification. More to the point of this subcommittee, it would help to provide demonstration and technical assistance to employers to use technology and other things to make the worksite accessible and accommodate the worksite and to use vocational rehabilitation counselors as a placement service for people who don't need rehabilitation and they just need a job and they need to be able to communicate with employers to obtain that job.

Have you had occasion to look at that kind of approach? Do you think that would be helpful? And where in addition to that would you go in terms of removing disincentives?

Dr. SIMON: I think it would be very helpful: I think the additional aspect here is the koseness of the word "vocational rehab" with relationship to the fact of the technology we are using; namely, that rehabilitation signeers either through educating the voca-tional people themselves or as part of the team should be incorrerated.

The second thing the people, for example, industrial engineers or labor management - assessment people from the econ c ic side, who are aware of what technology can do as part of it is make the proper placement for people in the workplace should be part of that team.

But I think in general the concept is very good.

Mr. BARTLETT. You-used the term "rehabilitation engineer" quite a bit, and "rehabilitation engineering team." Could you elaborate for us a little bit on what that discipline is and how extensively is that being used by vocational rehabilitation agencies? I assume that your recommendations go toward increasing the rehabilitation engineering.

Dr. SIMON. There are two aspects. Let me just take the rehabilitation engineer first. The rehabilitation engineer is basically an engineer whose specific task is the application of engineering and technology for the disabled individual. There has been little training on that, and I believe NIHR several years ago sponsored programs for it. There is only one of those programs, to my knowledge, that is left and that is at the University of Virginia for the specific education that way.

One of the major problems was the difficulty of having a job for them to go to. There were no specific jobs because the medical system did not provide for that kind of an employment for an individual. The rehabilitation engineering team is one who is related to the fact of applying that technology, of being knowledgeable about the aspects of the technology in relationship to a particular physi-



cal handicap and the degree of that handicap, and how to best apply it. Certainly that team is not a simple team of a physical therapist or a physician, b. someone who is familiar with that. The education for that right now is quite sparse, and the utilization for it in general has been little used by vocational rehabilitation, in general.

Mr. BARTIETT. You are suggesting that that is a major lack, or missing ingredient in the vocational rehabilitation agencies, and that is the use of rehabilitation engineering teams?

Dr. SIMON. Yes, I am.

Mr. BARTLETT. Is there such a thing as the discipline of rehabilitation engineer? I mean, is there a degree that one can get or is it just an occupation that one chooses?

Dr. SIMON. Again, there was an initiation of that, and currently to my knowledge there is one specific program for it at the University of Virginia. There is the general degree of bioengineering that many universities are giving. There is also the specific thing of individual departments of engineering such as electrical engineering and mechanical engineering which has a major in this specific area of application to medicine.

Mr. BARTLETT. Dr. Zill, one follow uestion. One thing that we have wrestled with during this height and for the last several years, and will wrestle with again is how to tie the costs of rehabilitation engineering or the costs of obtaining that full employment, the costs of technology—your colleague estimated that, in Texas anyway, that in over a thousand cases the cost was only \$838 per individual on an upfront cost.

What mechanism would you use to tie the payment of those costs to the enormous savings that accrue to the benefits from the absence of the payments that would be made?

sence of the payments that would be made? Mr. ZILL. Well, I think you begin to suggest that we need to look at some innovative social mechanisms. For example, we might consider is handicapped child insurance. Some sort of system where all parents pay into a fund or into an insurance against the possibility of having the enormous costs that come often with having a handicapped child. Some way of redistributing and, as you point out, bringing more into the present the costs that will be eventually paid out by society in the future because of not having these kinds of programs and possibilities.

Mr. BARTLETT. Thank you, Mr. Chairman: I yield bac: the balance of my time.

Mr. WILLIAMS. Thank you.

Mr. Zill, tell me the purpose of Child Trends?

Mr. ZILL. We are a nonprofit research organization. We do two kinds of things. We do national studies of children in families, and then we work with Federal agencies to try to improve statistics on children in families. We are supported now by grants from the National Science Foundation and the National Institute of Child Health and Human-Development, the National Institute of Mental Health, as well as some private foundations.

One of our efforts right now is to try to get the agencies to coordinate with one another so that the moneys that are spent on collecting data on children could be spent more wisely and provide



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data that would be of more use to researchers and to policymakers like yourselves.

Mr. WILLIAMS. Do you have data on the number of handicapped children not being served whatsoever by rehabilitation services?

Mr. ZILL I think we could make some rough estimate, though I think the data are not very good on that issue. I think in general you are talking—most of the data collection mechanisms of the Federal Government tend to be sample surveys. Even if those are large surveys, you don't have many cases at the extremes of the distribution, so that you are making estimates on the handicapped based on one or two cases that happen to be picked up even by a large survey.

Mr. WILLIAMS. Does Child Trends depend upon federally generated data?

Mr. ZILL: To a great extent, yes:

Mr. WILLIAMS. I see.

Mr. ZILL. We generate some of our own as well, but to a great extent we do. There is, of course, data from the schools on numbers of handicapped individuals. But as you are probably aware, those data are very suspect because the categorical definitions that are used by various States are not subject to any kind of independent evaluation. As a consequence, if you look at the trends from year to year in a given State, you will find several thousand children seemingly to jump from one category to another, say, in the State of New York.

Nevertheless, some of those numbers are the best ones that we have available. I think this committee, I would very much like to see you taking a look at how, without breaking the bank, those 32 a could be made better so that we could say something more definitive about children who are and who are not served.

Mr Williams. You indicated that the number of disabled chiliran will increase not in epidemic proportions in your judgment, but increase none heless. Are there any trends, countervailing trends but would indicate that the number of disabled children might accrease?

Mr. ZILL. Well, there are some very positive kinds of helps. I mentioned that some would argue that the improvements in neonatal technology are having some beneficial effects as well as keeping high-risk individuals alive. In addition, there is the use of amniocentesis in prenatal diagnosis and that will probably be having some beneficial effects, although I think it is going to be counterbalanced in the foreseeable future with the shift toward later matern. ages. Women are having children at later ages which produces some increase in the risk for handicap.

We are making some progress, believe it not, in the environmentel area. One of the very positive things that has resulted from Government programs is that there has been a decrease in blood lead levels of children and adults. This has been documented in the Health and Nutrition Examination Survey. Because of the EPA requirement that leaded gasoline not be used anymore. As you know, there is some association between high blood lead levels and intellectual handicar ping in children. So that is an example of a positive environmental development that is likely to result in fewer handicaps.



Mr. WILLIAMS. Dr. Simon, do you work with the private sector? Dr. SIMON. Yes, very much so. Mr. WILLIAMS. Would it be through the private sector that the

provision of rehabilitation engineers would proceed?

Dr. SIMON. Yes, as one means.

Mr. WILLIAMS. Can that proceed without public leadership?

Dr. SIMON. I don't believe it can. I think it needs the-

Mr. WILLIAMS. Yes. Why is that? I would tend to have the sense that it can't, too, but I don't know why:

Dr. SIMON. Well, I think what we are talking about is quality here. To go back to your question about are children being cared for? I think the answer is, in general, that you can provide medical care for them and everything. I think the question in this area is the quality and what has been mentioned before in terms of, for example, the wheelchair and the durability of it. The contention that do we need a wheelchair like this, for example? The private sector feels that, you know, that things are-it has not been made aware to them in terms of the long-term benefits that can accrue from a better wheelchair that up front might cost more money but in the long run, in terms of maintenance and everything else, may not be as good. That is difficult to get across in these times when everything is becoming tighter and needing to be justified without the absolute proof. At least until we get that proof of quality individual who can justify one, two, three, four, the specific aspects of it to say that this is better. I think it would be difficult for them to initiate that on their own.

Mr. ZILL. Excuse me. Mr. Chairman, can I just give one further remark in response to your question about unserved children?

Mr. WILLIAMS. Yes, sur.

Mr. ZILL. It is important for us to realize that of the 11 percent of total school enrollment now of kids who are getting various kinds of special education, the vast majority of them do not have visible disabilities in the sense of needing a wheelchair or being blind or hard of hearing. Most of them have learning disabilities; emotional disturbances. Those children come very much from minority and low-income groups.

I think that we need to think about the levels of service that they are receiving because they often are not as visible. It is not as easily placed in a handicapped category for which a solution is available. I think that the need for technology for these individuals, and this is the area again where you are likely to have substant i underservice because, in part, the schools and society blames these individuals; we tend to think that they are responsible for not learning or having the behavior difficulties in school. We need to think that about that segment of the handicapped population and get away from some of the stereotypes we have now.

Mr. WILLIAMS. Is that other segment, that is, those with noticeable physical handicaps, underserved to any significant degree?

Mr. ZILL. I think they probably are. I think that also there are socioeconomic differences there, although not as great. As someone mentioned here, the medical programs tend to be more likely to provide things. So if something can be classified as falling under Medicaid, for example, it is more likely to be provided. But I think there still are differences.



Mr. WILLIAMS. Those people, those children with the obvious physical abilities that are being underserved, I assume the definition of "underservice" would be that they aren't receiving fully appropriate service which is relatively within their availability. My question, however, goes beyond that.

I assume that given the common clity of the public school system and the requirements for universal mucation there are literally no children in America with signation physical disabilities who are receiving no service.

Mr. ZILL. No, but it may be something as simple as does the child's eyeglass prescription, is it appropriate so that he can see the blackboard this year, or is it 2 or 3 years old and not been tested recently?

Mr. WILLIAMS. Yes.

Mr. ZILL. It may be as simple a neglect of that sort, which does I am sure occur.

Mr. WILLIAMS. But am I correct in that assumption that those children with serious physical disabilities are being attended to in some fashion or other by the public?

Mr. ZILL. I think that is a reasonable assumption.

Mr. WILLIAMS. Mr. Bartlett, anything further?

Mr. BARTLETT. You were here during the earlier testimony. I wonder if you could answer as best you can as to your impression as to how much information on technology and technological innovations is reaching the consumer?

I note on page 6 of your testimony, Dr. Simon, that you cite the 11,000 commercial aids and devices specifically designed to assist disabled persons that is made known through a system by the National Rehabilitation Information Center, and then you tell us that many professionals don't know of its existence and it is not available to consumers at all.

Would it be useful to make that widely available? You are saying it is not widely available even though there are 11,000 different devices that are in it. Are you saying it is not very well utilized? And how would you change that?

Dr. SIMON. I think it is, if anything, I would say underutilized, but that is a reflection of basically the information getting out, and more and more people are trying to do that. We are trying to do that in a variety of ways such as of letting different publications from different groups know about it, to try to get it in the publications as much as possible. Technology now is certainly becoming a very media-attentive thing, even in the commercial media such as even my own laboratory has been on NBC and ABC News and things like that.

We need to do more: There is no question about it. I think by all the mechanisms we have—

Mr. BARTLETT. Is there a way to change that particular system so that an individual who has a disability and is looking for a way to get a job and hasn't figured out the key to that lock could access that system?

Dr. SIMON. I think the mechanisms are there. They just need to know about it more. Obviously, with computers, you know, and telecommunications systems that this becomes more available.



Mr. BARTLETT. Well, is this system accessible to home computers right now, do you know?

Dr. SIMON. I can't answer that directly, but I believe there is something in the works that if it isn't that it will be. I think it is. I know there has been a great deal of talk about it, and I don't know whether it is through Compu-Serv or one of the other ones. But I know there is a great deal of talk that it would be implemented, I don't know if it has exactly been implemented at this point.

Yes, it is the awareness of the existence of the person.

Mr. BARTLETT. I guess my other question then relates back to employment, and that is do you think it would be helpful to use vocational rehabilitation agencies for employment placement and counseling and adaptation even when a person doesn't need physical or vocational rehabilitation?

Dr. SIMON: Yes. It is the their awareness of the technology that is not there, but that is certainly a very good means within the system to do it.

Mr. BARTLETT: Do you have a sense that that would save the government some large sums of money by being able to eliminate the cash benefits to SSI and SSDI?

Ms. Roy. Excuse me. If I might.

Mr. BARTLETT. You: have been wanting to testify the entire morning.

Mr. WILLIAMS. Put the microphone closer to the lady. Please identify yourself for the record

Ms. Roy. I am Kathleen Roy, of the United Cerebral Palsy Unit, and I have the honor of accompanying Dr. Simon.

On page 5 we give an example of a student that we have in the unit with severe cerebral palsy, and it took only 11 weeks of full employment to pay back the entire sum of the cost.

Our proposed amendment that was enclosed for your perusal. I think in the next several months to make—so that there is a knowledgeable resource person at the State level and in fact at the office of technology in the State to be a resource to both rehab and consumers so that what is currently done can be disseminated.

I am not saying it is all that simple out most of it is not that difficult and not that costly. We believe the department can increase the ability of all persons particularly for the severely disabled. The unique thing about what we are talking about is that it can help me as a professional. It can also help the person with severe mental retardation, who wants to do more; and, thereby, we at the community can work together on this. The way the components work we can make great strides; and, in fact, get a big degree of help. Thank you.

Mr. BARTLETT. Thank you. Thank you very much.

That testimony, Mr. Chairman, she has been preparing that in her mind all morning.

I share your enthusiasm and your sense that these are not isolated examples in terms of the cost effecti eness of both rehabilitation engineering as well as just simply placement and some work site modification. The examples you have cited in your testimonies could be replicated day after day over millions of people at a tremendous cost savings to the American taxpayer and an unbelievable life saving to the recipients themselves. That is, once we can



establish, which we are going to have to do by law, + iat linkage between paying the up front costs and eliminating the downstream monthly payments, then I think we have a win-win situation in which everyone benefits, the taxpayers and the recipients themselves.

I thank you for your eloquent testimony.

Dr. SIMON. Thank you.

Mr. WILLIAMS. Gentlemen, we thank both of you, and you, too, Ms. Roy, for your testimony here this afternoon. It has been very helpful, and we may indeed as we move along toward reauthorization be in touch with all of you again for continued counsel. Thanks very much.

This hearing is mourned. [Additional m al submitted for the record follows:]



PREPARED STATEMENT OF DON V. MATHSEN, P.E. AND CHARLES M. PAGE, PH.D., OF THE University of North Dakota

INTRODUCTION

We were greatly honored by the opportunity extended by Congressman Pat Williams of Montana, a member of this Subcommittee, to present testimony relating to the role of technology in rehabilitation and related matters. The honor is three-fold. First to have been singled out to provide input to this group in its quest for information is especially a privilege considering the position of this Subcommittee and its responsibility. Secondly, we were honored to be invited to participate within the company of the other organizations invited which have major national and even international reputations within the area of technology development and dissemination. And third, we were honored to be invited because by comparison our efforts are small, and new, relative to others in this field. Because of this, it is a special distinction to have our efforts recognized and opinions solicited.

Actually, there is a fourth reason we feel honored and this concerns the major theme of our work and perspective and that is that they deal with matters "rural". Perhaps because of this special concern and experience on our part we might be able to offer the Subcommittee information about an aspect of rehabilitation technology that is unique and critical to its deliberations and study. It is then; in fact,our work within the area of "rural rehabilitation technology" that perhaps best gualifies us to offer information



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which we hope will be helpful to this group in its mission.

### RURAL PERSPECTIVE

It is estimated hat 68 million America e i. ral settings: Of this rule: 7.5 m lion a jnc '⊂ i zë some type of disability: There are various etc. a is shout the number of farmers who are absabled and further work heeds to be done in this drea. It is known, lowever, this agriculture leads all industries in fatalities with 55 death per 100,000. It also is estimated that 200,000 disabling injuries occur in the agriculture industry each year amounting to 58 per 1,000 workers. Interestingly enough, agriculture is folle : ; : y 50 deaths and 40 disabling injuries by mining for the same statistics, the second ranking in both categories behind agriculture; our nation's second major rural industry. While agriculture and mining are extremely hazardous industries, it should be noted that less than 20 percent of all rural residents are actually engaged in farming. Vehicular accidents, toxic conditions, and many other factors all contribute to the high incidences of death and disability in rural areas.

A host of rural living characteristics can be cited which help to identify this area of America as deceptively challenging to people with disabilities. Accessibility problems related to great distances to health and human service resources is commonplace in rural areas. The added expenses of transpor-

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tation and communication factors further burden those who live in rural regions. Harsh climate and other environmental factors are frequently typical of such areas contributing to difficulties for those already at a disadvantage because of chronic disease, or as a result of injury or accident of birth. Generally, opportunities such as for employment, vocational training, and other benefits are reduced for those in rural areas. For those working there are often unique disabilities associated with rural vocations which in turn limit possibilities for vocational rehabilitation when required. Rural life styles and values, coupled with environmental factors, typically contribute to a sense and reality of isolation. Disabling conditions, which are devastating in themselves, frequently must be confronted without the needed resources, both human and technical, that exist for most Americans who do not live in rural areas. Finally, in this partial litany of rural woes, the decided "urban orientation" of much that affects rural America can be verified. The expression of "too few; too far, to matter" is indeed all too often true.

Ma organizations, including the American Rural Health Association (ARHA), National Rural Health Care Association (NRHCA), American Council on Rural Special Education (ACRES), all of which we belong to, and others could provide additional information about the unique challenges continuiting rural people with special needs in this country. What we are attempting





to point out, however, is that a significant number of people in this nation live with disabilities in rural settings which call for special resources and responses. One such area, in our opinion, deals with "rural rehabilitation technology".

### MCRH & EES

About four years ago our two organizations collaborated on a proposal to the National Institute of Handicapped Research (NIHR) to establish a rehabilitation engineering center (REC) at the University of North Dakota. Our organizations are the Medical Center Rehabilitation Hospital (MCRH), which is part of the University, and the Engineering Experiment Station (EES), a division of the University's School of Engineering and Mines. For nearly 15 years the two units have informally worked together on projects related to bio-medical concerns of Helpital patients. The MCRH, incidentally, is a comprehensive free-standing inpatient rehabilitation facility which is 27 years old, completely self-supporting, and has treated over 41,000 rural patients. The EES likewise had a history of innovation but in research relative to rural needs such as renewable energy for northern climates, mining, and 1 gnite conversion processes.

The proposed core area of the anticipated rehabilitation engineering center was to be "rural" concerns. Normally, existing RECs have focused on a specific disabling condition or type of technology, e.g. mental retardation, mobility devices, etc.

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Again, o'r intent however was to focus attention and resources on the special needs of people with disabilities in rural mettin for technology, regardless of the type of disability or technology involved.

## ICRT

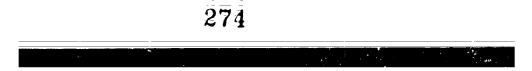
Our proposal was not funded. One of a number of our proposed tasks, however, was considered favorably by the cigective peer review committee. This was the notion of a "conference" dealing with rural rehabilitation technology. We took that reaction and turned it into a reality two y s later. The reality was known as the "International Conference on Rural Rehabilitation Technology", or ICRRT: It was held on the campus of the University of North Dakota in Grand Forks on CCCober 23-25, 1982. Attending were participants from 24 states and four countries. Included among the participants were over 50 vocational rehabilitation counselors and administrators from throughout the United States. A number of consumers, particularly di: abled farmers, along with a wide range cf rehabilitation professionals participated in the event. Included among the featured speakers was Dr. Douglas Fenderso., Director of the NIHR at that time. A total of 40 professional papers were presented dealing with a wide range of topics relating to consumer characteristics, aspects of living, service delivery models, and technologies which related to uniquely rural



situations. Copies of <u>ICRRT proceedings</u> continue to be requested from around the world. For the first time ever, ICRRT permitted people to gather to discuss the special challenges and resources confronting disabled people in rural settings. Considerable intcrest was expressed in the development of an ongoing network to insure the continued existence of an organization to focus on this concern.

### ICRAT-II

Thanks in part to the encouragement of last year's participants and the support of various organizations, such as the Paralyzed Veterans of America (FVA) which has helped financially sponsor the event; plans are well underway for ICRRT II. This will again be held at the Universit / of North Dakota on October 22-24; .... Approximately two dozen professional papers and audiovisual presentations covering a wide array of rural rehab te-h topics have been accepted. In addition, four major panels have been invited to consider conference themes including: rural hospital roles in rehabilitation; international rehab tech; ag-rehab information networking; and rural rehabilitation technology resources. Panelists include key professionals and major organizations from across the country in each of the selected areas. Registration pachets for the conference will be sent out shortly to nearly 10,000 individuals and organizations who have been added to the ICRRT





mailing lists since the beginning of this effort around the world. ICRRT II has been a dorsed by a number of organizations and the Huhabilitation Engineering Society of North America (RESNA) has sanctioned it as the of its special interest groups (SIG) on "rural rehations functions. RRTD

Since the initiation of ICART; we have also had the opportunity to begin a related and exciting project with the support of the Otto Bremer Foundation of St. Paul, MN. Known as the "Rural Rehabilitation Technologies Database" (RRTD) Project, we are in the process of gathering information for the first time ever on inventions, ideas, and innovations which can benefit people with disabilities in rural areas. Although various catalogues and directories have been assoubled in recent years, including the excellent work by Alexandra Inders, Gregory L. Diron, the Veterans Administration, and others, no such listing specifically designed for those weedins and information in this country has been gathered to our 2. The resulting cathingue, which ought to be availkn. able ir earl, 1986, will appear in both print and diskette form for use by professionals and consumers alike. Thus a devic . which may only be in drawing form from an inventor in western Pennsylvania to modify a certain piece of farm machinery; could be shared with a VR Counselor or rehab angineer



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in Toxa: Likewise parents of a handicapped child in Puerto Rico might find out about an idea that has worked for an indegendent living center in Upstate New York.

We are any excited about the way in which the RRTD complimerts t. . ICERT offorts as a means of focusing attention on ople in rural areas for techthe special needs of disabl eloped simply does not work nology. Some of what has b in rural settings, while some \_\_quires modification. The classic example involves an electric wheelchair which beautifully permits the young quadraplegic to move about a medical center, attend some schools; and work in some businesses...in orban settings. Often in fural areas, nowever, this same young person is faced with the need to modify this technolog, to function on a farm or in a small town without paved street perhaps hundreds of miles from needer tepair/replacement resources. The response which we have received thusfar to our efforts in both the database and conference activities suggest that there is considerable interest in this area to the in this country and around the world.

# TECHNOLOGICAL ENHANCEMENT

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national efforts to develop selected technologies for specific populations is far more organized than our methods for sharing information about that whic reen developed. What seems to be needed are in the and more stards to help spread information about activities, organizations, devices, data banks, and resources in general in this area.

Both professionals and consumers are the prime autiences that need to be targeted for such information systems. A addition, we have found that government officials, manufacturers, educators, and numerous other groups in our society could benefit considerably by knowing more about what is taking place in these areas:

There is a tendency to view .ehabilitation technology today as primarily confined to the use of computers by the severely disabled. While this is a very exciting area of development, and the subject of numerous conferences, newsletters, and commercial ventures, we feel that this is only a small aspect of technological enhancement taking place in America and throughout the world at this time. We have been impraced, for instance, with the numbers of individuals and organizations working in the area of "low technology": This is loosely defined as the development and use of devices; techniques; resources, and information which is generally free or readily available to disabled individuals and those conterned about them. There is a wealth of efficient, low-cost hids and



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equipment being sevised to assist disabled persons with a variety of task.. The use of these inexpensive aids to enhance daily living and related activities by disabled people is an exciting and productive area for further exploration. We are pleased to see the recognition of this type of need as evidenced by the recent listing of such a knowledge dissemination and utilization project among the NIME funding priorities for fiscal year 1985.

In that professionals, like the disabled individuals whom they attempt to serve, tend to function in isolation in ural creas, is necessary to find ways to bring them togo or. We feel that ways need to be found to permit those who are concerned with this topic to communicate their internand accomplishments on a regular basis. Certainly confer newsletters; and other techniques are valuable actively in this area: The need for networking and collaborative efforts in general are perhaps recognized as of greater importance in rural areas than in any aspect of our society.

A great deal of effort has already been expended through the development of ICRRT and the RRTD in identifying individuals and organizations who have a commitment or responsibility in the area of rural rehabilitation technology. This work needs to be continued and expanded upon in the future. One transitional step which we would like to develop is the launching of a communication network in this area. An initial part





of this network would be the operation of an electronic bulletin board for the sharing of messages to and from parties interested in this aspect of rehabilitation technology. Such an information "Center" would begin to help focus interest in this field. Eventually an ongoing "Center" which would carry out information dissemination; research and development training, and service delivery activities would seem desirable. The intent would not be o duplicate the work of existing programs or organizations but to draw attention to their best achievements in areas important to lisabled individuals in rural areas, such as employment; and those concerned with them. Such groups might particularly include vocational rehabilitation counselors, Department of Agriculture extension agents; teachers; and others throughout rural America.

In addition to the organizations and individuals already mentioned as involved in rural rehabilitation technology, a number of others could also be bitch. Include' mere would be support which we have directly received from the American Association for the Advancement of Science (Advancement for the American Hospital Association (AHA) with their concern for the continued development of ICRF and related efforts. Bill Field of Purdue and a colleague of his Roger Tormoehlen, who is now at the University of Wisconsin, are also doing very interesting work concerning disabled farmers and their needs in particular. The mobile rehabilitation engined of the recently started up



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through the efforts of the Virginia Department of Rehabilitative Services and KC drow Wilson Rehabilitation Center, involving DRS Commissioner Altamount Dickerson Jr. and David Law, is an imaginative response to rural needs 5. She part of the country. Our of A CARES Project which has operated in rural western North Dakota to develop multidisciplinary rehabilitation services "closer to home" is still another example of an effective and innovative rural-oriented rehabilitation activity. Such a listing of model programs is growing steadily. It is only recently; however; that these efforts have begun to attract the recognition they require to be shared and c entually imitated in other rural settings.

### CONCLUSION

There is no question that technology in part Holds the key to unlock many of the doors preventing disabled individuals from full participation in American Society. It is our contention that there seem to be more doors for the diabled in rural areas and less keys than for their urban counterparts. We need to find ways to more effectively share the information currently being generated; particularly to those who live and labor in rural isolation. We have attempted to identify both some of the unique challenges confronting those involved in rural ... abilitation technology; as well as highlighting some of the resources being developed in this area. We would hope that the Subcommittee in its consideration of the Rehabilitation Act of



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1973 mi it pay special attention to the needs of the nearly 9 million Americans with disabilities living in rural settings: Our own efforts in this area of technology development a d information dissemination demonstrates that much can be done and much remains to be accomplished. Recognition of this challen e and the accomplishment to date by this Subcommittee, and in turn by the Federal government, would be a significant step toward addressing some of the key issues concerning rural rehabilitation technology.

> --Don V. Mathsen, P.E. Director Engineering Experiment Station School of Engineering & Mines Charles M. Page, Ph.D. Director Office of Clinic.1 Development Medical Center Rehabilitation Hospital University of North Dakota Grand Forks; North Dakota June 23: 305



[Whereupon, at 12:23 p.m., the subcommittee was adjourned, to reconvene subject to the call of the Chair.]



# REAUTHORIZATION OF THE REHABILITATION ACT OF 1973

## WEDNESDAY, 'ULY 17, 1985

## HOUSE OF REPRESENTATIVES, SUBCOMMITTEE ON SELECT EDUCATION, COMMITTEE ON EDUCATION AND LABOR, Washington, DC.

The subcommittee met, pursuant to call, at 9:30 a.m., in room 2257, Rayburn House Office Building, Hon. Pat Williams (chairman of the subcommittee) presiding.

Members present: Representatives Williams, Martinez, and Bartlett.

Staff present: S. Gray Garwood, staff director; Celinda Lake, majority legislative associate; Colleen Thompson, clerk, and Pat Morrissey, minority senior legislative associate.

Mr. WILLIAMS. Today we will be focusing on the issues of training and technical assistance in this meeting of the Subcommittee on Select Education.

We hope to hear a broad range of porspectives today. Witnesses will represent the Federal agencies, State agencies, and private providers of services, counselors, and programs which train counselors.

In the most recent amendments to the Rehabilitation Act, the Congress reaffirmed its commitment to training and stated our sense of its increasing importance as rehabilitation services have become more technologically sophisticated and the disabled population more diverse.

The need for training and the technical assistance which supplements training has also grown with our commitment to serve the more severely disabled. Obvicusly, the first issue in training is the availability of qualified personnel which comes with their expertise from the education community.

We have explored in the past certification for counselors, and expressed our desire to have qualified persons hired at all levels of the relability tion system. Once counselors are hired, we are concerned with in-service training to keep them abreast of rapid changes occurring in the rehabilitation area and any shifts in priorities which may come as programs evolve.

Even with good and continued training, certain expertise may not exist at the Stote or even the regional level, so we are interested in what needs exist and provision made for consulting outside experts. We will hear today from witnesses who are involved in each of these area:





The Congress also recognized the need for special training in independent living, client assistance, and section 504 and the amendments that we enacted 2 years ago. We will be interested to know how that is progressing.

In previous hearings we have heard of the importance of developing further independent living services and incorporating the orientation of rehabilitation engineering, which will make even more independence possible for many disabled clients. We are interested in what training and technical as istance initiatives need to be taken to meet these goals.

The Congress has also requested an annual survey of shortages which should be addressed with training. We would request that that report be presented as soon as possible. We would be interested to hear today of any initial findings which might be available us.

Importantly, the rehabilitation property orimarily concerned with providing services to clients. Apply matches we have been concerned with spending the limited ready we have directly for disabled persons. However, we have all spinzed that cuts in training and technical assistance can be false economies which often dramatically diminish the quality and quantity of the services actually movided.

an \* Federal Government; the States and private providers, w contributing at the appropriate level. By their nature, tr. and technical assistance may be uniquely part of the Federa isibility.

Thuss are the issues we will be exploring today and throughout the reauthorization process. And, of course, we look forward to hearing the witnesses' views on those questions.

My colleague Mr. Bartlett.

Mr. BARTLETT. Thank you, Mr. Chairman, and I welcome this additional hearing on the reauthorization of the Rehabilitation Act.

I have said in the past, and will repeat again today, I am especially appreciative to Chairman Williams for the extended hearings that we are holding on the Rehabilitation Act this year.

I believe the Rehabilitation Act is one of the real success stories of the Federal Government over the past several decades. But the world is moving so fast for the disabled particularly with improving technology, that I think that it is critical that Congress have these extended reauthorization hearings to consider ways to improve the Tehabilitation Act.

I considered the two previous hearings on the act—one on Federal/State relations and the second on technology and employment to be very informative. It is my understanding that this hearing will focus on Federal support for rehabilitation personnel training and Federal technical assistance to State rehabilitation agencies. I commend the chairman for examining each of the sections of the act.

Now, I am particularly interested in information which will help us promote and ensure employment opportunities and independent living for persons with disabilities.

Advances in technologies play an important role in that effect. Equally important will be the training and continuing education



provided to rehabilitation personnel and the leadership and cooperation exhibited by rehabilitation professionals in Government in the private sector and on the frontline. Rehabilitation training programs are a 1 100 to e success.

I would here witnesses would address everal of the following spech in their testimony.

First, in terms of an overview, it is of special interest to me, and I think to members of this subcommittee and the Congress as a whole, to attempt to assess the impact that rehabilitation programs and rehabilitation training have on the overall deficit reduction. That is to say, rather than be constrained by the limited resources which we all know exists in the Federal budget. I repe that we consider ways to expand those resources by used the cost savings of persons who otherwise had been unamplement because employed and moving toward independent living.

Specifically on training, I would look for information on trainee exposure to job markets and the potential availability to the disabled; the extent of course work devoted to job development, job placement, and job site accommodation to see if that is adequate or sufficient; skill development and coordinating resources as well as allocating resources, and trainee exposure to, and involvement with, the needs of SSI and SSDI recipients:

I am particularly interested to see whether we have a coordination between the recipients of SSI and SSDI in training for rehabilitation.

In addition, I am interested in the cope and the focus of Federal technical assistance. I am aware of the transition in supported work initiatives of the Office of Special Education and Rehabilitative Services, and I welcome more information on the progress of that. These initiatives have highlighted the need for coordinated support systems that must be in place before a disabled person can benefit from employ: nt.

Such a need raises several policy questions in technical assistance requirements, and thus I would appreciate from the Secretary examples and illustrations of how\_OSERS and State agencies are working together to answer these questions and respond to technical assistance needs.

In particular, it is terribly good to see again this morning the ablest and brightest Assistant Secretary in the entire Federal Government, Assistant Secretary Madeleine Will—perhaps in the entirety of all federal governments of the world or the universe—the able Madeleine Will.

Mrs. WILL. Thank you.

Mr. WILLIAMS. Thank you very much.

We are pleased now to hear from the Assistant Secretary, Madeleine Will.

Ms. Will, it is nice to have you with us again, and we look forward to your testimony.



## STATEMENT OF MADELEINE WILL, ASSISTANT SECRETARY, OFFICE OF SPECIAL EDUCATION AND REHABILITATIVE SERV-ICES, DEPARTMENT OF EDUCATION

Mrs. WILL. Thank you, Mr. Chairman. I thank you for the opportunity to appear again before the subcommittee to provide testimony on the Rehabilitation Act.

You have ssked for information about the preservice and inservice training of rehabilitation personnel, and the planning and delivery of this training, and about RSA's role in developing meaningful postemployment services.

You also asked about the specifics of RSA's provision of technical assistance. This is a broad range of subjects and I shall briefly discuss each of them in turn.

I would like first to speak about the training of rehabilitation personnel.

RSA has historically supported a broad range of training programs designed to increase the number of personnel skilled in providing rehabilitation services to disabled individuals, and to improve the quality of professional practice in providing these services.

This range of training programs includes support for long-term training in a wide variety of rehabilitation professional fields: Experimental and innovative training to prepare new types of rehabilitation professionals; inservice training and continuing education for State vocational rehabilitation agency employees; training cf interpreters for deaf -resons and training for rehabilitation personnel in other agenci such as rehabilitation facilities, who work closely with State agencies.

- The Rehabilitation Services Administration currently supports preservice and inservice training in rehabilitation professional fields and programmeras including medicine and dentistry, counseling, prosthetice and orthoptics, administration, vocational evaluation and work djustment, nursing, physical and occupational therapy, independent living, speech-language pathology and audiology, rehabilitation of the blind, the deaf, and the mentally ill, job development and ob placement, and undergraduate education in the rehabilitation services.

The Rehabilitation Amendments of 1984 require RSA to move away from a talanced program of training which had been conducted in the past, and to begin directing training funds to areas of demonstrated personnel shortage.

RSA approached this change by reviewing currently available rehabilitation personnel supply and demand data. This review led us to conclude that adequate data and information are not currently available to permit the identification of personnel shortages in a consistent manner.

In addition, information is also scarce with respect to how specific training strategies would have an impact on particular shortage areas. For example, it is not clear that long-term training in degree programs is the most effective methods to reduce shortages of rehabilitation counselors.

To develop the information base necessary to target funds for training grants to areas of personnel shortages, RSA has contract-



ed for a study by Advanced Technology of Reston, VA. At the conclusion of this study in January 1986, RSA will be provided with a system design for collecting for estimating shortages of rehabilitation personnel and for making fund allocation decisions.

Based on that data, RSA can then begin to collect the information which will be submitted to Congress in subsequent annual budget requests.

in addition to the allocation issue, the curriculum content of training programs is a continuing concern. For instance, we are looking at counselor training programs to determine if improved course content on placement techniques is needed.

The purpose of the RSA training program cannot be achieved without considering curriculum content issues along with chortage issues. We plan to address curriculum issues through research and development, and through the use of annual funding priorities for training grants.

With respect to the training of rehabilitation professionals, there is one other area I should mention. When most people think of training under the Rehab Act, they think about the \$22 million program administered by RSA.

In addition, more than 80,000 individuals are trained annually under various programs of the National Institute of Handicapped Research [11]HR]. This training is short-term and usually provided through reasonch and training centers and rehabilitation engineering centers

These programs provide training, including graduate training to

o rehabilitation professionals more effectively provide rehabilion services, and provide training for rehabilitation research

sonnel.

The characteristics of NIHR's training activities are research based. Emphasis is placed on using training as a vehicle for translating research into practice. They are highly focused. Training provided by centers stresses specific techniques, methods and procedures rather than broad professional development.

Let me now move on to the top: of postemployment services. The Rehabilitation Act authorizes the provision of followup, follow-along, and other postemployment services. Since the law makes no conceptual or definitional distinctions between these terms, postemployment services has have me the inclusive term for all vocational rehabilitation services p. ovided after clients have been determined to be rehabilitated and their case records have been closed.

Some typical postemployment services are worksite modification, arrangement of job-related transportation, and other assistance through referrals to other service agencies.

From 1978 to 1982, some 3.7 to 4.8 percent of the persons rehabilitated received some form of postemployment service. Over the same over period, some 63 to 70 percent of these receiving postemployment services were considered severely disabled.

In actual numbers, there 9,000 persons receiving postemployment services in 1983. The latest available case cost data sho, an average case expenditure of \$425 for postemployment in 1982.

The shift in attention toward more severcly disabled individuals has focused interest in the area of postemployment services.



Historically, rehabilitation agencies served individuals who had adequate job skills prior to an incapacitating event. The function of rehabilitation was to make it possible for such individuals to rejoin the work force. Once a job was found and maintained for a 90-day period, it was assumed that the person could continue with little or no additional help, and generally this was the case.

However, more severely disabled people, particularly those with no prior work experience, often need additional help over longer periods of time. Some of the most severely disabled will, in fact, need supportive services over their lifetime to maintain employment.

An example of such long-term support would be the job coaches needed to assist severely disabled individuals at the worksite, which can be found in a supported employment project within an electronics firm in Seattle.

The RSA supported work initiative squarely addresses this issue of long-term support services for the severely disabled. Under our RSA supported employment demonstration program, we are asking States to use existing resources such as those now being used to support day activit, or work activity programs for supported employment program.

Specifically, we are asking States to use these funds to provide long-term post-empiryment servi as that severely disabled persons will need in order to maintain employment over a lifetime.

I give this background on the supported employment program because I want to make it clear that the vocational rehabilitation program, as currently authorized, should not be looked upon to provide all the services needed over a disabled individual's entire working life.

Shared responsibilities and contributions from other Federal, State and local agencies are essential in order to avoid these longterm costs that would lim'. the State vocational rehabilitation agency's ability to serve as many disabled persons as possible.

I would like to speak briefly now about our views on the provision of technical assistance.

We provide technical assistance under the Rehabilitation Act in a variety of ways. RSA is directly responsible for providing technical assistance to recipients regarding the application of Federal laws and regulations. This technical assistance may have been quested by a State agency or grantee to clarify a particular issue or situation, or it may result from program monitoring or an audit where possible problems or deficiencies have been identified and technical assistance is needed to ensure compliance with the law.

RSA also provides technical assistance to help States or other grantees or potential grantees develop programs and services in priority areas such as transition from school to work. Both the RSA central and regional office staffs provide technical essistance; however, the regional offices clearly have the major role in work on a day-to-day basis with States and other grantees.

For example, the RSA regional office in Denver worked with the independent living program in one State to improve financial management, and increase the extent and scope of services to severely disabled persons.



Regional offices have also been providing technical assistance in the development of transition programs. In one State, RSA regional office staff met several times with special ed and vocational rehabilitation directors and members of a State committee established to coordinate services. This technical assistance effort contributed to the establishment of linkages between VR and special clucation which will result in timely and appropriate referrals of disabled youth to VR service providers.

According to a survey of RSA regional offices, onsite monitoring and technical assistance for the basic State grant program has already been provided 246 times in fiscal year 1985 with a total of 289 visits planned for the year.

Onsite monitoring and technical assistance has been provided 158 times in fiscal year 1985 in conjunction with discretionary grant activities, and a total of 198 visits are planned.

In addition, there have been literally thousands of the phone calls, teleconferences, letters, meetings, conferences, and similar technical assistance activities not involving travel to a project site.

It should also be pointed out that technical assistance has been provided by RSA through programs which provide and encourage technical assistance to States and communities in a number of indirect ways. For example, a project with industry program in Seattle played a significant role in the provision of technical assistance to Washington State with the result that the State changed many of its policies and procedures to allow for the development of several new PWI-like programs receiving State support.

We do not always hear about these instances directly, but it is clear that the people trained and employed through our discretionary programs can and do provide much useful assistance to States and other service providers.

Thank you for the opportunity to describe our activities in these areas. I would be happy to answer any questions.

Mr. WILLIAMS. Thank you, Mrs. Will.

[The prepared statement of Madeleine Will follows:]

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PREPARED STATEMENT OF MADELEINE C. WILL, ASSISTANT SECRETARY FOR SPECIAL EDUCATION AND REHABILITATIVE SERVICES, U.S. DEPARTMENT OF EDUCATION MR. CHAIRMAN AND MEMBERS OF THE SUBCOMMITTEE:

THANK YOU FOR THE OPPORTUNITY TO APPEAR AGAIN BEFORE THE SUBCOMMITTEE TO PROVIDE TESTIMONY (N THE REHABILITATION ACT. YOU HAVE ASKED FOR INFORMATION ABOUT PRE-SERVICE AND IN-SERVICE TRAINING OF REHABILITATION PERSONNEL AND THE PLANNING AND DELIVERY OF THIS TRAINING, AND ABOUT RSA'S ROLE IN DEVELOPING MEANINGFUL POST-EMPLOYMENT SERVICES. YOU ALSO ASKED ABOUT THE SPECIFICS OF RSA'S PROVISION OF TECHNICAL ASSISTANCE. THIS IS A BEOAD RANGE OF SUBJECTS AND I SHALL BRIEFLY DISCUSS EACH OF THEM IN TURN. I WOULD LIKE FIRST TO SPEAK ABOUT THE TRAINING OF REHABILITATION PERSONNEL.

THE REHABILITATION SERVICES ADMINISTRATION (RSA) HAS HISTORICALLY SUFPORTED A BROAD RANCE OF TRAINING PROGRAMS DESIGNED TO INCREASE THE NUMBER OF PERSONNEL SKILLED IN PROVIDING REHABILITATION SERVICES TO DISABLED INDIVIDUALS, AND TO IMPROVE THE QUALITY OF PROFESSIONAL PRACTICE IN PROVIDING THESE SERVICES. THIS RANCE OF TRAINING PROGRAMS INCLUDES SUPPORT FOR LONG-TERM TRAINING IN A WIDE VARIETY OF REHABILITATION PROFESSIONAL FIELDS, EXPERIMENTAL AND INNOVATIVE TRAINING TO PREPARE NEW TYPES OF REHABILITATION PROFESSIONALS, IN-SERVICE TRAINING AND CONTINUING EDUCATION FOR STATE VOCATIONAL REHABILITATION AGENCY EMPLOYEES, TRAINING OF INTERPRETERS FOR DEAF PERSONS AND TRAINING FOR REHABILITATION PERSONNEL IN OTHER AGENCIES, SUCH AS REHABILITATION FACILITIES, WHO WORK CLOSELY WITH STATE AGENCIES.

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THE REHABILITATION SERVICES ADMINISTRATION CURRENTLY SUPPORTS PRE-SERVICE AND IN-SERVICE TRAINING IN REHABILITATION PROFESSIONAL FIELDS AND PROGRAM AREAS INCLUDING

MEDICINE AND DENTISTRY, COUNSELING; PROSTHETICS AND ORTHOTICS, ADMINISTRATION, VOCATIONAL EVALUATION AND WORK ADJUSTMENT, NURSING; PHYSICAL AND OCCUPATIONAL THERAPY, INDEPENDENT LIVING, SPEECH-LANGUAGE PATHOLOGY AND AUDIOLOGY; REHABILITATION OF THE BLIND; THE DEAF, AND THE MENTALLY ILL, JOE DEVELOP.ENT AND JOB FLACEMENT, AND UNDERGRADUATE EDUCATION IN THE REHABILITATION SERVICES.

THE REHABILITATION AMENDMENTS OF 1984 REQUIRE ESA TO HOVE AWAY FROM A BALANCED PROGRAM OF TRAINING WHICH HAD BEEN CONDUCTED IN THE PAST AND TO BEGIN DIRECTING TRAINING FUNDS TO AREAS OF DEMONSTRATED PERSONNEL SHORTAGE. RSA APPROACHED THIS CHANCE BY REVIEWING CURRENTLY-AVAILABLE REHABILITATION PERSONNEL SUPPLY AND DEMAND DATA. THIS REVIEW LED US TO CONCLUDE THAT ADEQUATE DATA AND INFORMATION ARE NOT CURRENTLY AVAILABLE TO PERMIT THE IDENTIFICATION OF PERSONNEL SHORTAGES IN A CONSISTENT MANNER. IN ADDITION, INFORMATION IS ALSO SCARCE WITH RESPECT TO HOW SPECIFIC TRAINING STRATEGIES WOULD HAVE AN IMPACT





ON PARTICULAR SHORTAGE AREAS. FOR EXAMPLE, IT IS NOT CLEAR THAT CONG-TERM TRAINING IN DEGREE PROGRAMS IS THE MOST EFFECTIVE METHOD TO REDUCE SHORTAGES OF REHABILITATION COUNSELORS.

TO DEVELOP THE INFORMATION BASE NECESSARY TO TARGET FUNDS FOR TRAINING GRANIS TO AREAS OF PERSONNEL SHORTAGES, RSA HAS CONTRACTED FOR A STUDY BY ADVANCED TECHNOLOGY, INC., OF RESTON, VIRGINIA. AT THE CONCLUSION OF THE STUDY, IP. JANUARY OF 1986, RSA WILL BE PROVIDED WITH A SYSTEM DESIGN FOR COLLECTING DATA FOR ESTIMATING SHORTAGES OF REHABILITATION PERSONNEL AND FOR MAKING FUND ALLOCATION DECISIONS. BASED UPON THAT DATA, RSA CAN THEN BEGIN TO COLLECT THE INFORMATION WHICH WILL BE SUBMITTED TO CONGRESS IN SUBSEQUENT ANNUAL BUDGET REQUESTS.

IN ADDITION TO THE ALLOCATION ISSUE, THE CURRICULUM CONTENT OF TRAINING PROGRAMS IS A CONTINUING CONCERN. FOR INSTANCE, WE ARE LOOKING AT COUNSELOR TRAINING PROGRAMS TO DETERMINE IF IMPROVED COURSE CONTENT ON PLACEMENT TECHNIQUES IS NEEDED. THE FURPOSE OF THE RSA TRAINING PROGRAM CANNOT BE ACHIEVED WITHOUT CONSIDERING CURRICULUM CONTENT ISSUES ALONG WITH SHORIAGE ISSUES. WE PLAN TO ADDRRISS CURRICULUM ISSUES THROUGH RESEARCH AND DEVELOPMENT AND THROUGH THE USE OF ANNUAL FUNDING PRIORITIES FOR TRAINING GRAMTS.

WITH RESPECT TO THE TRAINING OF REHABILITATION PROFESSIONALS, THERE IS ONE OTHER AREA I SHOULD MENTION. WHEN MOST PEOPLE THINK OF TRAINING UNDER THE REHABILITATION ACT, THEY THINK ABOUT THE \$22-MILLION-DOLLAR TRAINING PROGRAM ADMINISTERED BY RSA. IN ADDITION, MORE THAN 80,000 INDIVIDUALS ARE TRAINED



ANNUALLY UNDER VARIOUS PROGRAMS OF THE NATIONAL INSTITUTE OF HANDICAPPED RESEARCH (NIHR). THIS TRAINING IS SHORT-TERM AND USUACLY PROVIDED THROUGH RESEARCH AND TRAINING CENTERS AND REHABILITATION ENGINEERING CENTERS. THESE PROGRAMS: (1) PROVIDE TRAINING (INCLUDING GRADUATE TRAINING) TO HELP REHABILITATION PROFESSIONALS MORE EFFECTIVELY PROVIDE REHABILITATION SERVICES; AND (2) PROVIDE TRAINING FOR REHABILITATION RESEARCH PERSONNEL.

THE CHARACTERISTICS OF NIHR'S TRAINING ACTIVITIES ARE:

1. THEY ARE RESEARCH BASED: EMPHASIS IS PLACED ON USING TPAINING AS A VEHICLE FOR TRANSLATING RESEARCH INTO PRACTICE; AND

2. THEY ARE HIGHLY FOCUSED. TRAINING PROVIDED BY CENTERS STRESSES SPECIFIC TECHNIQUES, METHODS AND PROCEDURES RATHER THAN BROAD PROFESSIONAL DEVELOPMENT.

LET ME NOW MOVE ON TO THE TOPIC OF POST-EMPLOYMENT SERVICES. THE REHABILITATION ACT AUTHORIZES THE PROVISION OF FOLLOW-UP, FOLLOW-ALONG, AND OTHER FOST-EMPLOYMENT SERVICES. SINCE THE LAW MAKES NO CONCEPTUAL OR DEFINITIONAL DISTINCTIONS BETWEEN THESE TERMS; "POST-EMPLOYMENT SERVICES" HAS BECOME THE INCLUSIVE TERM FOR ALL VOCATIONAL REHABILITATION SERVICES PROVIDED AFTER CLIENTS HAVE BEEN DETERMINED TO BE REHABILITATED AND THEIR CASE RECORDS HAVE BEEN CLOSED. SOME TYPICAL POST-EMPLOYMENT SERVICES ARE WORKSITE MODIFICATION, ARRANGEMENT OF JOB-RELATED TRANSPORTATION, AND OTHER ASSISTANCE THROUGH REFERRALS TO OTHER SERVICE AGENCIES.



FROM 1978 TO 1982, FROM 3.7 PERCENT TO 4.8 PERCENT OF THE PERSONS REHABILITATED RECEIVED SOME FORM OF PUST-EMPLOYMENT SERVICE. OVER THIS SAME FIVE-YEAR PERIOD, PROM 63.6 PERCENT TO 70.7 PERCENT OF THOSE RECEIVING POST-EMPLOYMENT SERVICES WERE CONSIDERED SEVERELY DISABLED. IN ACTUAL NUMBERS, THERE WERE 9,274 PERSONS RECEIVING POST-EMPLOYMENT SERVICES IN 1983. THE LATEST AVAILABLE CASE COST DATA SHOW AN AVERAGE CASE EXPENDITURE OF \$425 FOR PUST-EMPLOYMENT SERVICES IN 1982.

THE SEITT IN ATTENTION YOWARD MORE SEVERELY DISABLED INDIVIDUALS HAS POCUSED INTEREST IN THE AREA OF POST-EMPLOYMENT SERVICES. HISTORICALLY, REHABILITATION AGENCIES SERVED INDIVIDUALS THE HAD ADEQUATE JOB SKILLS PRIOR TO AN INCAPACITATING EVENT. THE FUNCTION OF REHABILITATION WAS TO MAKE IT POSSIBLE FOR SUCH INDIVIDUALS TO RE-JOIN THE WORK FORCE. CACE A JOB WAS FOUND AND MAINTAINED FOR A 90-DAY PERIOD, IT WAS ASSUMED THAT THE PERSON COULD CONTINUE WITH LITILE OR FO ADDITIONAL HELP, AND GENERALLY THIS WAS THE CASE. HOWEVER, MORE SEVERELY DISABLED PEOPLE, PARTICULARLY THOSE WITH NO PRIOR WORK EXPERIENCE, OFTEN NEED ADDITIONAL HELP OVER LONGER PERIODS OF TIME. SOME OF THE MOST SEVERELY DISABLED WILL, IN FACT, MEED SUPPORTIVE SERVICES OVER THEIR LIFETIME TO MAINTAIN EMPLOYNINT. AN EXAMPLE OF SUCH LONG-TERM SUPPORT WOULD BE THE JOB COACHES NEEDED TO ASSIST SEVERELY D'SABLED INDIVIDUALS AT THE WORKSITE, WHICH CAN BE FOUND IN A SUPPORTED EMPLOYMENT PROJECT WITHIN AN ELECTRONICS FIRM IN SEATTLE.

THE ESA SUPPORTED WORK INITIATIVE SQUARELY ADDRESSES THIS ISSUE OF LONG-TERM SUPPORT SERVICES FOR THE SEVERELY DISABLED. UNDER OUR RSA SUPPORTED EMPLOYMENT DEMONSTRATION PROGRAM WE ARE ASKING STATES TO USE EXISTING RESOURCES, SUCE AS

THOSE NOW BEING USED TO SUPPORT DAY ACTIVITY OR WORK ACTIVITY PROGRAMS, FOR SUPPORTED EMPLOYMENT PROGRAMS. SPECIFICALLY, WE APE ASKING STATES TO USE THESE FUNDS TO PROVIDE LONG-TERM POST-EMPLOYMENT SERVICES THAT SEVERELY DISABLED PERSONS WILL NEED IN ORDER TO MAINIAIN EMPLOYMENT OVER A LIFETIME.

I GIVE THIS BACKGROUND ON THE SUPPORTED EMPLOYMENT PROGRAM BECAUSE I WANT TO MAKE IT CLEAR THAT THE VOCATIONAL REHABILITATION PROGRAM, AS CURRENTLY AUTHORIZED, SHOULD NOT BE LOOKED UPON TO PROVIDE ALL THE SERVICES NEEDED OVER A DISABLED INDIVIDUAL'S ENTIRE WORKING LIFE. CHARED RESPONSIBILITIES AND CONTRIBUTIONS FROM OTHER FEDERAL, STATE AND LOCAL AGENCIES ARE ESSENTIAL IN ORDER TO AVOID THESE LONG-TERM COSTS THAT WOULD LIMIT THE STATE VOCATIONAL REHABILITATION AGENCY'S ABILITY TO SERVE AS MANY DISABLED PERSONS AS POSSIBLE.

I WOULD LIKE TO SPEAK BRIEFLY NOW ABOUT OUR VIEWS ON THE PROVISION OF TECHNICAL ASSISTANCE.

WE PROVIDE TECHNICAL ASSISTANCE UNDER THE REGABILITATION ACT IN A VARIETY OF WAYS. ESA IS DIRECTLY RESPONSIBLE FOR PROVIDING TECHNICAL ASSISTANCE TO RECIPIENTS REGARDING THE APPLICATION OF PEDERAL LATS AND REGULATIONS. THIS TECHNICAL ASSISTANCE MAY HAVE BEEN REQUESTED BY A STATE AGENCY OF GRANTEE TO CLARIFY A PARTICULAR ISSUE OF SITUATION; OF IT MAY RESULT FROM PEOGRAM MONITCRING OR AN AUDIT WHERE POSSIBLE PROBLEMS OF DEFICIENCIES HAVE BEEN IDENTIFIED AND TECHNICAL ASSISTANCE IS NEEDED TO ENSURE COMPLIANCE WITH THE LAW. ESA ALSO PROVIDES TECHNICAL ASSISTANCE TO HELP STATES OF OTHER GRANTEES OF POTENTIAL GRANTEES DEVELOP PROGRAMS AND SERVICES IN PRIORITY AREAS SUCH AS TRANSITION FROM SCHOOL TO WORK. BOTH THE REA CENTRAL AND REGIONAL OFFICE

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STAFFS PROVIDE TECHNICAL ASSI TANCE; HOWEVER, THE REGIONAL OFFICES CLEARLY HAVE THE MAJOR ROLE AND WORK ON A DAY-TO-DAY BASIS WITH STATES AND OTHER GRANTEES:

FOR LXAMPLE, THE RSA REGIONAL OFFICE IN DENVER WORKED WITH THE INDEPENDENT LIVING PROGRAM IN ONE STATE TO IMPROVE PINANCIAL MANAGEMENT AND INCREASE THE EXTENT AND SCOPE OF SERVICES TO SEVERELY DISABLED PERSONS. REGIONAL OFFICES HAVE ALSO BEEN PROVIDING TECHNICAL ASSISTANCE IN THE DEVELOPMENT OF TRANSITION PROGRAMS. IN ONE STATE, RSA REGIONAL OFFICE STAFF MET SEVERAL TIMES WITH SPECIAL EDUCATION AND VOCATIONAL REHABILITATION (VR) DIRECTORS AND MEMBERS OF A STATE STEERING COMMITTEE ESTABLISHED TO COORDINATE SERVICES. THIS TECHNICAL ASSISTANCE EFFORT CONTRIBUTED TO THE ESTABLISHENT OF LINKAGES BETWEEN VR AND SPECIAL EDUCATION WHICH WILL RESULT IN TIMELY AND APPROPRIATE REFERRALS OF DISABLED YOUTH TO VR SERVICE PROVIDERS.

ACCORDING TO A SURVEY OF RSA REGIONAL OFFICES, ON-SITE MONITORING AND TECHNICAL ASSISTANCE FOR THE EASIC STATE PROGRAM HAS ALREADY BEEN PROVIDED 246 TIMES IN FISCAL YEAR 1985 WITH A TOTAL OF 289 VISITS FLARMED FOR THE YEAR. ON-SITE MONITORING AND TECHNICAL ASSISTANCE HAS BEEN PROVIDED 158 TIMES IN FISCAL YEAR 1985 IN CONJUNCTION WITH DISCRETIONARY GRANT ACTIVITIES, AND A TOTAL OF 198 VISITS IS PLANNED. IN ADDITION, THERE HAVE BEEN LITERALLY THOUSANDS OF TELEPHONE CALLS, 1ELECONFERENCES, LETTERS, MEETINGS, CONFERENCES, AND SIMILAR TECHNICAL ASSISTANCE ACTIVITIES NOT INVOLVING TRAVEL TO A PROJECT SITE.

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IF SHOULD ALSO BE POINTED OUT THAT TECHNICAL ASSISTANCE HAS BEEN PROVIDED BY RSA THROUCH PROGRAMS WHICH PROVIDE AND ENCOURAGE TECHNICAL ASSISTANCE TO STATES AND COMMUNITIES IN A NUMBER OF INDIRECT WAYS. FOR EXAMPLE, A PROJECTS WITH INDUSTRY PROGRAM IN SEATTLE PLAYED A SIGNIFICANT ROLE IN THE PROVISION OF TECHNICAL ASSISTANCE TO WASHINGTON STATE WITH THE RESULT THAT THE STATE CHANGED NANY OF ITS POLICIES AND PROCEDURES TO ALLOW FOR THE DEVELOPMENT OF SEVERAL NEW PWI-LIKE FROGRAMS RECEIVING STATE SUPPORT. WE DO NOT ALWAYS HEAR ABOUT THESE INSTANCES DIRECTLY BUT IT IS CLEAR THAT THE PEOPLE TRAINED AND EMPLOYED THROUGH OUR DISCRETIONARY PROGRAMS CAN AND DO PROVIDE MUCH USEFUL ASSISTANCE TO STATES AND OTHER SERVICE PROVIDERS.

THANK YOU FOR THE OPPORTUNITY TO DESCRIBE OUR ACTIVITIES IN THESE AREAS. I

WOULD BE HAPPY TO ANSWER ANY QUESTIONS.

Mr. WILLIAMS. Mr. Bartlett.

Mr. BARTLETT. Thank you, Mr. Chairman.

Mis. Will, I have a number of questions on how it is working, and I suppose these will be open-ended questions. If I fail at the end of each question to ask you the followup question—which is, what, if any, ways would you suggest in terms of a general direction that we improve these areas—please consider that followup question to be a part of each of my questions.

I suppose my first question is, what specific kinds of technical assistance do you provide in the field of transition services and what are the results? And what improvements can you see?

Mrs. WILL. As you know, we have an extensive amount of funding in this area as a result of reauthorization. All three of the components of OSERS, Special Education, Rehabilitation Services Administration, and NIHR, play a role in the funding, monitoring and supervision of the transition projects.

This, in turn, will create a need for technical assistance as both the special education agencies and the rehabilitation agencies and facilities try to create the kind of strong link that we are looking for from school to work for young people.

We have identified some best practices, exemplary projects that we are able to discuss with individuals who are interested in knowing about how to develop transition services, the methodologies to use, the strategies to use.

This year, under the NIHR authority, we hope to fund a technical assistance—actually, two in this area. One, to kind of compile the information that is now developing and that is being yielded by the project; and the other to look more at questions that are really systems oriented, how does one do a comprehensive system of transition.

Mr. BARTLETT. Do you have any quantitative data on results?

Mrs. WILL. Most of our transition projects are in their second year, so we would have preliminary reports, summaries from our



projects. In terms of numbers of individuals they may be working with

Mr. BARTLETT. Numbers of individuals are anecdotal of descriptions from the field as to the results.

I would ask unanimous consent that the record be kept open.

If you could essentially provide us, as we go into reauthorization, with a snapshot as to where we are in those transition services. And do you have any sense of what can be done to improve transition services?

Mrs. WILL. We have many cooperative agreements between agencies at the State level that are being developed and implemented.

I find it very exciting to go to States and meet with a broad group of State agency directors, and listen to them as they grapple with problems of funding and resources and mechanisms. I think that is proceeding very nicely.

We have, on the part of rehabilitation, a very significant interest and response to the need for transition services with State agencies looking to place counselors in schools to actually work with young people, to identify them and to help in the development of vocational objectives.

[Questions and responses:]

#### Question: Will you provide this Subcommittee with a "snapshot" view of the state of transitional services; preliminary reports or anecdotes that you may have and what is needed in the area?

Answeri

Transition activities in OSERS are conducted under both the Rehabilitation and the Education of the Handicapped Acts. State vocational rehabilitation agencies are major contributors to the networks of services being developed at State and local levels to assist in the transition from school to work. Staff members of State VR agencies have been active participants in the ongoing efforts to plan and provide transition services. The RSA Regional offices have been conducting intensive program development activities to assist in the establishment and coordination of transition services and will continue to do so as these activities evolve.

The great majority of the directly-funded transition activities sup-ported by OSERS have been under the authority of the Education of the Handicapped Act (EHA).

The special education transition program under Section 626 of the EHA is entering its second year of support for research and demonstration projects. The purpose of t's program is to assist handicapped youth in the transition from school to postsecondary environments such as competitive or supported employment. This purpose is carried out through the provision of assistance to projects that:

- (1) Strengthen and coordinate education, training, and related services that assist handicapped youth in the transition to employment, postsecondary education, vocational training, continuing education, or adult services; and
- (2) Stimulate the improvement and development of programs for secondary special education.

During Fiscal Year 1984 the Department of Education funded 34 demonstration projects to develop and demonstrate solutions to specific problems related to this area. The demonstration projects emphasize the implementation of strategies to improve the ability of service providers to assist handicapped individuals to make the transition to adult and working life. In Fiscal Year 1985 we expect to fund an additional 18 cooperative planning projects.

In Fiscal Years 1984 and 1985, we will have supported 19 research projects to develop strategies and techniques for transition to independent living, vocational training, and postsecondary education. Additionally, we will be supporting two research institutes which will (1) conduct long-term programmatic research activities focused on handicapped students' development of skills needed for community living and working, and (2) determine the effectiveness of various model projects and explore the implications of the findings emerging from our various research efforts.

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The transitional services activities have been in operation for less than a year. In an attempt to provide a "snapshot" view of the state of transitional services I have selected a few of our projects to highlight progress made to date. I will also cite some of the needs or problem areas which the projects have been encountering.

#### Community Services for Autistic Adults and Children, Inc., Rockville, Maryland

This program is intended to assist autistic individuals; many of whom have been previously institutionalized; secure competitive employment in the community. There are currently 39 clients placed in community employment. Job coaches are utilized at the worksite to assist in training and behavior management. This support is gradually removed as the employee becomes more independent. Approximately 10 of the 39 are currently working independently with assistance available if problems arise.

#### Richmond Unified School District, Richmond, California

The Richmond Project is working with severely handicapped students who will be "aging out" of school programs within two years. Currently, eight students are involved in community-based training and employment: Utilizing the services of job coaches, the individuals are being trained in areas such as food services, electronic assembly, and copy machine operation. Four of the students have completed the training phase and are working full time, and the other four are in training with their job coaches. The project expects to be serving 40 students during the 1985-86 school year:

# International Association of Machinists and Aerospace Workers, Washington, D. C.

The Projects With Industry (PWI) Model is being utilized in this demonstration model which is being conducted in Chicage and Los Anyeles. In the combined sites, 127 mildly and moderately handicapped youths are involved in the training and employment phases of the project. In the first eight months of the project, 35 youths have been placed in competitive employment earning an average salary of \$7,500. The jobs include maintenance, assembly, maching operation, and utility and warehouse work.

#### Human Resources Center, Albertson, New York

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The Human Resources project is working with 14 school districts in Nassau County, New York to assist in transitional planning and job placement for moderately handicapped students. There are currently 45 physically handicapped students enrolled, and it is expected that 10 recent high school graduates will be placed in competitive employment after the completion of their intensive summer intern program. On-the-job training is being provided in a wide range of occupations including animal care, secretarial work, repetitive assembly, and hospital housekeeping.



#### Dallas Independent School District, Dallas, Texas

A community transition model that involves cooperative efforts between the school district and community service agencies is assisting severely handicapped students in competitive and supported employment. The community service agencies are committed to providing the longterm support necessary to enable the handicapped individuals to benefit from community employment. Twelve students eventually will be placed in employment settings and a working model for cooperative services will assist other school districts to establish similar programs.

#### University of Colorado, Colorado Springs, Colorado

This project is working with the Colorado Springs school district to establish transitional plans for their moderately retarded secondary students. With the assistance of University personnel, 50 students have been evaluated and have had transitional goals developed for their IEP's. During the 1985-86 school year, the students will have job try-outs in the community. Extensive teacher training is being provided, and the school district is restructuring its curriculum to emphasize preparation for community life.

The majority of these projects emphasize employment in community settings. Son, of the problems projects have identified include:

- Transportation of students from home to job is difficult because few of the individuals can drive and public transportation is often not available.
- o Line supervisors, who usually do not hire handicapped persons, often lack adequate training or knowledge of the unique needs of the handicapped individuals they are required to supervise.
- Parents are often reluctant to encourage employment of their children because of the risk of failure and/or consequent loss of disability benefits; and
- o Students at the end of their educational experience often have not been prepared for community life during their earlier education.

We are also supporting some transition-related projects under the EHA authority for Postsecondary Education Programs for Handicapped Persons. Last year's priority emphasized services for mentally retarded and learning disabled persons. The program provides grants for model project: that demonstrate the provision of special or modified training to hand capped students of postsecondary age or in post-secondary settings.

(me project in Oregon has completed a cycle of work with young mentally retarded adults, all of whom were in sheltered workshops prior to being served under the project. All ten students served

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by the first cycle of the project are currently competitively employed as janitors, carpenters, housekeepers, landscapers or food preparets.

A project in North Dakota is providing short-term training to mildly mentally retarded and learning disabled students for employment as personal care attendants for the homebound and the elderly. The average student in this project is a young adult female with a learning disability, with no previous work experience, recently graduated from high school. The grantee was influential in obtaining the first vocational placement for each graduate of the pilot project, but some students have changed jobs since. One young woman with a secondary disability of hearing loss is now an employee of HIT Inc., in one of its new group homes. The only young man in the pilot project was almost immediately hired by Grafton State School, the major institution in North Dakota. Although the project assisted another young woman with her first job and contract, she has since created her own free-lance personal care attendant business and sometimes now refers calls to the project.

Mr. BARTLETT. Do you find any barriers, either psychological barriers or Federal Government barriers, or disincentives to persons who are students to them moving into full employment?

Mrs. WILL I am not convinced that there are barriers that the Federal Government has created other than just the complex nature and the requirements involved in providing transition services.

I think that there was an unfortunate occurrence in the early 1970's when a system had been developing which allowed for the State rehabilitation agencies to work very closely with the State special education agencies. Because the Federal Government disallowed a form of third-party payment, many of the cooperative arrangements that had been developing at the State level ceased to exist.

I think that in that cessation there was built up an attitudinal barrier—I guess one would call it—or a distance between the State rehabilitation agencies and the special ed agencies. This happened at the worst possible moment, I think, in the development of programs for young disabled people.

A few years later, 94-142 was passed and at that moment, one needed the greatest amount of coordination between the agencies. We are now coming back again and asking for close cooperation between the two systems, and it takes a certain amount of realignment.

Mr. BARTLETT. Well, let me give you an example as to the kind of barrier I guess I am looking for.

I had some people with the National Institute for the Deaf and the administrators of residential schools for the deaf tell me the other day that they had a very difficult time in inducing students to move into full employment because they would lose their Medicaid if they were on SSI.

Wouldn't you regard that as a barrier, for example? In other words, if you lose your medical insurance—

Mrs. Will. That is true. When I said I wasn't aware of the Federal Government, that was too broad. I was thinking in terms of my



own program. I am not sure that my own statutes and regulations create barriers.

There are problems that the Federal Government has created, and I think that the loss of medical benefits is an important disincentive. The prohibition on vocational training in title XIX would be another one.

But there is a further attitudinal barrier in that categorical programs are very rigid and inflexible and they are built around a system of constituencies which break down into minute parts, and it is very hard to take a general view of the problem and to look across the—

Mr. BARTLETT. So you would suggest that if there were a way for Congress to construct an organizational structure that broke down those minute parts of the Federal Government so that a disabled person would be able to deal with the whole array—whether it is between HCFA and Medicaid or SSI and SSDI and Social Security Administration or rehabilitation services and transition services and RSA or the local and State vocational rehabilitation agencies— I suppose what you are saying is that the lack of coordination that is inherent in that kind of a structure is a problem.

Mrs. WILL. Absolutely, I totally agree with that.

- I am not sure that we know how to go about making a coherent system. I have thought in terms of consolidating programs; I don't see that as workable. I don't know how one approaches the problem.

Frankly, what we have done is try to identify very specific disincentives, and to approach solving the problem by funding a demonstration or a research project. But the problem is a much larger one, and I don't

Mr. BARTLETT. Well, over the course of the coming 6 months, I think this subcommittee would appreciate you thinking through with us how to tackle that larger problem.

Mrs. WILL Beyond disability programs, I think it is a fascinating question about Government. I lock at it from a political science point of view, that we have come to the point when we have so many programs built around addressing specific problems of specific groups, and I think there is maybe some gridlock that is settling in.

Mr. BARTLETT. From a political scientist's perspective, sitting where we are, perhaps it is fascinating. From the perspective of a recipient, it is somewhat macabre and bizarre and debilitating.

Mrs. WILL. Yes.

Mr. BARTLETT. And I think it is one that Congress really needs to tackle, and we need your help to accomplish it.

Mr. Chairman, I appreciate the additional time. I have some additional questions which I can go into now.

Let me take one of those links, then, Madam Secretary, and ask you this. At some time in the past there was a very imperfect linkage between the vocational rehabilitation agencies, or RSA, providing services and SSI, or perhaps SSDI, not having to provide their continued monthly payments. At one time there was a link in which the rehabilitation agencies could tap into that stream of income dollars and use it for training and for employment placement.

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Not trying to go back to the past, but do you see some possibility or desirability of reestablishing that link so that for training and transition services, rehabilitation services could borrow from that future stream of income payments from SSI or SSDI, and use it for training and employment placement today, or at least placement?

Mrs. WILL. When I came to OSERS, I quickly realized that there was very little in the way of formal contact between Social Security Administration and the RSA program. I endorsed as a very important goal the idea of reestablishing links with that organization. --We have established a working group that identified data, reestablishment of data as a first objective, and we have worked toward that end.

Further, we have been directed by Congress to work with the Social Security Administration to provide training to cur respective fields concerning the work incentives that have been now included in the Social Security Act, specifically 1619 (a) and (b).

Thus, we have developed the video program and we are hoping to do conferences which will include the regional Social Security staff as well as the vocational rehabilitation staff.

We are encouraging the State agencies to integrate the Social Security eligibility determination function into the rehatilitation process, to look at that process from a management standpoint to see whether it can be improved.

So we have limited——

Mr. BARTLETT. You have made some tentative steps forward.

Mrs. WILL. Right.

Mr. BARTLETT. But no linkage of money

Mrs. Will. No.

Mr. BARTLETT. I wonder, during the course of we could also leave the record open, if you could provide some technical assistance from your office, essentially to provide us some options.

If there were a way to link the linited resources, as we refer to it, of training money or rehabilitation funds for employment, to the enormous dollars that are saved by SSI or SSDI, I wonder if your office could provide some technical assistance for thinking through the options.

[Question and response follows:]

Question. Will you provide this Subcommittee with options that could link rehabilitation programs to SSI and SSDI dollar savings? Answer: These issues are under study: The Department of Health and Human

Answer. These issues are under study. The Department of Health and Human Services [HHS] is currently pursuing studies and demonstrations which explore rehabilitation methods and techniques to apply to SSI and SSDI programs. For example, on May 30, the Social Security Administration [SSA] published a program announcement for 7 to 15 grants to demonstrate methods to assist SSDI beneficiaries to obtain employment.

I would like to provide information concerning this subject, based on my knowledge of the RSA role in administering the beneficiary rehabilitation program (BRP) prior to 1981. I do not wish to set forth specific options at this time as this would involve making legislative proposals or endorsements which would have to be coordinated with HHS.

While I cannot speak for the Department of Health and Human Services, it is my impression that during 1980 and 1981, discretionary programs were under continued review in an effort to achieve budget savings and the BRP was one of the larger controllable items in the SSA budget. At that time, also, there had been several General Accounting Office audits of the BRP questioning the management of the program and citing instances where State expenditures under the program, eligible for 100 percent Federal reimbursement, had not been deemed to have been made



with economy and cost-efficiency first in mind. The combination of these factors contributed to the elimination of the budget line item and the restructuring of the program in the present form. I believe that any consideration of future directions for the BRP should take this background into account since the Ways and Means and Finance Committees reacted to these factors when the program was restructured.

Mr. BARTLETT. Madam Secretary, I have a question on a subject that is not related to rehabilitation but it is related to the other hat you wear, which is the Education of the Handicapped Act.

We have had hearings and you have testified, and we have had markups here in this subcommittee on an act commonly called the attorneys' fees bill. And, as you recall, when we left off, I believe the administration's and my difficulty with the act that was passed out of the subcommittee related to administrative fees, a\*corneys' fees paid at the administrative levels in codification of 504

I understand that the other body took some kind of action yesterday that addressed those two areas, and I wonder if the administration has any kind of a new position on the bill, or has changed its position. I know you don't want to talk about it, but ' am going to ask you anyway.

Mrs. WILL: Well, yes, there was a consistent of the interval of the second sector of the sector of the sector of the sector of the sect

The Senate, the full committee marked up the attorneys' fees legislation, and the administration had major difficulties with the bill. The administration felt that the bill would result in the creation of a very cumbersome due process system that might not result in fair decisions, impartial decisions.

So we met with some Members of the Senate and recommended that the first draft of the bill, S. 415, a much simpler proposal, would be more acceptable with the addition of two further provisions—one being a requirement that parents file a complaint and use the due process available to them below the court; and second that a provision included that restricted the amount of damages that a public interest, publicly funded organization representing parents in due process in court could recover. I think that there is general agreement that this may be the best course to follow, proposal to settle on.

The administration's perspective was that although we would rather not see automatic reimbursement for individuals who have used the due process system, that with the requirement for exhaustion almost forcing people to go through that level of the process, it made sense to allow the court the discretion of awarding reimbursement.

Mr. BARTLETT. Thank you.

Mr. Chairman, I appreciate the additional time.

Mr. WILLIAMS. Mrs. Will, oftentimes after we hear from administration witnesses, who usually present a fairly rosy picture of the efforts in which they are involved, we then hear clients and users of the system who present a less rosy picture. By that time, the administration witnesses are gone and aren't able to respond to it.

So let me read to you very quickly short pieces from the testimony of two of the witnesses who are to follow you today, and you can respond to them while you are still with us.

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First:

In terms of technical assistance, we have serious problems. The major resources for State agencies for technical assistance traditionally has been the regional office of the RSA and at times the central office.

During the past three years, however, because of inadequate funds for travel, it has been next to impossible to get regional office personnel to the States for this purpose.

#### Another witness will say this:

Most importantly, adequate travel funds for RSA staff to come to the States and provide technical assistance to agency personnel is critical. Current funding levels are adequate only for program monitoring purposes, leaving the real need woefully neglected.

As for technical assistance to rehabilitation facilities, the basic problem is that there has been no Federal funding for technical assistance programs in the State rehab agencies for nearly 5 years.

How does that connect with what you told us?

Mrs. WILL. Well, I don't think I would agree with the underlying premise of those two statements, which is, that little or no technical assistance is being delivered. Although I can agree with the specifics in the statements.

There have been reductions in travel. The Department has set priorities for travel in the area of monitoring for compliance and monitoring for waste, fraud, and abuse compliance in technical assistance, the conferencing being the last, the attendance at conferences, the last on our list of approvable activities.

ences, the last on our list of approvable activities. Having said that, I do think that we have a very comprehensive and solid program of technical assistance. You know, RSA, the State, Federal VR Program, is 65 years old. During that time you have seen, I think, a dramatic increase in the capabilities and the expertise of the State agencies.

Moreover, I think we have seen a shift in the way we at the Federal level think about providing technical assistance. Although we provide technical assistance from the headquarters and from the regional offices, it is a very important function.

What I tried to outline in our testimony is that we see technical assistance being provided in multifaceted ways through NIHR research and training centers, the regional engineering centers; we provide technical assistance through specific contracts, and through the examination of policy questions; we have involved telephoning, conferences, teleconferences, as well as off-site analysis and on-site analysis.

So I would argue that the rehabilitation program is basically healthy. We have the caseload trends to point to, that shows disabled people are being successfully rehabilitated. I think that the record is a good one to point to at this particular juncture in the program.

Mr. WILLIAMS. Thank you.

There is another matter which I want to try to clarify in my own mind. In the budget justification sent out some time ago, you stated that you were requesting a reduction in training funds because you did not have sufficient data for the allocation.

You state in your testimony Lere today—quoting now—"It's not clear that long-term training in degree programs is the most effective method to reduce shortages of rehabilitation counselors."

Yet in the July 11th Federal Register, you announced the final funding priority for fiscal year 1985 will be long-term training.



On the surface that sounds inconsistent-please explain it to me. Mrs. WILL. I am not sure I have the thrust. We published the announcement for long-term training and-

Mr. WILLIAMS. You tell us in the budget justification that you are requesting a reduction in training funds. You told us today that it is not clear that long-term training in degree programs is an effective method to reduce the shortage of rehabilitation counselors. But 1 week ago in the Federal Register, you announced the final funding priority for 1985 would be long-term training.

Mrs. WILL. I think that those statements might be-or inactions might be considered inconsistent.

Basically what we are telling Congress in the budget proposal for this year is that we do not have the kind of information that we wish we had:

When Congress in reauthorization asked for an annual report on training needs, we examined our training program and determined that we didn't have the right data. That led to a study which is trying to do two things: First, to develop a collection or a system of data collection, and second, collect the information that will allow us to make decisions about shortages in various disciplines in rehabilitation.

So our policy in the meantime, absent the information which will begin to come in during the spring of 1986, is basically a hold pattern. We are not making any radical changes or shifts in various training areas. We are continuing to fund along the lines that we have funded the past several years.

We do not know whether in rehabilitation counseling one wants to put more emphasis on preservice as opposed to inservice at this point. So we are going to continue to fund in the comprehensive way that we have in the past few years.

Mr. WILLIAMS. Finally, there was appointed a task force in 1984 which has now issued this document which contains seven recommendations designed to make RSA's training system more effective. I am sure you are familiar with the document.

Have you accepted the recommendations? Do you have an opinion on them? And, if you are favorably disposed toward them, have

any of them yet been put into place, or are there plans to do so? Mrs. Will. That was a report that came about as the creation of a special task force.

Our opinion at this point is, looking across a whole range of studies that have been done in the area of training, that often the sample is narrow and/or there is little ability to verify the kinds of information in the studies.

We look at those recommendations with great interest, but frankly we are going to wait until we have our larger study completed to kind of check recommendations against the information that we get in our own study.

Mr. WILLIAMS. Again, our thanks for being with us. It is always a pleasure to have you with us.

Mrs. WILL. Thank you, Mr. Chairman. Mr. WILLIAMS. Going on to panel two, Mr. Russell Baxter and Mr. Altamont Dickerson. Mr. Baxter is the commissioner of the Arkansas Division of Rehabilitation Services. Mr. Dickerson is the





commissioner of the Virginia Department of Rehabilitation Services.

We are pleased to have both of you gentlemen with us.

As is common practice in this subcommittee, we now request that each of the remaining witnesses do your best to limit your testimony to 5 to 7 minutes. As you get close to the end of that time, I will tap this gavel lightly, and I would appreciate it if you would try at that point to summarize your testimony or complete the remainder of your testimony.

We will also now institute the 5-minute rule with regard to questions from the members of the committee.

Mr: WILLIAMS: Mr: Baxter, we are pleased to have you here today, Commissioner, and you may proceed.

### STATEMENTS OF E. RUSSELL BAXTER, COMMISSIONER, ARKAN-SAS DIVISION OF REHABILITATION SERVICES; AND ALTAMONT DICKERSON, JR., COMMISSIONER, VIRGINIA DEPARTMENT OF REHABILITATION SERVICES

Mr. BAXTER. Thank you very much, Mr. Chairman. I appreciate very much the opportunity to give you ideas as I see them relative to the Rehabilitation Act.

I have been in rehabilitation since 1955, starting as a counselor and moving into the current position in 1965. I have had a chance to have input into the deliberations of this committee previously, and I have had a chance to have input into the development of regulations with the Rehabilitation Services Administration, so I have watched closely the development of the act.

I see it as an extraordinary act; an act of balance; an act that has everything in authority that is necessary for an individual who is disabled or eligible to become vocationally rehabilitated; an act to provide independent living skills for those needing independent living skills and not yet having the capability of employment; an act that not only has the comprehensive services but has training capability to get the staff, the quality staff, and the skill development that is necessary for quality services; an outstanding research program not only through the research and training centers but through research and demonstration, rehab engineering centers and so on; an outstanding independent living authority; an outstanding employment authority; and an outstanding Civil Rights Act for the disabled.

But we have great concerns, very great concerns, because we are not doing an inadequate job. We are not serving. At times we are ignoring disabled people, because we serve 1 out of 15 that come to us for vocational rehabilitation.

I heard the Chair, and I think Congressman Bartlett made statements of this type before without that specificity, but that is a fact. It is a real tragedy considering the needs that we have today, considering the pressures that you have on you for expanded services, that we have on us for expanded services. But more than that, the pressures of disabled people, whose pressures are based on individual need.

This pressure and this inadequacy is brought about basically as a part of the overview leading into the three subject areas, the fund-



ing problem, the authority problem is not there. There may be a problem in leadership also. But in terms of funding—if I can refe. you to my attachment A, particularly page 2 of that, the detail is on page 1 of A—I think it shows most vividly the problem that we have in funding.

Using the Consumer Price Index and charting the actual dollar appropriation as compared to the purchasing power, as compared to the number of rehabilitations; and you can relate this to the number of people served; also, you can see that the number of people served and the number of rehabilitations pretty well parallel the purchasing power, not with increased appropriations.

This is exaggerated by a lot of other things, also. Attachment B shows the new authorities that, even with the decreasing purchasing power, the new authorities that we have received since 1973, the new priority on serving a severely disabled individual, post-employment services, services to family members.

Exaggerated also by a new universe that is coming to us: brain injury, learning disabled, independent living, and now a new thrust in supported employment; exaggerated by the loss of Social Security funds, SSDI and SSI, \$200 million now impinging on section 110 primarily; a new exaggeration in the loss of vocational education funds.

I heard Congressman Bartlett express concern at the vocational education hearing about what the new emphasis on disadvantaged would mean to disabled. In Arkansas, that new change cost us 95 percent of our vocational education funds to train disabled workers—95 percent.

These are all exaggerations of a loss of purchasing power and severe decrease in the number serviced and the number rehabilitated. So we do have the pressures.

We do have the enabling legislation—there is no question about it. This goes into the same problem in training, and even worse, if you look at my last attachment, D, we had not only a decrease in purchasing power for our in-service training, we have had a decrease in dollars.

The heading on that page is a little misleading, if I can note that. It eavs "In-Service Training." The left column is "Overall Training Funds," a decrease from \$27.7 million down to \$22 million. The right column is its impact on Arkansas in-service training, a decrease from \$80,000 to \$68,000. This year we have just been notified that \$68,000 goes to \$62,000 for in-service training.

The most critical element of the training authority in the act, the authority to upgrade skills, to bring new skills, is also very important. I don't know what a proper balance is in terms of your specific questions.

Most State agencies are most concerned about the training programs that impact most directly on State agencies, and certainly that is inservice training, that is continuing education, that is rehabilitation management, the ability to train our managers and our supervisors.

Facility administration, one of the most critical aspects of our program serving a large percentage of our clients, receiving approximately 30 percent of our appropriations, both private and public. Those are preservice programs, postservice programs that



impact on our service delivery system. Those are the ones we are most concerned about.

That is not saying that preservice is not important. Certainly rehabilitation counseling is; certainly rehebilitation of the deaf, rehabilitation of the blind, interpreters of the deaf—those are very important programs. But they don't impact on us nearly as much as we would like them to, and certainly not nearly as much as our postservice training.

Continuing education programs have been exceptional to us in the past few years because of their ability to move in the new thrust, in the new initiatives easily. Employment, the use of technology in employment, marketing jobs, things of this type, things that we don't have the ability to do in in-service training. All of them are important in postservice.

Technical assistance. Here, as in some of the other areas presented by the Assistant Secretary, we do have a serious problem. It may have improved in terms of regional office staff, but before the last 3 or 4 months, we could not access regional office staff for pure technical assistance.

You can't get it anywhere else in terms of program considerations, in terms of program knowledge, in terms of overall management systems. This is a serious problem.

There is one other problem, and that is the loss of facility technical assistance. Again, a very important program. Public Law 93-12 had a good clause on facility consultation, 304(e)(1), I believe. But when Public Law 95-602 was passed, it had deleted facility consultation, moved the rest over to title V.

So RSA said, well, they will use section 12. Well, section 12 didn't have the words even though it did I ave technical assistance to private and public organizations, and we lost spending after 1 year. This is extremely important. This is one of the technical amendments that I would ask consideration of.

Postemployment services, finally, this also impinges on the decreasing purchasing power. Postemployment is important, very important, to the maintenance of personnel on the job, of employees on the job, disabled people on the job.

Any kind of service can be provided that would allow the person to maintain his job, any kind, but it is used not nearly often enough because of inadequate funding.

We know the pressures are great, and we accept the pressures. We know we are not doing an adequate job. But we want you to know that we are willing to do anything necessary to improve this.

know that we are willing to do anything necessary to improve this. We are looking at other resources. We are getting other resources. But we are a long way from servicing 50 percent of those people that need it. We won't be able to do it with just a cost of living increase. We are not only willing but we are very anxious to do this type of thing.

Thank you very much, Mr. Chairman.

Mr. WILLIAMS. Thank you.

[The prepared statement of E. Russell Baxter follows:]



# PREPARED STATEMENT OF E. RUBSELL BAXTER, COMMISSIONER, ARKANSAS DIVISION OF REHABILITATION SERVICES

I am E. Russell Baxter, Commissioner of the Division of Rehabilitation Services in Arkansas. I represent one of the eighty-four (84) agencies responsible for the delivery of services to persons with disabilities under the Rehabilitation Act. I have served in a number of capacities in the State/Federal program; entering it in 1955 as a Rehabilitation Counselor. I have been in my present position since 1965.

I am delighted to be invited to provide testimony on issues relative to Rehabilitation Personnel Training, Post Employment Services and Provision of Technical Assistance.

This 64-year-old program is a major resource for vocational rehabilitation services in the State/Federal service delivery system. I have watched the development of the Rehabilitation Act since 1955 when I was employed as a Counselor and much more closely since 1965 when I was appointed to my present position. With my participation as a provider of services to persons with disabilities during that time and with some input into the various amendments since



1973 and the promulgation of regulations; I have reached a point of believing without any question that the Rehabilitation Act is the most complete and the best balanced legislation in the Human Service field. This Act provides: ä direct šervice program för physically and/ör mehtally handicapped individuals with the authority to do anything necessary to assist an individual to reach a vocational goal; a training program to assure qualified staff and to upgrade staff to meet changing priorities, advanced technologies; and state and national initiatives; and a research program to work constantly through research toward the improvement of the service delivery system and staff competencies to provide quality service: The balanced system embodies all of the elements necessary for a successful Rehabilitation program. I firmly believe that it is imperative to maintain this balance.

I am concerned as all State Vocational Rehabilitation administrators are that we do have inadequacies and that quite often we are not able to provide all services that we are authorized to provide or serve all peeple that are eligible for services: I present to you, however, that the authority for services is excellent, that there are excellent services with high qualified staff in most States; but that State Agencies under this Act cannot provide all services needed by all eligible disabled people primarily because of inadequate funding. Even though State Agencies have many excellent services and qualified staff, they serve approximately one out of fifteen eligible for service and even then on a limited basis, not even having the ability

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to provide all authorized services. He know many persona with disabilities and advocacy groups also share this same concern and we know that you share the same concern. We obviously are only touching the tip of the iceberg. Is it any wonder that we have increasing pressures on us for expanded services from disabled people and their advocates as you do. It is a tragedy that we cannot provide all services needed because the cost benefit of our program is excellent and the need for services is severe: Even in this period of great technological improvements, we cannot take advantage of many newly developed technological aids because there is just not money to do so, denying many disabled persons or at best delaying many persons with disabilities from being considered a part of the greatest improvement in the Rehabilitation field since the passage of the Act, in my opinion. This is a missed; or at pest a l-layed; tremendous opportunity to-make a significant difference in the lives of many disabled citizens.

This concern is exaggerated by the fact that the first graduates of the new Special Education legislation of 1973 are now coming out of school. Special Education students have been involved in a mandated "least restricted environment," including whatever is necessary for the special education of handicapped students. They expect this same mandate for Rehabilitation. Although the authority in the Rehabilitation Act accommodates that mandate, the funds for rehabilitation programs do not. (See Attachment A).

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We see the same kind of pressure by an increasing universe of potential slightle applicants. This includes persons with brain injuries, with learning disabilities, with severe needs for independent living skills and for supported employment service. It is very difficult to accommodate this type of demand with less than a cost of living increase.

A listing of the new authorities in the Act in addition to the new emphasis on 'severely disabled' compared to funding since 1973 clearly shows the increasing problem of serving fewer clients each year. (See Attachment B).

To emphasize this further; Arkansas and the Nation serve a small percentage of those eligible and that is decreasing. (See Attachment C).

An important part of the balanced program is staff training. The same funding problem exists here, however. Even with significant new authorities, the funding for services for staff training • has remained relatively fiat. (See Attachment D).

It is not possible with flat funding to obtain qualified personnel or to upgrade staff in new techniques and developing technologies and at the same time provide on-going staff development. Those programs most directly impacting on the State/Federal service delivery system, which is the system that I represent, are in-service training, continuing education, and those programs sending many graduates to State Rehabilitation Agencies or upgrading staff in Rehabilitation Agencies. This includes Rehabilitation Administration and Management Training, and Facility Administration Training in post-employment areas; and Rehabilitation Counseling in pre-employment. Other programs in pre-employment are important but there is not much direct



impact on State Agencies. It, therefore, is difficult to state what the best balance would be, but the State Agencies desire much more emphasis on those programs directly impacting their staff's needs.

The same post-entry programs, particularly in-Service training and continuing education but also Administration and Management and Facility Administration Training, are able to respond very quickly to changing training needs. This is because State Agencies and Rehabilitation Services Administration Regional Offices can have Significant impact on the types of training and intensity of training in post-service activities. The preemployment programs usually exist in a university setting and invaribly that structure does not allow quick change. A curriculum change very often takes two or three years.

It is difficult to understand how RSA is planning to make the necessary change to impact on improved service delivery in spite of the mandate of P.L. 98-221. RSA has had a National Training Task Force and has supported studies for this purpose, but at this point we have seen absolutely nothing develop whereby the State Agency can realize improvement or allow RSA to justify its training allocations. A current contract with Advanced Technology, Incorporated, to study relative training needs should be completed during the next fiscal year. The 1986 budget has already been developed by RSA; I believe, and it can have very little impact on the 1987 budget. I likely we are looking at 1988 for results from RSA; even with the mandate.

The University Rehabilitation Counsulor Training programs are structured so that they have a primary emphasis on serving a severely disabled population. Universities do this well by



placing an emphasis on problem solving skills such as problem analysis, synthesis of the literature and application of behavioral principles: The "severely disabled" concern has been operationalized by the accreditation (Council on Rehabilitation Education) and certification (Commission on Rehabilitation Counselor Certification) bodies in theil formal procedures for granting accreditation to rehabilitation education programs and certification of graduates of those programs. Other restrictions in university programs, however, do not really allow them to provide what State Agencies feel would be a capable staff member. For example, university programs do not present a practical approach or a beneficial approach in placement and job development. Most of the university training is purely academic for this purpose, which is just not adequate for placement: Practicums and internships cannot remedy this.

In-service training is available to keep counselors upto-date with changing technology and changing demographics of the population Rehabilitation serves. A great emphasis is placed in this area not only by in-service training but also by the continuing education programs funded by RSA and by the R&T programs funded by the National Institute on Handicapped Research. All of these programs are extremely critical to the upgrading of Rehabilitation staff in all areas of competence, including technological change and demographic changes. It is only one example of the extraordinary authority of a balanced program. Once again, however, increased funding is imperative.

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Post-employment services are provided to many Rehabilitation clients. The basic means for enabling staff to effectively provide such service are in-service training, continuing education, and research and training center training. This is one of the new authorities of the 1973 amendments but the cost of the authority was not considered apparently, because nothing was appropriated for it. Of course, any client is eligible who needs post-employment services to maintain employment. The full range of Rehabilitation services are authorized, but such services are inadequate because of funding levels.

In terms of technical assistance, we have serious problems. The major resource for State Agencies for technical assistance traditionally has been the Regional Office of the RSA and at times the Central Office. During the past three years; however, because of inadequate funds for travel, it has been next to impossible to get Regional Office personnel to the States for this purpose. What little travel they have done has been to monitor or provide program review or to address crisis situations. This service is invaluable and is critically needed in the States. Increased travel allowances would be the biggest improvement in technical assistance at the current time:

Another problem, however, is the technical assistance to facility programs. At one time there was an authority for RSA to provide technical assistance for the improvement of Rehabilitation facilities Section 304(e)(1) of P.L. 93-112



provided authority for technical assistance either directly or by grant or contract: P.L. 95-602 removed the authority (I believe inadvertently), which was extremely valuable for the improvement of facility programs. These are significant programs, since approximately one-third of our funding goes to private or public facilities, primarily for the purpose of serving severely disabled clients. Technical assistance to facilities needs to be restored if possible - approximately \$200,000 annually was available for this purpose.

If the regional office were more available for the provision of technical assistance and if technical assistance to facilities were restored, nothing else would be necessary, even the provision of technical assistance for transitional services. Research and Training Centers, as well as Continuing Education Centers and State Agencies, have had very significant transitional services provided since the 1960's. The primary problem is funding. The technological and other improvements could be handled through our normal resources for training.

Finally, I cannot see that an Administration's "desire" to move more responsibility for service delivery to the State, local and private agencies has any impact on our service delivery system, nor would technical assistance be needed. The State/Federal Rehabilitation program has alway: provided most of its service at the local level by private agencies. In Arkansas fully 90% of our services are purchased at the local level, even though we have one of the largest comprehensive rehabilitation centers in the Country operated by the



Agency, as well as three other facilities. I am sure that is typical of the overall Country. RSA's technical assistance, therefore, needs to relate only to their ability to get to the States to assist in ensuring the delivery of appropriate services.

In summary, I very strongly believe that we have an outstanding Act: We can provide any services needed for vocational rehabilitation, we can provide staff training to assure quality services, we can provide on-going research to constantly improve services, we can provide independent living services and independent living center services for those not yet ready for vocational rehabilitation; and we can provide special employment services such as projects with industry; community service employment; and business opportunities for handicapped individuals. All of this presents an exceptional, balanced program opportunity for disabled people.

We serve, however, only approximately one out of fifteen eligible for services and we cannot even provide complete services that we have authority for. The demand for services cannot be met, however, because of limited resources. Some authorities in the Act are not even funded. We have pressures for expanded service,; the Congress has pressures for expanded services, and certainly disabled people have pressures for expanded services. If we continue to have a mandate for expanded services, it will be difficult to accommodate with the current resources available to us. We are willing and in fact, very anxious to provide more and better services than we are able to provide now.

Full Text Provided by EFIC

Thank you very much for providing me the opportunity to appear before this Committee. I feel very strongly about the State/Federal Program of Rehabilitation, the outstanding Act that we have, and this Committee's interest to improve the lives of persons with disabilities in this Country.



Section 110 Funding - Rehabilitation

H-ILDERAL APPROPRIATION	: OF CHANGE	CPT***	\$ OF INCREASE	CONSTANT DOLLAR	ARK ALLOCATION	S OF CHANGE
72		127.3				
73 589,000,000		138.5	11.2	425,270,750	9,070,110	
-4 035,813,070	7;2	155,4	16,9	409,146,070	9,396,179	3.3
25 680,000,000	6.7	100.3	10,9	408;899;570	10;378;818	915
76 720,309,318	5.6	174.3	8.0	413;258;170	10;479;805	.3
+ 180,000,000*					281,886 *	
77 740,309,000	2.7	188.6	14.3	392,528,630	10,881,603	3.0
78 760,472,049	2.7	202.9	21,4	374,801,370	10,728,690	- 1.6
79 817;484;000	7.0	229:9	13,3	355,582,420	12,441,592	13.5
80 818,920,283	. 2	258.4	12.5	316;921;820	12;364;901	- 1,1
81 857,259,000	<b>4.</b> 3	272.4	8.9	313;604;620	12;573;372	1.1
82 856,905,538	.3	292.4	3.9	293,059,160	12,515,170	5
83 943;900;000	9.3	303.5	3.8 <sup>2</sup> *	- 311,104,940	12,870,205	2.3
84 1;003;778;007	 6.0	315.5	4.0	318,154,670	14,308,767	10.0
85 1,100,000,000	9.0				14,869,956	3.9

\* One-quarter Allocation Due to Change in Federal Fiscal Year

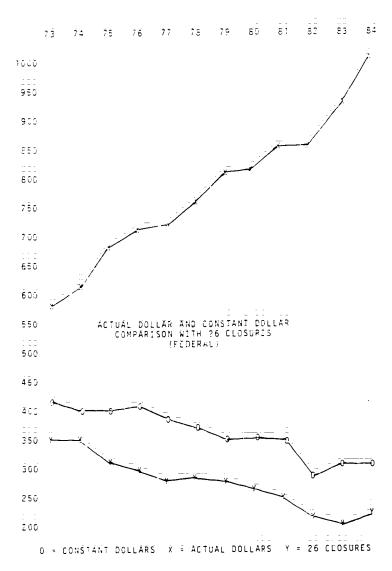
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\*\* Rough Approximation of Buying Power of 1969 Which = 310,096,530

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\*\*\* CPI = 1967 Base Year







# NEA CONGRESSIONAL AUTHORITIES SINCE 1973

5.1. 33-112 and its amendments has required the states to assume a creater responsibility for program development involving administrative responsibility for

- a. the individual written rehabilitation plan
   The individual written rehabilitation plan has required agencies
   completely reorganize their systems of forms minagement ind
   Las required addifional entries into data processing systems.
- upon the time available for service delivery to clients. The alternative to this is the hiring of additional personnel which increases financial burdens in a time of economic scarcity.
- C: <u>Feyering on the national evaluation standards</u> The yearly report on national standards has mide additional demands on specialized staff and required more data processing capability.
- d. <u>expansion of program evaluation efforts at the state level</u> Although the requirement for more thorough program evaluation is not specified in fine detail in Federal regulations; it makes extra demands on staff time and data processing equipment.
- c. <u>service to family members</u> Service to family members is desirable, but requires more professional and support staff time and usually involves effecting solutions to complex social problems and requires additional service funds.





- f. post-employment services
  - fost-e-plovent services also courre additional devices in professional and support staff and reduires addits null course funds.
- policy consultation for consumer input Policy consultation for consumer input becauses a large amount of time by sources said members to effect 5 descal and county result and mightes additional service funds.
- h. <u>annual reordering of priorities of service for the severals</u> <u>mandicapted</u>
   The annual reordering of priorities requires a bonsiderable amount of ongoing attention to service programs to ensure that services are being delivered in the most elfective and sufficient manner to the scheroly disubled;
- statewide study for determining need for services to the severely indicatived
   The innuml statewide study to determine the needs of the severely disabled readeres a heavy input of highly skilled personne, whe must deflect information which server as the basis for the revision of services to the severely handicapped.

All of these activities require much in the way of support services and personnel. In many states, data processing expansion is prehibited by the ledislature unless extra funding sources can be obtained. State personnel policies drequently limit the hiring of additional starf. Many states are experiencing economic retrenchment and are intually laying off personnel. There is an ever increasing bost spiral which advances faster than agencies, whility to acquire additional funds. Many states have afficience while deterronic data processing systems while others have no electronic while processing systems available to rehabilitation egencies. The net result of these new reduirements is that agencies have had to curtoil service delivery capability and reduce case service funds in order to meet them.



# CASELOAD HIGHLIGHTS 1973-1984

YEAR	NUMBER SERVED YEAR NATIONAL ARKANSAS		- SUBER REHIVELLETATED NATIONAL AREAN SAS	
34500 9000 9000 9000 9000 9000 9000 9000	1,156,315 1,201,661 1,244,335 1,235,446 1,235,446 1,104,487 1,104,487 1,105,235 1,055,235 9,38,537 9,38,537 9,38,1850	x 6, 3 24 3 3 3 4 4 3 3 3 4 4 3 3 3 4 4 3 4 5 3 4 4 4 3 4 5 3 4 4 4 3 4 5 3 4 4 5 3	500, 200 501, 178 501, 178 502, 205 502, 205 505 502, 205 505 505 505 505 505 505 505 505 505	

#### DEMOGRAPHIC HIGHLICHTS

- 1: Nationally, there are 12,102,000 KOH-Institutionalized disabled persons of working age.
- 2: Nationally, 9,533,900-of these persons are out of the labor force: this leaves 3 557,100 in the labor corret 4,386,500, 58,5% of men are out of the work force. 5 158,400; bs of weren are out of the work force.
- 3. In Orlansas in 1980; 175,668 people reported one or more disabilities; 12.7; of all working age Arkansans; the highest propertien of any state in the nation, reported a disability.
- 4. In stransas in 1990; 5: 092 disabled working sige persons participated the labor force: this was ranked Joth in the nation of those disabled persons who participated in the labor force.
- 5. The National Center for Health Statistics estimates that 3213 million Amyricans are disabled to some degree.
- c: In\_1983, the UIS: Commission on\_Civil\_Rights review of the various surveys and other material estimated that between 20 and 31 million persons are disabled (Setween 9) and 13.75).
- In Arkahsäs, 11. the definition of "disability" is expanded to exclude only children under age three and institutionalized persons, the total number of disabled persons jumps to 20.1% of the state perulation.





5. Data reported in 1985 indicatés thé population of Arkansas is 2,328,000; if 20:15 of the total population, excluding children ükder age three and institutionalized persons, is clubied there are currently about 267,928 disabled persons of all ages. This total number is 2006 times reported (175,008).

Feetnotes - Citations

- 1: B5We; Erank; "Getting the Job Done" (Participant Handbook). Ortober 1984, Page 4.
- 2. 1513, Fäge 51
- 5. Ibid; Page 11.
- 4. Ibid, Päge II.
- 5. From a note to my files November 9, 1954 summarizing media reports and other material.
- Gorski, Robert, "How Many Are There? Some Statistical Light on Disability", <u>Disabled USA</u>, 1984.
- Disability News Data, U.S. Council for the International Year of Disabled Persons, Washington; DC, Spring, 1981.
- Funk & Wassall's New Encyclopedia 1985 Yrarbook; Pages 452-457.



## IN-SERVICE TRAINING FUNDS

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YEAR	FEDERÁL - <u>APPROPRIATION</u>	ARKANSAS ALLOCATION	ARKANSAS 5 CHANGE
19-01-2	\$27,700,000	\$ 80,000	
i9-34	15,572,000	75,120	-2.3%
: 1974-75	22,200,000	45,570	- 41.65
1975-10	22,200 000	<b>-</b> 8;120	71 4°
1970	30,560,000	83,465	6.8%
1577-78	30,500,000	96,797	15.4%
1978-79	50,500,000	95,581	-1.3%
1979-80	28,500,000	98,797	3.48
1980-81	21,675,000	88,274	-10:7%
1981-82	19,200,000	38,000	55
1982-83	19,200,000	67,180	- 23 - 7%
1983-84	22;000,000	68,000	1.2%
1984-85	22,000,000	68,000	0 \$

In 1985 Arkansas received \$12,000 less for In-Service Training that in 1973:



Mr. WILLIAMS. Commissioner Dickerson.

Mr. DICKERSON. Thank you, sir. I appreciate the opportunity to come out of the country, and come across the river and into Washington to participate in this. This is my first appearance before a congressional committee, and I appreciate the opportunity.

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Russ has given some statistics in his charts, and I would agree with those and think that they are pretty much in line with Virginia and other States if we were to do an analysis, and I have done a preliminary analysis.

Peters and Waterman, in talking about "In Search of Exceltalk about the quality of continuous creativity. Those of us lence," who are on the firing line every day try to do this creatively but, gentlemen, it is becoming increasingly difficult to continue to create when you have problems with some of the things that are being talked about today.

My written testimory is available but I will try to speak extemporaneously about some of my concerns.

I agree with Mr. Baxter that the Rehab Act is the most dynamic, comprehensive piece of legislation ever implemented.

I am going to reverse my topics a little bit and talk about technical assistance. I think that this program provided the impetus for improvement of the facility programs as nothing else had.

What it did was brought outside expertise into States. There was a national registry of experts who could come in and talk about and help facilities in many areas, such as fiscal management accounting, product development marketing, quality control, special equipment design, industrial engineering methods, resource development, and community strategic planning. The States do not have such a cadre of experts who can do this, and so I feel that the program has had a negative impact upon the facility programs in the States.

As mentioned, this has not been available for at least 4 or 5 years and it has had a negative impact on the programs. I think that the average cost ran about \$300 per onsite visit, and I think that we got much more than \$300 out of that.

I think the technical assistance should be directed toward the support of overall rehab agency goals. It might be possible that RSA could come in and do an evaluation with States as to what the impact has been on them in their facilities for providing this type of technical assistance, and find out that there is a great need there:

Postemployment, I think there are certain assurances provided doing a postemployment followup because the client and the employer can feel some sense of security knowing that this type of followup will be available.

For example, a person who may be in a job may find that a piece of equipment needs to be modified or adapted in order to maintain the person on employment. These types of activities and services are available presently, and I think that they can be taken care of through the services of rehab engineering or other techniques.

The piece of equipment that is being adapted during the postemployment period may make the difference between success or continuous employment and termination of the employee. It does give the employer some assurances about hiring this person.



Mrs. Will talked about preservice training and mentioned inservice training. I tend to feel that preservice training is very important, and is providing a creditable job for those persons who are coming out and going into rehabilitation positions or other positions that deal with disabled persons.

However, I believe that we cannot deny the fact that in-service training, in my opinion, is probably as much or more important than preservice training as far as emphasis is cc erned, because when that new rehab counselor gets on the job he is going to have a lot of knowledge, philosophical attitude toward his job. But when he first begins to deal with persons with severe disabilities and the problems that they face, he is going to have a tremendous bout of realism all of a sudden.

Inservice training, I think, is vital if we are going to keep up with the demands that we are faced with now.

For example, we talk about medical technology and the impact it is having on the rehabilitation system. I can tell you today that this is a situation that we need to look at very carefully.

We are getting new groups of disabled persons. For example, cystic fibrosis is a new disability; these people are living now to the age that rehabilitation can work with them. Hemophilia, with the new treatment that is being done with those types of persons, we are getting them.

We have already talked about head-injury training. This is vital for our rehabilitation counselors. The rubella epidemic that we had in the 1960's, these persons are now being referred to rehabilitation. They present not just a problem of deafness, but they have multiple problems.

Our rehabilitation counselors need in service expertise in order to keep up with this change that is going on in the medical field.

I am very appreciative of the fact that this committee is taking these hearings to look at this situation. I feel that, as we work it out together, I appreciate the opportunity of a service provider coming before your committee to give you some firsthand information about what is going on out there.

I appreciate very much what you are doing. I would be glad to answer any questions.

Mr. WILLIAMS. Thank you very much, Mr. Dickerson. We appreciate having you here, and particularly for the first time before a congressional panel.

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[The prepared statement of Altamont Dickerson follows:]



## PREPARED STATEMENT OF ALTAMONT DICKERSON, JR., COMMISSIONER, VIRGINIA DEPARTMENT OF REHABILITATIVE SERVICES

My name is Altamont Dickerson; Jr., and I am Commissioner of the Virginia Department of Rehabilitative Services. The Commonwealth's program of rehabilitation was established in 1920; a few months prior to the passage of Federal legislation, and my Agency operates the oldest comprehensive rehabilitation center of its kind in the nation.

I entered the field of rehabilitation in 1956 as a rehabilitation counselor and have served in my present capacity for the past 10 years. My Agency and my staff are known throughout the country for their innovative ideas and creative approaches toward improving and expanding services for persons with disabilities. For this reason and my dedication to enriching the lives of Americans with disabilities, I am pleased to provide testimony on issues relative to Rehabilitation Personnel Training; Post Employment Services and Provision of Technical Assistance.

I füllý belleve in and support the Rehabilitation Act--both in philosophy and in programmatic implementation. We, in Virginia, in fact believe so stronglý in pursuit of the rights of persons with disabilities that the 1985 State Legislature passed legislation ensuring equal opportunity

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for the disabled. "The Virginians with Disabilities Act," which just went into effect a couple of weeks ago; is patterned after the Federal Act and prohibits discrimination in all phases of life's activities. Six of the bill's nine chapters address my Agency and its programs for recipients of services--both in the areas of vocational rehabilitation and independent living: This acknowledgment of the importance of services to the disabled at the State level is in line with the Federal Government's commitment through the Rehabilitation Act, and I concur with Mr. Russell Baxter of Arkansas when he says that the Federal law "is the most complete and best balanced legislation in the human service field."

Vocational Rehabilitation; in my opinion; is the most cost-effective government program in existence today. It is an investment which ensures a high return for everyone concerned. It is an investment in our most valuable resource--our people! Vocational rehabilitation and independent living provide our disabled citizens an opportunity to contribute and excell in the American tradition. Furthermore, vocational rehabilitation is an investment of dollars which yields a return that cannot be boasted by any other government program. For example, Virginia's investment during the past blennium resulted in productive employment for more than 10,000 disabled citizens. Translated into dollars, this effort amounts to yearly income totalling more than \$66 million and equals an <u>annual</u> return of at least \$5.4 million in tax payments to the State, local and Federal governments.



In-Service Training

With specific regard to the issues being addressed today; it is in-service training that assures State agencies of the means to keep all staff updated in new techniques and developing technologies. Advances in medical information and the recognition of employment possibilities that were not previously available for some disability groups; make on-going staff development imperative if we are to provide the highest quality of service delivery possible. For example, advances in rehabilitation of the traumatically brain-injured population led Virginia to place great importance on related training for all service delivery staff. For this one disability group alone, over \$8,000 of in-service training funds were allocated. However, additional basic Section 110 funds were needed for the development of training materials, including a film which has been used not only to educate my Agency's employees; but the community as well. Although these were funds well spent and with national impact, if additional Federal funds for in-service training were available, more State funds could have been allocated to provision of services.

Unfortunately, at a time when the need for in-service training is so great, the Federal funding trend reflects a decline from \$97,616 in 1980 to \$85,800 anticipated in 1985.

Inherent in the mechanisms of most State agencies the Relabilitation Services Administration (RSA) is the ability to respond quickly to changes



in in-service training needs. Identification and prioritization of training needs which reflect service delivery issues occurs annually. The task of change for university based pre-service programs is much more difficult.

Our institutions of higher learning are able to provide excellent programs that emphasize the severely disabled population, the medical aspects and employment expectation of this group. However, upon graduation, academic preparation alone is insufficient. The responsibility falls once again to in-service training to fully prepare those newly employed to be true assets to the Agency. Again, additional funding is needed.

À variety of in-service training is available in the newly emerging technological areas such as computer-oriented employment and rehabilitation engineering. RSA and the RST programs have taken the lead in such "high-tech" training. However, state-of-the art technology comes only at a great cost.

Most Importantly; adequate travel funds for RSA staff to come to the States and provide technical assistance to Agency personnel is critical. Current funding levels are adequate only for program monitoring purposes, leaving the real need woefully neglected.

#### Technical Assistance

As for technical assistance to rehabilitation facilities, the basic problem is that there has been no Federal funding for technical assistance



programs in the State rehabilitation agencies for nearly five years. Removing support from this important program at a time when Federal spending was being cut back indicates the low priority that apparently has been given to this program and the lack of understanding of its accomplishments in the past. Community organizations, both public and private, have a wide array of technical assistance needs that can be most effectively met (cost-wise and impact-wise) through short-term problem-solving consultant services coordinated by the State rehabilitation agency: Organizational providers of services to disabled persons have many problems associated with the development, management and improvement of their programs to meet the challenges of a changing environment. The State rehabilitation agency does not maintain a staff of experts that can even begin to respond to the specialized problems encountered by rehabilitation facilities and other organizations nor can the State agency afford to take case service dollars to purchase outside assistance for these groups. The problems that have been identified for which technical assistance is often requested include fiscal management/accounting; product development marketing; special equipment design and engineering methods; resource development/funding; and community/strategic planning.

Technical assistance initiatives at the Federal level have reflected for some time the increasing Federal emphasis upon <u>quality</u> assurance and occentralized methods for implementing systems that ensure the provision of appropriate services to rehabilitation clients. The two chief axamples of RSA's efforts in this direction are the Client Assistance Program





(CAP) and the San Diego Case Review. Each of these Federal initiatives reflects a concern for the States' compliance with standards and practices through technical processes designed to ensure appropriate and quality services to clients.

Technical assistance programs must be directed toward the support of ov.rall rehabilitation agency goals and should be targeted on an annual basis (with adequate Federal appropriations) toward specific program needs that cannot be met through traditional or other means. The State rehabilitation agencies and RSA should equally insist upon follow up and evaluation of all technical assistance services provided to more adequately document the accomplishments of the program. Surveys should be routinely conducted to identify areas of technical need and to illustrate the set-back that has been experienced in the development of community resources as a result of a lack of funds for technical assistance. To foster the development of transitional services, technical assistance is needed in the areas of program design/curriculum development; community/family education and advocacy; case management; and inter-agency relationships in the areas of policy, programming and funding responsibilities.





Mr. WILLIAMS. Commissioner Baxter, you mentioned in your testimony that—I think you said that "we serve 1 out of 15 that come to us." Are you speaking about your State or nationally? Do you mean 1 out of 15 potential clients, or 1 out of 15 of those who, in fact, aggressively apply to the service?

Mr. BAXTER. One out of 15 that would actually be eligible.

Mr. WILLIAMS. Is the inability to serve more than that financially based?

Mr. BAXTER. Almost totally financially based, looking at the loss of purchasing power and the many types of things that have been impinged by the—I don't know whether I mentioned, for example, SSDI and SSI, a loss of \$200 million there.

The graduates, as you mentioned in the June 11 hearing, of Public Law 94-142, for the first time, they are expecting the same mandate they tried in school in the least restricted environment, and they should have it. We can't respond to that. The act accommodates it in terms of authority.

Mr. WILLIAMS. You have been a commissioner now for I guess 20 years, if I read your testimony correctly. Have the standards for counselors improved during those 20 years, and more importantly, have the standards been realistic to the point of improvement in the counselors?

Improved standards and improved counselors, of course, are two different things, and it is more important that the counselors improve than the standards do. I am asking you about the connection.

Mr. BAXTER. Absolutely. Both in accreditation of counselor rehabilitation programs and the certification of rehabilitation counselors, the quality of the counselor, has improved.

There are still some problems in preentry programs, primarily, I think, based on the fact that it is too hard to change a curriculum in a university in the time that you need to change it. But they are handling the topic, as I said in my paper, of severely disabled quite well. It has been operationalized into the standards both for certification and accreditation. So, yes.

Mr. WILLIAMS. Mr. Dickerson, in Virginia are you experiencing the same type of inability due to natural constraints to serve a vast majority of citizens that need your services? Mr. DICKERSON. Yes, sir. We have approximately 190,000 persons

Mr. DICKERSON. Yes, sir. We have approximately 190,000 persons with disabilities who are eligible for our services right now, and each year we serve from 20,000 to 30,000 of these people. So it is about a 18-, 19-percent difference there.

The problem is not getting any better because of, as I mentioned, the increase of improved medical technology and the fact that more and more younger people are becoming disabled, particularly head injured and spinal cord injured.

For example, a head-injured person will take approximately \$100,000 to get that person into the system. I had a registry passed in 1984 wherein every head-injured person and spinal cord person has to be referred to our agency within 7 days by all the hospitais.

We have already registered over 4,000 new head-injured cases in Virginia over the last year. There are about 14,000 of these right now.

We have registered over 300 new spinal cord injury cases. The head-injury cases, as I mentioned, cost about \$100,000 apiece; the



spinal cord injured can run from about \$45,000 to 75,000 apiece depending on the type of the injury.

When you are required to serve all disabilities, then you have to come down to a situation where you say, well, if two persons come into the rehab today, one is a severely injured spinal cord person and one who might have another disability, which one do you spend your money on?

The one with the lesser disability would be easier to rehabilitate and get back to employment, but yet the severely disabled person is going to cost the taxpayers a lot more money to keep them in a dependent stage. So these are the kinds of choices that we are having to make today as to who is going to get the services.

I sincerely believe that all persons deserve the same type of consideration and priority, but we are being forced to make these choices. They are difficult because the families are saying, well, what are you going to do for me?

Mr. WILLIAMS. Mr. Baxter, a final question, you mentioned in your testimony that the act provides authority for excellent services. Your State and others at your level do all you can to see that the services delivered are indeed the best possible.

You indicated both in your testimony and in response to a question that financial constraints prevented delivery of services that might be of as good quality as possible if more finance is available.

My question goes beyond that to the quality of the leadership available to you and to other State commissioners, at both the regional and the national level. It is a difficult question because I don't want it to be misunderstood by the administration or by you. But you have been in this job for 20 years now and it would be interesting for this panel to hear your answer to the question that went to—as best you can answer it—that went to your opinion of the expertise, responsiveness and ability of those with whom you deal in both the regional and the national level today compared with other years.

Mr. BAXTER. I am happy to respond to it, Mr. Chairman.

I know the Assistant Secretary very well. I have never known a more committed lady for what she is doing.

I question the leadership that she has got in her office. The program knowledge basically has gone. There is a lot of program knowledge in the regional office, a tremendous amount of program knowledge. I can use Dallas, my region, as well as any of them, but all across the country it is strong.

It has been almost impossible to access them, as I have already said. There are some good people in RSA, in this less-restricted RSA right now. But the top leadership is gone in RSA. It is not there. We are not getting leadership from them.

NIHR is a little different. NIHR has got some good leadership, and they responded to us quite well. Both technically and programmatically, it is very good.

Even your statement is symptomatic of what has happened; When I testified 10 and 15 years ago, they didn't walk out. They stayed around. They wanted to see your concerns. They wanted to talk to you about your concerns. I think that is symptomatic.

I think that the information that Madeleine gave today, she was very sincere in it, very committed, really believed what she was



saying. But it was foreign to those people at the service delivery system in the State agency level.

We disagreed on technical assistance. We disagreed on training. We disagreed even on the fact that she said historically we have retrained, we didn't serve-that is just not true. She depended on a source that lacked program leadership to get that information.

Mr. WILLIAMS. Mr. Bartlett. Mr. BARTLETT. Thank you, Mr. Chairman.

I am not sure if I have a followup question to that, so let me go back to an earlier comment, both in the testimony and in response to one of the questions. You both referred to what I think you have accurately described as limited resources of your agencies for rehabilitation, and limited resources that are far more limited than the need that you see in terms of being able to rehabilitate someone and put him into full and productive employment.

First, an observation, and I really just want to make an observation that I think is very clear and everyone agrees with even though we may not like it, and that is, any Federal program that is going to be an appropriated item is going to be subject to limited resources in the 1980's, and probably ought to be, no matter how good a job it does.

The difficulty that this committee has, or the subcommittee has, is that there are virtually unlimited resources with nonappropriated items that are referred to in Federal vernacular as entitlements, SSI and SSDI.

And so, on the one hand, we have limited resources for agencies that retrain and rehabilitate someone and get him back into the employment rolls, and we have unlimited resources to provide dependent care.

So my question is, do you see-I mean, I suppose my observation is for the next 20 years Mr. Baxter, that you can come up to Congress and say, "send us more money among the limited resources for appropriated items," that will be an uphill battle that probably we are not going to win, even though I think you are probably right.

So my question is, do you see as feasible and/or desirable establishing some kind of link of borrowing from those unlimited resources of continued cash-flow kinds of payments into the future in order to rehabilitate people now and get them into employment and get them off of the dependent care rolls using SSI or SSDI?

Mr. BAXTER. I am in favor of anything that will do that, Congressman; 2030 has some excellent ideas in it. Title VI is good in the Rehabilitation Act; as it is right now, it is a good title. However, two parts of it are not funded.

If we got into it through a 2030 type of approach, this would give us another technique and maybe Congress would be willing to appropriate money for those particular approaches.

If I can just add one-two parts. We access a lot of funding that we used to access for vocational education. We access a lot of funding-title XX, Medicare, Medicaid, and so on. A lot of programs, special education, that we are far from being able to render services in spite of the cost benefit, in spite of the severe need.

The thing that I didn't mention in my testimony that I think I put in my written testimony, the thing that is most difficult to take



is technology access. This is the greatest boon to handicapped people, I am convinced, since title V or maybe since the act itself.

With proper technology access, handicapped people can do just about anything in the world, from their own bedside to a job on an assembly line. But the funds are not there, as you heard over and over in your last hearing.

But I think Congress maybe, and certainly the public in general, does not know what is available and what this can do for handicapped people.

Mr. BARTLETT. Mr. Dickerson, of the clients that are served by your agency, do you know what percentage receive SSI and SSDI?

Mr. DICKERSON. I don't have that exact figure, but it is probably in the neighborhood of what Mr. Baxter stated. I did do some checking on his tables and on the statistics that he had, and it runs pretty much about the same, I think, in the States.

I might add, also, that I think this is such a critical issue. I think the whole attitude of the institutionalization has descended upon not just the mental health area but I think that those people now are accessing rehabilitation programs.

Our deinstitutionalization study under way with our legislature has indicated that there are 44,000 chronically mentally ill now who come home from hospitals who are in need of rehabilitation services. Well, how are we going to serve these people unless we are able to access this additional pot of the money that you are talking about?

And I think that is a very good issue; because you take, for example, over the last couple years in Virginia, we have put back to work in excess of 15,000 people. Now, they are earning in excess of \$70 million in wages and salaries, and they are paying back in excess of \$6 million in State, local and Federal taxes.

So how can you argue that you want to take money away from a program like that and continue to breed dependents; it doesn't make any sense.

Mr. BARTLETT. What percentage, placement percentage, do your respective agencies have? What percentage do you end up placing into permanent employment?

Mr. BAXTER. Ours run between 75 and 80 percent in competitive employment.

Mr. BARTLETT. Competitive employment.

Mr. BAXTER. Right.

Mr. BARTLETT. Mr. Dickerson.

Mr. DICKERSON. It runs about the same, yes:

Mr. BARTLETT. Could you use that same placement service for people that you haven't rehabilitated? If they don't need rehabilitation, do you ever place people just simply, in the SSI or SSDI rolls, into competitive employment?

Mr. BAXTER. With the use of section 110 funds, we have restrictions. We have to meet eligibility requirements and we have to provide substantial services. So I would presume that unless we do that, we cannot provide the placement.

Mr. BARTLETT. So you do not.

If we change the law to permit you to, could you do it feasibly? Could you use the same placement network to place people that don't require rehabilitation?



Mr. BAXTER. Well, right now our caseloads are ridiculous. It would be imposing something else on a counselor that lready makes him inadequate because of just the numbers.

The bigger problem is the disincentives, which you address in 2030 and this kind of thing. We serve some of these cases; we always have.

But if we could remove the disincentives, if that bill passes, it would go a long way to serving a lot more of those particular clients.

Mr. BARTLETT. Thank you.

Mr. WILLIAMS. Gentlemen, we thank you for your good testimony and counsel, and particularly for the frankness of your responses.

I will ask Marita Danek and Faith Kirk to come to the hearing table.

Mr. WILLIAMS. Ms. Danek is the director of rehabilitation counseling education at Gallaudet, and is here representing the American Rehabilitation Counseling Association; and Ms. Kirk is the executive director of the Governor's Committee on the Employment of the Handicapped in Maryland and is here representing the National Rehabilitation Counseling Association.

Ms. Danek, we are pleased you are with us today and please pro-

## STATEMENT OF MARITA DANEK, DIRECTOR OF REHABILITATION COUNSELING EDUCATION, GALLAUDET COLLEGE, REPRESENT-ING THE AMERICAN REHABILITATION COUNSELING ASSOCIA-TION; AND FAITH KIRK, EXECUTIVE DIRECTOR. MARYLAND GOVERNOR'S COMMITTEE ON EMPLOYMENT OF THE HANDI-CAPPED, REPRESENTING THE NATIONAL REHABILITATION COUNSELING ASSOCIATION

Ms. DANEK. Yes. Mr. Chairman and members of the subcommittee, my name is Marita Danek. As you mentioned, I am director of the rehabilitation counseling training program at Gallaudet College here in Washington, DC.

I am a certified rehabilitation counselor and I have been in the field of rehabilitation for 19 years. I have worked in State agencies and in other settings serving serverely handicapped individuals, mainly deaf individuals.

Today I am representing the American Rehabilitation Counseling Association, a division of the American Association for Counseling and Development. Our organization is committed to clarifying the role of the rehabilitation counselor, formulating and maintaining training and professional standards and increasing public understanding and awareness of the need for the rehabilitation and habilitation of persons with disabilities.

Because of these interests, we are especially appreciative of the focus of your hearing today and the opportunity to provide testimony. We are an organization firmly committed to the concept of a professional consumer partnership. Our organization and the profession of rehabilitation counseling exists because individuals with disabilities are entitled to the same human rights that accrue naturally to able bodied people.



My testimony today focuses on three important sections of the Rehabilitation Act of 1973. The first is the importance of Federal support for both pre- and postservice trainee to ensure an adequate supply of trained and qualified rehabilitation counselors to provide appropriate services to individuals with disabilities.

The second concerns the need for Federal support for technical assistance; and the third focuses on the importance of post-employment services to maintain employment.

Several recent studies which are cited in my written statement have shown that the continuing need for rehabilitation counselors exists. For example, in the Mentz study, by 1990 as many as 33,000 new rehabilitation counselors will need to be trained to meet the needs of disabled people in rehabilitation facilities alone. The need for rehabilitation counselors is greater in terms of absolute numbers than the need for any other rehabilitation professional.

This is reflected in the very large number of full-time positions currently established in every major rehabilitation setting. This was established in a recent study that was commissioned by RSA through the RRCEPS and published in April 1985.

Unless there are sufficient numbers of trained rehabilitation counselors these positions, new positions, and also positions that occur because of turnover will be unfilled or will be filled by poorly qualified individuals.

The knowledge and skills required to do an effective job as a rehabilitation counselor are multiple and complex, have been well documented in research studies, and are identified in the certification standards of the Board for Rehabilitation Certification and the accreditation standards of the Council on Rehabilitation Education.

The American Rehabilitation Counseling Association believes that the person with the disability deserves no less than the best trained and qualified rehabilitation counselor. Now, what do we mean by "best trained and qualified rehabilitation counselor?" We believe that a master's degree in rehabilitation counselor?" We believe that a master's degree in rehabilitation counseling is absolutely essential for an individual to have the minimum skills to provide persons with disabilities the level of rehabilitation services they are entitled to.

These skills must be maintained, refined and built-upon through in-service and continuing education. The association believes in the need for Federal support for both pre- and postservice counselor training.

I don't want to be put into the position of saying if you could only have one which would you take; or how do you allocate it between these two very important training modalities. By "postservice" I mean inservice and continuing education—complement each other. Both are necessary but neither one is sufficient by itself.

This support, particularly preservice support, is necessary if our profession is going to be able to compete in attracting capable, bright, enthusiastic young people into our profession. It is essential that short-term courses be made available to employed rehabilitation counselors to keep them abreast of new advances in the field.

We recommend that Federal funding be restored for in-service training to be provided by universities with rehabilitation counselor training programs and other types of facilities already equipped



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to give relevant courses to upgrade professional skills. Universities are in the business of training.

To paraphrase Gerbers, training is our business, our only business. We are full-time trainers. We can respond to changes in the field, to technological advances, to new information.

For instance, this fall I will be offering a course in trends in special education and rehabilitation. I am going to tap into some of the expertise of the individuals in this room, pull together and provide a course that will serve the community in terms of what are the new initiatives in both of these important areas. This course was instigated in April and it will be offered beginning in August.

In terms of technical assistance, there has been no funding for technical assistance since 1980. The funding for this important support program was relatively small, less than \$2 million. However, it did a fantastic job.

We recommend that the technical assistance program be reactivated and handled by the RSA regional offices, as it was in the past. This was always a cost-effective way of bringing a host of services to rehabilitation settings. With the new emphasis on transitional programs, this is a must for implementation.

We strongly endorse postemployment services to help maintain the rehabilitation client in employment. The importance of postemployment services cannot be underestimated since the first several months of employment can be critical, and this is very true-especially true for many individuals with disabilities who need periodic support and counseling to maintain their employment.

Again, research has shown that the rehabilitation failure - te can be reduced. We know recidivism is a problem. Individual returning to State agencies for additional services. This failure rate can be reduced by developing a comprehensive followup and follow along program.

Thank you for the opportunity to present this testimony. We stand ready to provide any additional information you might wish.

[The prepared statement of Marita Danek follows:]

PREPARED STATEMENT OF MARITA DANER, PH.D., ON BEHALF OF THE AMERICAN REHABILITATION COUNSELING ASSOCIATANY

Mr: Chairman and mambers of the Subcommittee, my name is Marita M.Danek, Ph.D. I am Director of the Rehabilitation Counseling Program at Gallaudet College in Washington, D.C. Today I am representing the American Rehabilitation Counseling Association(ARCA), a division of the American Association for Counseling and Development. Dur organization is committed to clarifying the role of the rehabilitation counselor, formulating and maintaining training and professional standards for rehabilitation counselors, and increasing public understanding and awareness of the need for the rehatilitation and habilitation of persons with disabilities. Because of there interests, we are especially appreciative of the focus of your hearing to and the opportunity to provide testimony.

J would like to present testimony soday negarding three important sections of the Renzbilitation Act of 1973 The first of these to be addressed is the importance of and need for trained qualified rehabilitation counselors to provide appropriate and effective services to disabled citizens) the second concerns the need for federal support for technical assistance and the thind focuses on the importance of post-employment services to maintain job placement.

Prior to preserving this testimony, I would like to convey for the record and at the request of the President of the American Rehabilitation Counselors Association (ARCA), Edna M.Szymanski, some of our beliefs ind objectives. We are an organization firmly committed to the concert of a professional-consumer partnership. Approximately one out of te. U.S. citizens have some degree of impairment resulting from a physical or mental disability. Dur organization and the profession of rehabilitation counseling exists because these individuals with disabilities are entitled to the same human rights that accrue naturally to able-bodied reople. So our profession is grounded in a basic belief in human\_rights; the value of work; and a partnership with persons with disabilities. But good intentions, and the right attitude is not sufficient, Rehabilitation counselors must also possess the Knowledge and skills to see beyond the limitations imposed by a disability and respond to the strengths of the individual and the resources of the environment and how both can be harnessed to return that individual to work.

NEED FOR TRAINED REHABILITATION COUNSELDRS: There is a continuing need for trained and qualified rehabilitation counselors. Federal funds for rehabilitation training are needed to attract sufficient numbers of bright errousiastic young people into two year masters level training programs.

Several recent studies have identified the need for rehabilitation counselors in rehabilitation agencies, facilities, and other settings. A study conducted by the Research and Training Center at the University of Wisconsin-Stout(1980) indicated that as many as 33,000 MEW rehabilitation counselors will need to be trained to meet personnel needs in rehabilitation facilities by 1980. The need for rehabilitation counselors was greater than for that of any other rehabilitation professional. The demand for all types of personnel to



serve persons with disabilities in facilities will be somewhere between 100,000 and 300,000.

In April, 1985 a nationvide study conducted by the Regional Rehatilitation Continuing Education Programs at the University of Missouri-Columbia reported on the manpower shortage and training needs of rehabilitation personnel. It noted that rehabilitation counseling ranked second of all rehabilitation disciplines in the number of total FUNDED positions (full time equivalent) in FY-84 in every major rehabilitation; setting. (Total funded positions equals those previously employed plus positions prasently open). Unless there are sufficient numbers of trained rehabilitation counselors through 1990, these positions will go unfilled or will be filled by untrained and Unquelified individuals:

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The American Rehabilitation Counseling Association believes that the person with a disability the consumer of rehabilitation services, deserves no jess than the best trained and qualified rehabilitation counselor available.

Therefore, the Association believes strongly in the need for both pre and post service training. The masters degree in rehabilitation counseling from a program accredited by the Commission on Rehabilitation. Education (CDRC) provides entry level skills into the profession. These must be maintained, refined, and built upon through in-service and continuing education.

THE REED FOR A DEFTH OF KNOLLEDGE. The knowledge and skills required to do an effective job as a rehabilitation counselor are multiple and complex, have been well documented in research studies and are identified in the certification standards of the Board for Rehabilitation\_Certification and the accreditation standards of the Commission of Rehabilitation Education.

Rehat ilitation Courseling requires a firm grass of at least three different frames of referencesthe individual; the environment and the interrelationship between the two. Formal training at the master's level is necessary: (j)to understand the individual; (2)asses the medical and psycho-social aspects of disability and resultant functional limitations, (3)determine appropriate long and short tarm goals with the client, (4)utilize community resources; (5)provide job development and placement pervices including ob restructuring and modifications when necessary, (6)and apply new technologies to rehabilitation barriers. Over the past decade we have seen an explosion in information and new technologies related to these tasks e,9. new advances in medicing, pharmacology, bioengineering, and job placement methods to name a few.

When you couple this information explosion with the emphasis on Serving the most challenging rehabilitation clients-the severely disabled - the need for highly competent and well prepared rehabilitation counselors becomes even more critical.

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Research studies by Professor George N. Wright of the University of Wisconsin and others clearly indicate that the complexity and multiplicity of rehabilitation counselor functions requires at least the master is degree. Other studies show that trained; master is level counselors are more likely to accept difficult (severally disabled) ceses and to achieve their Successful rehabilitation; have greater emereness of the client's strengths and weeknasses; and are better able to cope with berriers to rehabilitation(e;; disincentives to work and motivations) problems; and do not svoid time consuming cases(i:: clients who require a professionel counseling relationship to become employable). Formal training is the versable that discriminates best when considering effective sevices that increase the likelihood of successful client outcome which is suitable client placement.

Federal training support is essential if our profession is to be able to compete with other professions in attracting cepable students into greduate training programs which prepare them to become rehabilitation counselors. As with education and other human service professions the selary level of rehabilitation counselors and other rehabilitation professionels has not kept pace with other professional fields? e.g. business, engineering, medicine2end, es e result, our recruitment of good students is en increasing problem. The Federel support provided by rehabilitation student stipends (end tuition) for graduate level education is greatly needed as a proven way of attracting students who will become qualified professionals.Training funds; is it the case with research funds; are not readily available from state legislatures. It is imperative that federal funds be made available for this purpose:

LE believe thet strong and Knowledgeable federal leedership which is sensitive and responsive to the needs of disabled citizens is required to insure more then just adequate levels of services to persons seeking rehebilitetion. Many states because of their freesing needs, often employ rehebilitetion counselors who era well intentioned but lack the requisite formal treining. Federel involvement is critical to provide incentives to the states to modify, where necessery, their hiring prectices and employ only qualified counselors es required by the Rehebilitation Act of 1973, es amended. We realize that the stetes shere the major responsibility for the implementation of this vitel state-federal partnership, however, strong federal leadership is needed to set the tone, end provide guidance end objective eveluation standards for the states. It is unfortunate that the regulations do, not specify, in any great detail what "qualified personnel?[meani. We\_believe]thet the regulations[should require. certification;;specifically:the:designation;:Centified Rebabilitation Counselor (CRC) for ell newly hired rehabilitation counselors efter 19271

INVSERVICE TRAINING: ANOTHER KEY TO PREPARING COUNSELORS FOR THE 1980'S AND BEYOND. Currently, we have numerous rehebilitation counselors functioning in e wide range of settings. To be effective, it is essential that short term courses are made evaluable to these

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personnel to keer them abreast of the latest knowl dge in the field. Courses are needed in everything from the use of computers in job finding to issues, techniques and studies in "supported work" and transitional programs for retarded and other developmentally disabled perulations.

TECHNICAL ASSISTANCE NEEDS: A MUST FOF THE FIELD TO REEP PACE. The need for Technical Assistance (TA) is greater now than ever, since TA, which was supplied by RSA and its 10 Regional Diffices, has ceased as of 1980 due to lack of funds. The funding for this important support program was not much money(less than \$2 million per year), yet its impact was crucial to assist facilities in gaining needed input from yarious experts on a short-term besis. We recommend that the Tachnical Assistance Program be reactivated and handled by the RSA Regional Offices as they have cone in the past. This was always a cost-effective and inexpensive way of bringing a host of services and objective evaluations to.a large number of rehabilitation settings. throughout the nation. With the new emphasis on transitional programs

POST-EMPLOYMENT SERVICES: TO HEEP MAINTAIN JOBS POSt-employment Services (PES) was mandated in the original Rehabilitation Act of 1973; Unfortunately; implementation has been, at best, spotty eround the U.S. The importance of PES is obvious to anyone in the field, since the first several months of employment can be critical and this is especially true for some individuals who need periodic support and counseling to maintain their employment. One study of Post-Employment Services (funded by ESA/NIHP) by the Postgraduate Center for Mental Health in New York City noted that the rehabilitation failure rate for mentally disabled persons can be reduced significantly by developing a comprehensive follow-along program. The implementation of this research project continues in New York City and is implemented with the cooperation of the New York State Office of Vocational Rehabilitation. Here is an example of new Knowledge developed cooperatively with Federal funds and a private and state vocational rehabilitation agancy, Unfortunately; the model is not being utilized ōñ žný largé,ščále∵Ončé,again,limited <u>f</u>unds<u>,for</u> such\_prog<u>ram</u>s\_as PES is as much the problem as is the lack of staff to implement this föllom-mp at the local level;

THE REHABILITATION COUNSELOR: THE CENTRAL POINT IN IMPLEMENTING THE VOCATIONAL REHABILITATION PROGRAM. To summarize, the besic value underlying the profession of rehabilitation counseling is a belief in

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the rights of persons with disabilities to full participation in all aspects of society; including employment. It is clear that a large portion of the general population has some disabiling condition; that any of us are subject to some disabiling condition of any security at any time; that persons with disabilities frequently have difficulty in accessing or benefitting fully from employment, education, recreation, housing; and other areas of life that most of us take for granted; and that a disproportion at number of disabled people are unemployed or underemployed when compared to the general population.

As Ms. Szymanski, President of ARCA stated, the above facts and values don't change with political trends and changing service delivery systems, but remain as foundations and constant challenges for the Profession. Rehabilitation Counseling stands on its own and in partnership with persons with disabilities. We must continue to improve our skills in order to be more effective in our mission; be it the public or private sector. The clientele of rehabilitation programs deserve the best and the most competent service providers.

We are extremely appreciative of your interest in our thoughts and wish to thank you and past members of the Congress for your foresight and sensitivity in sarving disabled citizens and their families over the past 65 years. We look forward to your deliberations on the reauthorization of the Rehabilitation Act. We at the ARCA stand ready to assist the Congress in any way possible to strengthen vital programs for persons with disabilitation.

Mr. WILLIAMS. Thank you very much.

The interruptions and bells you hear are the announcement that we have a vote. However, Ms. Kirk, if you can keep your testimony to about 5 or 6 minutes, we would be able to hear you before we go vote and then we could return for members' questions if you both can stay with us.

Ms. KIRK. Fine; Thank you, Mr. Chairman. I appreciate your knocking when my time is up.

I have a mild case of dyslexia, so I don't normally speak from written notes. But I really want to make sure that we get some key points in.

As you state, my name is Faith Kirk, and I am here today to give written and oral testimony on behalf of the National Rehabilitation Counseling Association.

I currently serve that organization as its legislative subcouncil chair. I am a certified rehabilitation counselor and have worked in the field of rehabilitation for 16 years—all of it within the State of Maryland—first as a rehab counselor, then as a rehab supervisor, and my current position is executive director of the Maryland Governor's Committee on Employment of the Handicapped for the last 5 years.

I have been very honored and proud to be part of the State/Federal program. I think the program has as its goals a very high degree of what needs to be done—the best quality service for persons with disabilities so that they can become real members of the mainstream of our society.

We agree, though, the members of NRCA very much with your eloquent remarks as you opened these hearings 3 weeks ago, Mr. Chairman, when you said, basically, it is a good program, and it is doing good things, but it has got to do them an awful lot better if we are really going to serve citizens with disabilities.

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We, as I said, agree with this. We hope today that we can reiterate and show some areas that really need some real study if this is going to happen.

Pat Mundt who is also with CRC, and the president of NRCA is very sorry that she could not be here today, and has asked me to share with you some very key elements regarding the cornerstone of making a better program, and that is the rehabilitation counselor.

They are on the frontline. They are the ones who provide the direct service to the rehabilitation consumer, and we have got to make sure they are the best. But there are some problems, and I would like to point out some of those.

First, the term "vocational rehabilitation counselor" as used by State personnel is just a title. It has no uniform standards, no uniform qualifications, and it means many different things in many different States. However, the term and the title "certified rehabilitation counselor" does have uniform standards, uniform qualifications.

Marita's organization and mine—and you will be hearing from Donald Dew, his organization, and many of the witnesses that you will be hearing from today have worked with us in the profession of rehabilitation counseling to set up those standards, to set up those qualifications that one must meet before they can even apply to try to get that title, certified rehabilitation counselor.

Once someone obtains that title, they can't keep it forever unless they do something. Counselors must have 150 hours of continuing education every 5 years. If they do not get that 150 hours, they must resit for the examination to again show that they do have skills and competencies and haven't lagged behind. It is an everchanging field, new populations, new technologies, and counselors must stay current.

That is that preservice that we were talking about and the inservice that must happen. We think that it is very strange that if you look closely at the Rehabilitation Act and the regulations that implement and define the act, you find that there are regulations and the qualifications for physicians, psychologists and many others who provide a certain service to the consumers of vocational rehab. Yet the only mention of qualifications for the cornerstone of the program, the rehabilitation counselor, is the word "qualified." Nowhere in the act or the regulations are those terms defined.

In summary to these points that I have made, it should be clear that vocational rehabilitation at the State level is a program. Persons employed as counselors in these programs to serve disabled consumers must represent the best trained and best qualified that the field has to offer.

If this is to take place, standards must be established in the act and the word "qualified" defined. This won't just happen. We need your support. We need your assistance. We need your help.

Persons with disabilities deserve the best. We, again, want to say that there are people because of this lack of guidance, who are hired who may not have the training, qualifications, or the skills to do the job as it must be done. I think that this was vividly pointed out to you in the hearings on July 11. Two consumers of service



that, really, their testimony really hit me hard, and I want to talk about it a little bit now.

One, a young lady from Maryland who stated in her testimony it wasn't the desire on the part of the rehabilitation counselor, but oversized case loads and in some instances, lack of training. Another consumer from Denver stated that the only qualifications for rehabilitation counselor or a job placement person in Denver was a degree, any degree, and I don't think if you have a degree in archeology you have the skills and qualifications that it takes to do what you need to do to help a person get from a state of dependence to a state of independence.

Mr. WILLIAMS. Ms. Kirk, let me interrupt you there to recess this hearing for a short time while we go vote and if you will both remain with us, we will have some questions and allow you a moment or so to complete your testimony when we return in about 10 minutes.

[Recess.]

Mr. WILLIAMS. I call this hearing back to order. Ms. Kirk, we will ask you to take 1 minute and conclude your testimony.

Ms. KIRK. Enough about the negative. I et's look a little bit more on the positive on what we can do. We in the profession of rehabilitation counseling really take very seriously all of the skills, and the knowledge that must be possessed by the rehabilitation counselor to do the job right.

Just look for a minute—they must evaluate the skills, talents, similar benefits, job modification, job restructuring, and training. They must look at the psychosocial aspects of the disability, and at how the disability relates to the world of work. I could go on and on and on. It is all spelled out in my testimony.

All of this information must be synthesized and then must be shared with the person themselves to help them make some very important decisions about how they are going to go on to get themselves from a state of nonjob readiness to a state of job readiness, from a state of dependence to a state of independence.

When you look at all these skills and talents, it is not going to happen with just a degree in anything. It is certainly not going to happen unless we continue to keep those who are providing the service very well trained and very knowledgeable.

Training, as I have said, both in- and preservice is extremely important. Further, though, training, both pre- and inservice isn't enough, we have got to also look at some other key things, one of those is the size of the caseload.

When you as a rehab counselor are carrying a caseload of approximately 100 to 200 people, you can't really do the indepth work and a lot of what you would like to do without a lot of complaints. Why is it taking so long? You know, long waiting list. It is 5 weeks and I am not evaluated yet. You know, what about my training, and on and on and on.

Many rehab counselors have the skills and talents, but they can't do the job right when they need to do it with those sized caseloads. Add to the above equation all the new technology, the emphasis on supported work, the new populations that must and need to be served, and it can't be done with large caseloads without proper training. Another thing that we have got to bring into the equation



is the fact that in many, many State rehabilitation counselors are not paid good salaries.

Therefore, we are not attracting the brightest, the best trained, the most qualified. These people are being whisked away by private rehabilitation and other rehabilitation work settings, and also by private industry.

We have also talked about technical assistance, and I would like to just reiterate and support what was said by Mr. Baxter and was said by Marita Danck in terms of the fact that there was a program, there were a lot of experts on contract to RSA. This was handled out of the regional office. The money isn't there. This is not being done.

there are not getting to the people who are providing the service. We must look very carefully at doing something about that and getting that program reinstituted.

I would like to close this testimony with another quote from your opening statement you made on June 11, 1985. You emphasized that our society is in the midst of a series of civallenges and changes to which the rehabilitation system must respond. The technological revolution has the potential to completely redefine what is possible in terms of rehabilitation.

I would like to share a story with you about my experience that really points this out and why what we are talking about must happen. When I started as a rehabilitation counselor there was a gentleman from Maryland who was severely disabled. We did not have the technology or the skills at that time to really help him become rehabilitated.

When I became a rehabilitation supervisor 6 years later he was rereferred to the agency and there were programs and there was technology that allowed us to take him from a state of being a tax taker to a taxpayer. We were able to work with George Washington University and Collie Mallot's demonstration program for homebound employment. We provided him appropriate computer training and the modifications that had to be done by the computer. He was then able to work for a Federal agency out of his home with telephone hookup. He is doing very well and is a contributing member of our society.

But if we had not been able to use that technical skill of Mr. Mallot's program, which was only a demonstration grant, and it ran out, and a lot of that is not really being put into the system because we don't have the money to hire the kinds of people to do that, and I wasn't aware of it, and I hadn't gotten some additional training and been able to use that as a supervisor to help  $n\bar{y}$  counselors, Mr. Horace Rabbit would still be sitting at home vegetating when he didn't have to.

I would like to close with saying, to keep pace with the enormous changes, we need rehabilitation counselors who are well equipped to work in this dynamic field. We also need more inservice training to educate those already working in the field.

The bottom line, Mr. Chairman, is the need for truly qualified, well-trained to serve the disabled persons and to facilitate their entry and reentry into the mainstream of American life. If this is to happen, there must be provided standards for those who will



work as rehabilitation counselors in our State/Federal program. We must provide adequate salaries to pay them; we must give additional tools and knowledge to the many excellent counselors who are already working in our State/Federal program; we must cut down on the caseload size; and we must work to ensure that adequate funds are made available to accomplish this:

I am afraid, sir, this will not happen without a strong Federal presence and strong Federal guidance. We in the National Rehabilitation Counseling Association want to work with you and we are very honored that you have allowed us to speak with you today.

Thank you very much.

[The prepared statement of Faith Kirk follows:]



### PREPARED STATEMENT OF FAITH S. KIRK, CRC, ON BEHALF OF THE NATIONAL REHABILITATION COUNSELING ASSOCIATION

<u>Mr. Chairman and distinguished members of the Subcommittee on Select</u> Education:

My name is Faith Kirk and I am hore today to present testimony on benalf of the National Rehabilitation Counseling Association (NRCA) of which I am the Legislative Subcouncil Chairperson. Currently I am the Executive Director of the Maryland Governor's Committee on Employment of the Handicapped. I am a Certified Rehabilitation Counselor (CRC) and have worked for 16 years in the State of Maryland in the rehabilitation field, first as a Rehabilitation Counselor and then Rehabilitation Supervisor, and now in my current position for the last five years.

It has been an honor and a privilege to be a part of the rehabilitation movement over the past years. I have been proud to be part of the State-Federal partnership whose goals are of the highest order...serving citizens with disabilities who desire to partake in the American dream and be independent and self-sufficient. As you pointed out so eloquently, Mr. Chairman, in your opening remarks at hearings just a few weeks ago, "despite our successes in the Vocational Rehabilitation program, we have a long way to go in developing the most comprehensive and effective program and that people with disabilities overall suffer between 50 and 80 percent unemployment...."

We cannot agree more with your statements and hope to provide you with our ideas to help make the Vocational Rehabilitation program better and more responsive to the recipients of our services, the consumer who is the focal point of our efforts.

Patricia Mundt, CRC, the President of NRCA, who could not be here with us today; has asked me to convey the following key points regarding the main element in providing quality service to the consumer of rehabilatition services...the "Vocational Rehabilitation Counselor". These points are provocative, yet realistic and completely achievable with congressional and administrative leadership.

- "Vocational Rehabilitation Counselor" does not equal Rehabilitation Counselor. These terms have been used very loosely and have not been defined adequately in the Rehabilitation Act or Regulations to implement the Act.
- 2. "Vocational Rehabilitation Counselor" as used by state personnel systems is merely a job title. The title, unfortunately, carries with it no standard criteria or qualifications as are carried by the Certified Rehabilitation Counselor (CRC). Those of us who conside ourselves professionals and who make up the membership of NRCA; have worked hard to develop criteria and standards that must be met to qualify for and obtain the title of Certified Rehabilitation Counselor.

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3. Congress\_needs to be encouraged to use the "CRC" .Certified Rehabilitation Counselor) as the standard for "qualified personnel" in the Vocational Rehabilitation Act and its Amendments. We find it strange that the Act and its Regulations define criteria and standards for doctors, psychologists and others who provide services to clients of Vocational Rehabilitation. The only mention made, however, regarding the standards for the cornerstone of the program, the "Vocational Rehabilitation Counselor", is the word "qualified" and nowhere is this defined.

To sum up these points, it should be clear that Vocational Rehabilitation at the state level is a program, and persons employed as counselors in these programs to serve disabled consumers must represent the best trained and qualified the field has to offer. If this is to take place, standards must be established in the Act and the word "qualified" defined.

In your hearings of June 11, 1985, Mr. Chairman, we heard from a number of recipients of State Rehabilitation services. One consumer from Maryland noted that, "it wasn't a lack of desire on the part of "Vocational Rehabilitation Counselers" to assist, rather wireasonable-sized caseloads and ill-trained counselors who were frustrated in their attempts to provide adequate and appropriate services." Another witness from Oregon voiced similar problems including the devastating remark that; "in Oregon, for example; the only including the devastating remark that; "in Oregon," for example; the only including the devastating remark that; "in Oregon," for example; the only including the devastating remark that; "in Problems including the devastating remark that; "in Oregon," for example; the only including the devastating remark that; "in Oregon," for example; the only including the devastating remark that; "in Oregon," for example; the only including the devastating remark that; "in Oregon," for example; the only including the devastating remark that; "in Oregon," for example; the only including the devastating remark that; "in Oregon," for example; the only include eleveloper is a college degree --- any kind of a degree!" These statements again vividly\_point out that without guidelines in the law and regulations persons are hired and called "Rehabilitation Counselors" even though some do not have the proper training, experience or background to perform the job properly.

Rather than dwell on the negative, it is time we faced the issue of how to best ensure that only the best, brightest, and well-trained people arconsidered qualified to work with disabled persons toward their rehat. Issive goals. Those of us in the profession of Rehabilitation Counseling take very seriously the needs of disabled persons and the complexities that are involved in the work of rehabilitation. Counselers need to evaluate interests, abilities; limitations; medical aspects of disability; personality development, perform job analyses; look at job modifications, occupational information, job placement strategies; similar benefits, post-employment services and then synthesize all of this information so that they can provide guidance, support and help to persons with disaoilities as they make appropriate choices and plans to take themselves from a state of dependency to independency and employment. In addition, they must also have a genuine cesire to work with individuals.

As you can see from this brief profile, there is no substitute for Well-trained individuals. Training, whether it is in-service or pre-service, takes time, effort and funds.



Further, to provide comprehensive and indepth service, counselors in the State-Federal program cannot continue to work with over-sized caseloads. In most areas of the country, counselors are carrying caseloads of 100-150 persons. These caseloads do not allow the time to do the job the way it should and must be done.

Add to the above equation the new technologies, the emphasis on supported work programs, an emphasis on severely-disabled persons, and new medical and bio-engineering techniques, and the need for pre and in-Service training and smaller caseloads becomes even more critical than it has been over the past decade.

While the field of Vocational Rehabilitation has various organizations at the national, state and local levels who are working to have these needed changes occur, we encourage a strong leadership and coordinative role for the Federal government, for without it what must happen will not happen.

We cannot turn over the role of training solely to the states to fund. For one thing, states may have very limited funds available and leadership that may have little understanding of the training need: of rehabilitation professionals. As an inducement for states to participate in training, nowever, an 80%/20% ratio of Federal and state dollars should be considered. We mist stop the erosion of Federal dollars available for pre and in-service training.

The need for technical assistance to a wide range of rehabilitation programs and facilities is an area that has been missing for the past six years. Prior to that time; technical assistance was handled by the Rehabilitation Services Administration (RSA) Regional Offices where they could dispatch experts to assist rehabilitation facilities in objective program evaluations and in the development of job finding techniques. This centralized Federal approach worked well. To my knowledge; nothing has replaced this formalized national network. I would urge, therefore, in this time when technical assistance is needed now more than ever, that funds be allotted for technical assistance to be handled once again by the mechanism already in existence, namely the 3CA Regional Offices.

Consideration must also be given to providing adequate funds so that more counselors can be hired by the individual state programs so that counselors can cut their caseload size without depriving disabled citizens an opportunity to obtain services or be put on a long waiting list. Another point which must be raised is the salary raid to "Vocational Rehabilitation Councelors" in the State-Federal program. In most areas, they are very low and do not provide a standard to attract the most qualified and brightest into the program. Many of these individuals are being courted by private rehabilitation and other work settings who provide better salaries, smaller caseloads, the opportunity to be more creative and freedom to do the job the way they have been trained to



I Would like to close this testimony with another gude from your opening Statement made of June 11, 1985, Mr. Chairman. You emphasized that "our society is in the midst of a series of changes to which the renocilitation system most respond. The technological revolution has the potential to completely respective what is possible in terms of renacilitation..." To keep pade with the enormous changes, we need Rehabilitation Counselors who are well-equipted to work in this changes, we need Rehabilitation Counselors who are well-equipted to work in this changes, we need Rehabilitation for the training to educate those already working in the field. The bottom line, Mr. Chairmon is the need for truly qualified, well-trained personnel to serve disable persons and to facilitate their entry or ne-entry into the mainstream of American life. If this is to happen, then we must provide standards for those will work as Penapilitation Counselors in our State-Federal programs. We must provide adequate salaries to pay them, we must give additional tools and knewledge to the many excellent counselors who are already working in our State-Federal programs, and We hist work to ensure that adequate functions are made available to accompliant this.

We also know from experience that a strong, sensitive and knowledgeatle Federal presence is realed to implement this vital program on a national basic. Please let us know how we can help you in your important task. The National Renabilitation Counceling Association is ready to assist. There you

Mr. WILLIAMS. Thank you.

Ms. Danek, as the administration moves to place seemingly ever more responsibility for delivery services to the State, local governments, and also to private agencies, the appropriate role of the Federal Government in providing leadership and support in this vital effort is brought into question.

Let me just ask you to respond in your specific area of expertise, what is the appropriate role of the Federal Government for the remainder of this decade or perhaps the 15 years left in this century?

Ms. DANEK. Well, as you know, I am an administrator of a preservice training program. I can see no substitute—I wish I could because it would certainly make things easier. I am not telling the administration anything they want to hear, and I know it. I wish there were some substitute for Federal expenditures for preservice training. It is an impossibility.

For instance, when I say it is an impossibility, I cannot see States picking up preservice training. I believe strongly in the need for preservice training as providing individuals with the foundation upon which to build.

But I do not see States picking up the cost of preservice training. First, they don't have the funding to do this. Second they have no assurance that the individuals that they train through 2 years of master's level training are going to then go to work for them. Without this kind of assurance, the States are not going to pick that up.

My other concern comes from my experience in my own program. We train for nationwide needs of deaf consumers. We have a training program in rehabilitation counseling which focuses on working with deaf clients. We are one of only two fully accredited, by that I mean core accredited, programs.

Our students come from all over the puntry. Without a Federal presence, there is no other way that the cost of these students coming to Washington and studying for fyears could be picked up. It is a 2-year, full-time program.

Did I respond to that?

There is no substitute in some areas for the Federal presence.



Mr. WILLIAMS. Ms. Kirk, you mentioned that the preservice education that is provided to counselors develops within them the appropriate skills and talents, however, they are unable to properly acquire those because of the ever-increasing caseloads.

It seems to me that that condition has existed almost without exception throughout the life of this national effort. If that is true, why are i't the training institutions teaching different skills and talents given the fact that we should have learned by now that those counselors are going to be overburdened with a caseload for which they are not being trained to handle.

Ms. KIRK. I have got to answer your question in two ways. First, I think we have to look at the fact that many of the individuals who get into our programs because there are no across-the-board qualifications are in different abilities to handle some of this.

If you have a master's program and you get a person with a master's degree, their ability to handle some of this is going to be a little bit better than, say, a person in some States that all you need is a high school diploma or undergraduate degree.

How do you train? There were many courses in time management that I was given as a rehab counselor and as a rchab supervisor, I had a master's though it wasn't a rehab counseling, I went beyond and got 60 credits in rehab counseling. In time management, there is only so much time in a day and you can only manage so much. Also many of the disabilities that were being dealt with back then were not as complex as they are now.

You know, with the emphasis on severely disabled, with closed head trauma, the learning disabled, and the severe emotional problems that we are now trying to deal with, they take a lot more time. There is a lot more complexity involved.

You can only do so much with time management. It doesn't ever change the fact that you can't deal with 200 people on a caseload.

Mr. WILLIAMS. Mr. Bartlett.

Mr. BARTLETT. I wonder-for either of you, really, what kind of training in job development, in job placement, do your counselors receive? Is it adequate? Could it be more? Does it work?

Ms. DANEK. OK. First of all, we have the Commission on Rehabilitation Education which sets standards for core curriculum in rehabilitation counseling. As a requirement, in order to be accredited, a program must have at least one course in job development and placement.

Of course, job placement is the reason for rehabilitation. The emphasis on placement permeates the other course work. But, yes, all programs do have at least one course in job development and placement.

We also have 600 hours of fieldwork experience as a requirement, and a great deal of the emphasis in the fieldwork experience is on job development and placement.

Mr. BARTLETT. Is the job placement and job development training adequate? Should there be an increase particularly in in-service?

Ms. DANER. Well, in preservice we are training for local kinds of skills. I think in in-service, you are really training for the setting. We are talking about different things and I think certainly it is a good thing. Certainly you have to constantly have courses to

inform you about new developments. So, yes, I would think that it would be for in-service.

Mr. BARTLETT. Some of the witnesses have hinted around or perhaps stated it directly that money spent—Federal money spent for inservice training has far more impact than Federal money spent for preservice training. Do you agree with that or disagree? How would you see the priorities?

Ms. DANEK. Well, again, just to reiterate what I said before. They complement each other. One cannot substitute for the other.

Mr. BARTLETT. Do you think the balance is about right now or are we spending too much on one and too little on the other?

Ms. DANEK. Well, the trend recently has been to spend less on preservice training. I believe that until we have fully qualified counselors, and by that I mean individuals who have a master's degree and who are certified, then we still need to put as much money as we can into preservice training to ensure an adequate supply of these individuals.

Now, if you put a person without the appropriate qualifications into a rehabilitation setting, within a couple\_of years and with a good healthy dose of inservice and continuing education, you will bring that person up to standards. Let's face it:

But what happens in those intervening years? From my own experience as a counselor, I had no exposure to deaf people when I went and worked for a State agency. I did have a master's degree. I made some terrible mistakes with my clients. In retrospect I feel terrible about it. I had absolutely no way cl understanding this population. I had no experience in deafness. I nad no exposure to the language or the population. I made some terrible mistakes; some terrible misunderstandings.

I learned.

Mr. BARTLETT. Mrs. Kirk.

Ms. KIRK. I agree with Marita, but I think we need to look furthe: How are the preservice dollars being spent. In the last year I have been informed and we have learned that in RSA they want to do a study in terms of undergraduate programming and we see that there is more money going into that.

Now, we have all of the research—we have, you know, reams and reams—that all of the profession has done and it is showing that the entry level needed for rehabilitation counselor is the master's degree program. An undergraduate degree is a more generic kind of thing.

I think we have to look not just at money but how is it being spent. The same thing for inservice. Every year our training officer gets the priority kinds of things that must be included in the training plan in order to get training dollars. They have to submit a proposal.

I think that we have to look more closely. It may be that even though this is a training priority for a national, they are doing OK in certain States in this area. But they really need to use those training dollars more in service for other kinds of things.

So that, again, more of an indepth look has to be given not just to the dollars but what are we using those dollars for.

Mr. BARTLETT. Let me ask you a specific question in terms of the use of those dollars. I have a list in front of me of the dollars expended for long-term training and established rehabilitation disciplines. The largest dollar expenditure of the entire list, which looks like some 15 items, the largest dollar expenditure is for rehabilitation medicine, \$2.5 million. That compares for less than that, but still around \$2.5 million, for rehabilitation counseling. Only \$350,000 for occupational therapy. Only \$540,000 for physical therapy; \$465,000 for job placement; \$50,000 for independent living personnel.

Do those ratios sound correct to you? Would you have the largest expenditure for rehabilitation medicine?

Ms. KIRK. I am trying to frame it in such a way—they are all very important. Certainly we need good medical individuals who understand disability as it relates to work, and don't look at people with disabilities as sick and we are going to put them in nursing homes.

On the other hand, medicine has been around for an awful long time. They have had a lot longer to get their act together and they have a lot of inservice training. For a doctor, one of the things I look at is how recent is he and what has he done in terms of keeping up.

The field of rehabilitation counseling has not been around as long as the field of medicine or the field of occupational therapy or some of these others, and so we still are in a critical need to make sure that we are training them.

In the beginning—and I think maybe that is one of the easons why people have never changed their standards or there are no uniform standards, there were no rehabilitation ounselves a nen the program started. So they were pulling them from related fields, from the field of education, from this field, and then hitting them real hard with lots of doses of training once the stat on the job.

That has changed: We have developed good training programs But we have got to use them and we also have to make sure that our State and Federal people are hiring qualified, certified rehabilitation counselors.

Mr. BARTLETT. Ms. Danek.

Ms. DANER. The situation with rehabilitation medicine and rehabilitation counseling, for example, is very different. There is a severe shortage of physiatrists. I understand almost a 100-percent demand for physiatrists, trained physiatrists. This is a new specialty in rehabilitation medicine. Their training is expensive. So those considerations are taken into account when supporting training programs.

Something else to look at, however, is that once a person completes a training program and become a physiatrist, they have an adequate standard of living and they have an adequate salary to justify the cost of the training. What I am saying is that in rehabilitation counseling, the salaries alone cannot be a draw for individuals to enter training programs the way they are in law, medicine, and other fields, which are very high paying.

We need a carrot. We have dedicated people. We have bright, conscientious people going into the field, but we need a carrot to induce them to enter our training programs. In that case it does not occur I do not believe in rehabilitation medicine.



The carrot is that they will have their 2-year master's level program almost completely paid for them, the cost almost completely covered so that they can afford-many of the individuals who come into our programs are employed professionals. They are giving up jobs, jobs in social services and allied areas, to come back and go through this training. It is a great sacrifice.

Even with the stipends and the tuition support, it is a great sacrifice for em.

Mr. WILLIAMS. We appreciate both of you being with us and sharing your thoughts with us today.

We now ask the last panel of the day to come forward, Mr. Cholette, Mr. Dew, Mr. Harles, and Ms. Novak-Krajewski.

I am pleased to have each of you with us. We need to end our hearing by 25 after the hour. It is now a quarter to. That would give each of you 5 or 6 minutes for your testimony and then 5 minutes to Mr. Bartlett and myself for questions.

If you run over that much, the time will have to come out of the next person to speak or Mr. Bartlett.

Mr. BARTLETT. If you run under, does the time accrue to me?

Mr. WILLIAMS. If you run under, the time accrues to Mr. Bartlett. That is our tradeoff today.

We are delighted to have you with us, Mr. Cholette: Please proceed.

STATEMENT OF ROBERT CHOLETTE, PRESIDENT, EASTER SEAL/ GOODWILL FOUNDATION OF NEW HAMPSHIRE AND VERMONT, REPRESENTING THE NATIONAL EASTER SEAL SOCIETY; DONALD W. DEW, DIRECTOR, TRAINING AND RESEARCH UTILI-ZATION, RESEARCH TRAINING CENTER, GEORGE WASHINGTON UNIVERSITY, REPRESENTING THE NATIONAL COUNCIL ON RE-HABILITATION EDUCATION; CHARLES HARLES, DIRECTOR, **GOVERNMENTAL AFFAIRS, NATIONAL ASSOCIATION OF REHA-**BILITATION FACILITIES; AND ALEXA NOVAK-KRAJEWSKI, CO-ORDINATOR OF PROGRAMS FOR THE DISABLED, DELAWARE **COMMUNITY COLLEGES, REPRESENTING THE AMERICAN ASSO** CIATION OF COMMUNITY AND TECHNICAL COLLEGES

Mr. CHOLETTE. Good morning, Mr. Chairman, and members of the subcommittee. My name is Robert Cholette, and I am the president of the Easter Seal/Goodwil. Industries Foundation of New Hampshire and Vermont. I am testifying today on behalf of the National Easter Seal Society.

I would 'ke to briefly summarize the national society's views and submit a more detailed statement for the record.

As someone with 20 years experience as chief executive officer of a nonprofit rehabilitation service agency, I appreciate the subcommittee's interest in personnel training, technical assistance, and service delivery under the Rehabilitation Act.

These activities are critical to the provision of effective and appropriate rehabilitation services. Easter Seal affiliates participate in virtually every aspect of service delivery under the Rehabilitation Act.





In over 30 States Easter Seal Society serve vocational rehabilitation clients under cooperative agreements with State agencies. In New Hampshire, Easter Seal is the largest nonprofit provider of State vocational rehabilitation services.

Three Easter Seal Societies act as client assistant programs under title I, and many more operate projects with industries, centers for independent living, and special recreation programs.

Recently Easter Seal affiliates have expressed an interest in transition services, supported employment, and related Federal initiatives. The Rehabilität Act places considerable emphasis on the utilization of nonpromeorganizations in the provision of services.

For this reason, the National Society firmly believes that, one, the Federal Government has a major stake in the competence and success of nonprofit rehabilitation service providers; and, two, that resources under the act be invested in these providers at a level commensurate with their delivery of rehabilitation services.

Service providers like Easter Seal are frustrated by the shortage of qualified rehabilitation professionals. Although the Rehabilitation Training Program supports preservice and continuing education programs, it traditionally neglects the unique staffing needs of nonprofit ervice providers. As a result, it illities lack staff and must delay, even deny reha-

As a result, it illities lack staff and must delay, even deny rehabilitation in the state of the staff and must delay, even deny rehabilitation in the state of the state

The National Society believes that the preservice training grant allocation process must be revised to accurately respond to nonprofit agency requirements. We were encouraged by congressional mandate to link grant allocation to areas of documented personnel shortages. However, RSA he were very slow to implement the system.

It is equally important to increase postemploy ient training opportunities for community-based person sel under the act. Inservice grants are almost always awarded to State vocational rehabilitation agencies to provide continuing education to their employees.

Rarely are community-based rehabilitation professionals included in these training exercises. The national society recommends that preference be given to State agency inservice training proposals which include nonprofit facility staff.

We also recommend that a distinct program priority be established which promotes inservice training for nonprofit rehabilitation professionals.

Under cooperative agreements with State agencies, nonprofit facilities are active partners in a provision of comprehensive vocational rehabilitation services. Unfortunately, the per diem payment method used by State agencies frequently places facilities at a financial risk.

Under cooperative agreements, facilities typically operate vocational rehabilitation programs for State agency clients. To do this, facilities must commit resources, including staff, equipment, and building space. Problems for facilities arise when State agency compensation, which is based on a projected client utilization, fails to cover the true cost of maintaining program capacity.



For example, in New Hampshire, Easter Seal recently received a \$117,000 vocational rehabilitation grant to construct transitional building units. State agency clients are housed at an established daily rate, but because of the status "temporarily out of vocational rehabilitation services money," it cannot refer clients. Without expected referrals, our costs per client have increased

Without expected referrals, our costs per client have increased dramatically. However, no adjustment has been made to the daily rate by the State.

The national society recommends that State agency methods of payment for services be revised to reflect the actual cost incurred by the nonprofit facility in serving the vocational rehabilitation client. Vocational rehabilitation counselors generally view job placement as a State agency function.

We appreciate the opportunity to submit this testimony, and for the National Society and myself, we thank you.

Mi. BARTLETT [presiding]. Your entire testimony will be made part of the record.

Mr. CHOLETTE. Thank you.

[The prepared statement of Robert Cholette follows:]



PREPARED STATEMENT OF ROBERT CHOLETTE, PRESIDENT, EASTER SEAL-GOODWILL INDUSTRIES FOUNDATION OF NEW HAMPSHIRE AND VERMONT ON BEHALF OF THE NATIONAL EASTER SEAL SOCIETY

Good morning, Mr. Chairman and members of the Subcommittee. My name is Robert Cholette and 1 am the President of the Easter Seal-Goodwill Industries Foundation of New Hampshire and I am testifying today on behalf of the National Easter Seal Society:

The National Society is a private, nonprofit agency dedicated to helping persons who have disabilities reach their full potential. Easter Seal Societies provide a wide range of renabilitation and related services; including physical, occupational and speech-language therapies, vocational evaluation and training; camping and recreation; educational services, psychological counseling and support services. Last year, more than one million people received Easter Seal services nationwide.

As someone with twenty years experience as chief executive officer of a nonprofit rehabilitation service agency, I appreciate the Subcommittee's interest in personnel training, technical assistance and service delivery under the Rehabilitation Act. These activities are critical to the provision of effective and appropriate rehabilitation services.

Easter Seal affiliates participate in virtually every aspect of service delivery under the Rehabilitation Act. In over thirty states; Easter Seal Societies serve vocational rehabilitation clients under cooperative agreements with State Agencies. In New Hampshire, Easter Seals is the largest nonprofit provider of vocational rehabilitation services. Three Easter Seal societies act as Client Assistance Programs under Title I and many

more operate Projects With Industry, Centers for Independent Living and Special Recreation programs. Recently, Easter Seal affiliates have expressed an interest in transition services; supported employment and related federal initiatives.

The Rehabilitation Act places considerable emphasis on the utilization of nonprofit organizations in the provision of servies. Under Title I; nonprofit renabilitation facilities provide evaluation; treatment and training services to assist people with disabilities to become employed. These facilities vary considerably in size, range of services are sophistication. In every instance, however, they are devoted to delivering high quality, cost-effective rehabilitation services. It is estimated that more than twenty percent of vocational rehabilitation services financed annually by State Agencies are delivered in nonprofit rehabilitation facilities:

Voluntary agencies are major participants in discretional v program development activities under the Act. They demonstrate innovative service programs in special recreation; on-the-job training; independent living and other rehabilitation-related areas. In addition; these agencies are often the site of a vast array of support services.

For many individuals with disabilities, community-based rehabilitation centers represent a major force if their lives. Facilities and staff are a vital source of encertonal support and skilled assistance through which personal fulfillment, independence and vocational goals can be achieved.

For these reasons, the National Society firmly believes that: one) the federal government has a major stake in the compe-



tence and success of nonprofit rehabilitation service providers; and two) that resources under the Act be invested in these providers at a level commensurate with their delivery of renabilitation services.

Service providers like Easter Seals are frustrated by a shortage of qualified rehabilitation professionals. Although the Rehabilitation Training program supports preservice and continuing education programs, it traditionally neglects he unique staffing needs of nonprofit service providers: a result, facilitic lack staff and must delay and even deny renabilitation services to eligible individuals. Personnel shortages have, in many areas; created a "seller's market" among trained rehabilitation professionals. To attract staff, facilities must pay increasingly higher salaries; which drives up the overall cost of service delivery:

Additionally, frequent staff turnover drains away scarce facility resources through ongoing hiring and orientation activities. This problem is particularly evident in fast-prowing state: like New Hampshire and Florida: Nonprofit administrators attribute the high rate of staff turnover, in part, to the lack of continuing epication opportunities for facility-based remahilitation professionals.

The National Society believes that the Act clearly intended for the staffing needs of nonprofit rehabilitation facilities to receive equitable attention under the Rehabilitation Training program. We are convinced that immediate action is needed under this program to insure that skilled facility-based professionals



are available to meet the needs of people with disabilities.

The preservice training grant allocation process must be revised to accurately respond to nonprofit agency requirements. We were encouraged by the Congressional mandate to link grant allocation to areas of documented personnel shortages. However, RSA has been very slow to implement this system.

It is equally important to increase post-employment training opportunities for community-based personnel under the Act. Inservice grants are almost always awarded to State Vocational Rehabilitation Agencies to provide continuing education to their employees. Rarely are community-based rehabilitation professionals included in these training exercises. The National Society recommends that preference be given to State Agency inservice training proposals which include ranprofit facility staff. We also recommend that a distinct program priority oe established which promotes inservice training for nonprofit rehabilitation professionals.

Under cooperative agreements with State Agencies, nonprofit facilities are active partners in the provision of comprehensive, vocational rehabilitatio: services: Unfortunately, the per diem payment method used by State Agencies frequently places facilities at financial risk.

Typically, cooperative agreements require facilities to operate vocational rehabilitation programs for State Agency clients. To do this, facilities commit resources, including staff, equipment and building space. Problems for facilities arise when State Agency compensation, which is based on client utilization, fails to cover the true costs of maintaining program

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For example, in New Hampshire. Easter Seals received a \$117,000 vocational rehabilitation grant to construct transitional housing units: State Agency clients are housen at an established daily rate. But, because the State is temporarily out of vocational rehabilitation monies, it cannot refer clients. Without expected referrals, our costs per client have increased dramatically. However, ho adjustment has been made to the daily rate paid by the State.

The National Society recommends that State Agency methods of payment for services be revised to reflect the actual costs incurred by nonprofit facilities in a ling vocational renabilitation clients.

Vocational rehabilitation counselors generally view job placement as a State Agency function and are reluctant to pay facilities for such services. However, community-based facilities are ideally situated to place vocational rehabilitation clients directly into jobs. In fact, such placement is often an integral part of their service program. The National Society recommends that State Agencies be encouraged to use and duly compensate community-based facilities for job placement services.

Technical assistance under the Rehabilitation Act is invaluable to nonprofit service providers. Facility administrators are continually searching for new ideas and alternatives to enhance the cuality and delivery of rehabilitation services. However, ted iccal resources raiely permit the use of expensive program consultants. As a rejuit, service providers are restricted in their ability to implement program improvements or

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initiate innovative services in response to community needs.

As recently as 1981, RSA coordinated the matching of consultents to the needs of space fic rehabilitation service providers: Expert consultants provided technical assistance on a wide range of topics, including accounting, contract producement, safety, work evaluation, engineering and program services. The rewards of this program were many. Facilities benefited enormously from on-site consultation and subsequent implementation of expert recommendations. RSA, which received detailed reports on each consultation, acquired state-of-the-art information in matters : interest to rehabilitation facilities. This information was then disseminated nationwide for use by other rehabilitation service providers.

Furthermore, the rehabilitation community realized a substantial cost-savings under this program. Federally-sponsored assistance costs less than comparable consultation purchased in the marketplace. Unfortunately, these activities were curbed under the 1978 Amendments and eliminated four years ago:

The National Society proposes the the Rehabilitation Act be amended to restore the statutory authority for technical assistance; as it existed prior to 1978. We recommend that Title III, Part A; of the Act be amended to include a section entitled "Technical Assistance"; which reads:

- "(1) The Secretary shall provide by contract with experts or consultants or groups thereof; technical assistance --
  - (A) to rehabilitation facilities; and
  - (6) to any public or provate agency; institution, or facility.



(2) In order to carry out this section; there are authorized to be appropriated such sums as may be necessary:"

The National Society strongly supports this amendment: At an average estimated cost of \$1,000 per consultation; this technical assistance program represents a sound means of helping honprofit rehabilitation facilities serve people with disabilities.

In our view, restoration of a technical assistance program represents one of several rederal initiatives needed at RSA to bolster support for nonprofit service providers: Easter Seals recommends that a facilities unit be established within RSA to coordinate programs and policies affecting public and private rehabilitation facilities: A major role of the unit would be the provision of guidance to facilities regarding the implementation of new federal initiatives, including transition services and supported work.

Similarly, we support the immediate reactivation of the Facilities Task Force at RSA. The Task Force, comprised of RSA staff and representatives of national rehabilitation service providers; provides a regular forum to discuss issues and polcies affecting rehabilitation facilities and the individuals they serve:

Lastly, the Nationa Sciety is concerned about the dramatic loss of staff at RSA over the past few years. Since January, 1984, the RSA workforce has been reduced by about sixteen percent, or the staff positions. Most of the reduction has occures at the SA central office. We unge the Subcommittee to review this situation and take any action needed to insure that a

reduced workforce does not impede RSA's ability to effectively carry out its federal responsibilities:

I am pleased to have been given the opportunity to testify before the Subcommittee. On behalf of the National Easter Seal

Society and myself, thank you for considering our views.

Mr. BARTLETT. Mr. Donald Dew.

Mr. DEW. Yes, sir; thank you.

We have, of course, written testimony. We have that for the record, and I think I could best use my time by sharing with you five points that are of interest to the National Council on Rehabilitation Education.

First let me say that I am from George Washington University and might be in trouble. I have a joint appointment, one in the medical school where for a number of years we had a rehabilitation me licine grant. That is not the case now. We also have a Regional Rehabilitation Continuing Education Program and a Graduate Counselor Folucation Program with the Department of Education.

First, let me say that the National Council on Rehabilitation Education represents over 100 colleges and universities around the country who have as their interest and concern both preservice and inservice and continuing education and that we work extremely close with the Council of State Administrators, the National Rehabilitation Association, and other organizations who are interested in serving disabled persons.

The comments made earlier today by Commissioners Baxter and Dickerson regarding technical assistance are completely 100 percent supported by our organization. Technical assistance as related to grantees and certainly State agencies as Baxter and Dickerson indic ted is literally not available.

Multoring is somewhat in effect via telephone, but good technical assistance, regardless of what people tell you, is not there.

Directly related to training and both preservice and inservice and continuing education—one of the issues clearly seems to be what are we doing to ensure that training needs are changing as the needs of rehabilitation change, and what are we doing to keep up with the needs of people that serve disabled persons.

One of the groups that I think quite often take somewhat of beating are graduate programs in rehabilitation at universitie. What they are criticized for is that you are just not keeping up the new technology and the needs of the practitioners.

I would suggest to you that as long as RSA and other Federal organizations on an annual basis chan  $\rightarrow$  their priorities, a list which looks six and eight long, that is not the place for graduate training programs to change every semester what they offer to professionals that are going to be qualified to work and serve the disabled.

Now it is not to say that programs are not available for special courses and course programs, we need to constantly evaluate our curriculum. We do that. That mechanism is in place.



The basic body of knowledge, good counseling skills, good medical information activities are basically constant, and that is not the place to make those changes. Where we do try to impact on acute issues in rehabilitation are the inservice training and the continuing education program.

I would like to give you an example of the region that I am in, region III, and something that we did last year, which I think points this out, and then share with you another problem that we have. Last year it was decided that clients who suffer head injuries would be a regional which ty. We needed to really get in there and develop programs a. present this information to primarily State rehab counselors and, in addition, rehab facilities people. About 20 percent of ur total moneys go into providing training for rehab facilities people.

In addition, as we all know, the initiative of transitioning from school to work is an issue that we needed to develop training programs on. In a matter of months, in less than t months by pulling together the continuing education program, the inservice training programs, the counselor education program at George Washington University, the R&T Center at George Washington University, two regional resource training centers, and a number of professionals that work with the National Head Injury Foundation, and so on, we developed programs in both of these areas and delivered the programs in less than 6 months to over 300 rehabilitationists and developed programs for followup:

So the vehicle is in place, I think, in terms of in-service, continuing\_it, and also the importance of working together to make an impact on these issues.

Now, we come into one of the problems. Next year the priorities will not have head injury in it, most likely. I suspect we will have transitioning, but we will have another list of three or four different kinds of areas that we should give priority. This is where I think some of the difficulty comes in terms of trying to develop programs. We turn around having new priorities and it makes it very difficult for people that are involved in training and education.

It is being done and I think there are vehicles for doing both. But it is not an either/or.

In addition, this area of job placement and making impact on job placement, there has been a mechanism put in motion that a national consortium made up of 11 universities around the count y receive annually about \$400,000 which works out to something like \$30,000 at each university. These universities are located in all of the 10 regional offices and their primary focus for the past 3 years has been to develop programs specifically related to job development and job placement and they have been doing this job.

There is evidence in region IV in terms of numbers showing that there are more placements in some of the States in that region as a result of this continuing education training.

Finally, the notion of new technology in training—we get hit with this quite a bit. There are some people that would lead you to believe that you can throw up a satellite and train everybody around the country. That is one way to de



If you are training in the area of counseling skills, some of the skill areas, skill development, you do need a classroom, you do need one-on-one, you do need itedback.

Now, you should be using, I think, dec tape. You should be using some of the otner technology. But, again, it is not this business of technology, the satellites doing the whole job, it is just not there.

Finally, I think that, Mr. Bartlett, your comment about . . . neys are just not going to be available, there is no sense in comine here each year saying "we need more money, we need more money," that is going to be an up-hill battle. So we have got, I think, be able to demonstrate that we are—those of us in education and training working together to ensure that we are not duplicating and that we are not—that we are working as best we can as an organization and as separate groups to ensure the training is delivered.

I believe that we are doing that. My example about region III and that training conference that brought together approximately six organizations, both their money and their talent, demonstrates that we are trying to move in those areas.

Thank you very much.

Mr. V LLIMS: Thank you very much.

[The p: d statement of Donald Dew follows:]



## PREPARED STATEMENT OF DONALD WILSON DESCED.D., PAST PRESIDENT, NATIONAL COUNCIL ON REHABILITATION EDUCATION

fr. Chairman, Members of the Subcommittee, ladies and gent ment. My name is Donald Wilson Dew, Associate Professor of Education at The George Washington University, and Past President of the National Council on mehability on Education (NCRE); an organization composed of educators, training ۰s. researchers and students. We prepare and maintain the competencies - t y of rehabilitation personnel the assist a portion of this nation's millions of disabled Americans needing rehabilitation services to find employment and to live independently. Our organization, which represents over a hundred universities and colleges, works closely with the Council of State Admir strates of Vocational Reharilitation (CSAVR), the National Rehabilitation Association (NRA); the National Rehabilitation Counseling Association (NRCA); and the Presdident's mittee on Employment of the Handicapped (PCEH). Over the years our membership has assisted the Rehabilitation Services Administration (RSA) of the U.S. Department of Education by conducting surveys and study is related to our training mission and the needs of the state/Federal Vocational Rehabilitetion program. In addition to conducting and participating in training needs assessments at regional and national levels; NCRE members have participated on committees and trask forces which have as their mission the review and development of strategies which make our ultimate training and rese ich efforts both meaningful and productive.

I am pleased to have this opportunity to provide testimony on issues



Or June 11th; I sat in the rear of this Committee Roum as a spectator stening to consumers discuss their experiences, both positive and negative, the with this Hation's State/Federal Vocational Rehabilitation program. Concerns presented by the panelists were directly related to training and educational needs of professionals working in the rehabilitation field today. Also, I listened to representative. from such consumer organizations as the National Head Injury Foundation as they discussed many issues which, in order to resolve; will require quality pre-service and in-service training as well as continuing education. Of course; it is very clear that training is not the total answer for many of the concerds that we have as we serve this decion's disabled population. Training, for example, cannot replace good leadership nor can training take the place of adequate funding to insure that programs are established and continued. Iraining can, and does, affect personne, preparation and skills which are directly related to outcomes. This, in turn, translates into more effective client services.

A look at the funding for training within the Rehabilitation Services Administration over the past eight years shows a decrease from \$30,500,000.00 in 1576-77 to \$22,000,000.00 for 198: -55 This came at a time when additional emphasis was being placed on services to severely disabled persons, when the Rehabilitation Services Administration's priorities changed annually, and when many states were undergoing personnel changes. During these years many university programs were terminated and competent, well-trained faculty were forced to leave Universities and colleges or go into other fields.

The Rehabilitation Act as it exists today is comprehensive and balanced legislation which allows for creative services to be provided to a wide tange of persons with disabilities.

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A rehabilitation counselor today can develop in Individualized Written Rehabilitation Program (IW-1) for his or her client tallore toward comprehensive evaluation or assessment. They are able to provide vocational training, counseling and guidance, placement assistance and post-employment services: The IWRP is only limited by the counselor's and client's own creativity; but unfortunately itequal program and funding are often not available. Our problem is simply that which only serving a fraction of the keep up with the demand for new qualified counselors and the training needs of employed counselors and adminise rators. This is not because of the Rehabilitation Act and existing training program, but the funds to fue, the programs have been lacking. The Rehabilitation Act allows for the opportunity to provide comprehensive services and should not be changed:

Trose educators and trainers associated with, and the supporters of, pre-service, in-service and continuing education training programs continue to to responsive to the everchanging training needs of rehabilitation personnel. While flexibility is important it must be understood that two-year graduate programs in rehabilitation counseling; facility administrat in and vocational evaluation, for example, cannot and should not change core content ennually. There are basic bodies of knowledge and skills which need to remain constant. This is not of each of example, it special coursework cannot be developed to focus on a select topic or issue. University graduate programs have the mechanism to accide this, the better vehicle for addre ing acute issues has been in-pervice and continuing education programs. Last year in RSA Region III, my redom, it was decided to develop a training program to address services related to head injured individuals and also specific training related to the craisitioning of clichts from school to work: in matter of mont comprehensive programs were planned and the vertice is nearly 500



rehabilitationists from state agencies as well as from private rehabilitation facilities. We pulled together personnel and monies from state in-service training programs, Regional Rehabilitation and Continuing Education Program's, Regional Resource Centers, Research and Training Centers, and professional associations in planning. Materials developed for these programs were used by rehabilitation inselor education programs. This same scenario goes on around the country.

Mr. Chairman, I can tell you the muchanism for educators and trainers : respond quickly to changing training needs of rehabilitation personnel is in place and working: I must also say that at times, this mechanism is overused. We cannot continue to offer quality programs to a larger audience with fewer --ainers and educators on limited dollars. We cannot continue to respond to what some call the "disability of the month training syndrome" without more indepth planning and follow-up training. We need a comprehensive national training plan which is a product of the best thinking of all persons interested and affected by training.

The field of rehabilitation today is exciting. New advances in cechnol ., procedures and practices are being explored and advanced daily. Our rehabilitation research programs continue to focus on creative issues while reducing the dissemination/utilization time required to put findings :... use: What is missing today is a technicial assistance program: Traditional., this has been a role carried out by the Penabilitation Services Administration Regional Offices, but monies ar simply not available for technical assistance purposes such less for .c.: e on-site contact with State Vocational Rehabilitat Apencies.



adequate travel and support funds for this purpose. If dan-s little sense to have experienced, well-trained personnel office-bound.

In Summery, we ask renatilitation personnel to perform a number of highly skilled tasks today. They and to understand medical conditions, know evaluation and assessment productes; and be skilled in counseling and placement and be familiar with community resources. In the morning the rehabilitationist may see Clists in a helping relationship; and in the afternoon he or she may meet with employers to discuss job modification. All of this and more is done for several disabilities which affect many individuals differently.

Disabled persons deserve the right to have qual: ed personnel assisting with the rehabilitation process. State agencies need to employ qualified staff from recognized training ograms. Rehabilitation personnel must have the opportfunity to keep abreast of new practices and technical assistance must be available when needed.

The Rehabilitation Act presently allows for preparation, training and continuing education. What is needed now is federal commitment, leadership, funding, and action. We stand united and resay to assist your Committee in any way possible to acheive our mutual goal of ensuring quality rehabilitation services to disables persons through the preparation of qualified personnel:

On Sehalf of the Meridual Council on Rehabilitation Education, than you for this opportunity to share our concerns and hopes.





Mr. WILLIAMS. Mr. Harles.

Mr. HARLES. Mr. Chairman, my name is Charles Harles, and I am associate director of the National Association of Rehabilitation Facilities. We are an association of over 500 rehabilitation facilities and 21 affiliated State chapters.

Our stated purpose is to enhance the capacity of facilities to provide quality services to disabled people. Let me talk briefly about our training and technical assistance. Rehabilitation would not be the successful program it is today were it not for the cadre of trained professionals who provide these services.

The strength and effectiveness of the program is dependent upon an adequate supply of training competent practitioners. It is estimated that rehabilitation facilities alone will need between one and 200,000 new staff before 1990 given the growth of the programs just over the past several years. This need for additional personnel is obviously compounded by recent efforts to reduce Federal funding available for training programs.

NARF was pleased when OSER: announced early this year its report to Congress on training needs that new categories and new emphasis will be placed on training rehabilitation facility personnel. The increased emphasis on job development, placement, support work and transitional programs is also wellowe, and there is a need to cognize that vocation evaluation and work adjustment are also areas where there is a continuing need for trained personnel to provide adequate services.

While the recognition e' the priorities by OSERS has acknowledged the overall support for training programs, obviously something to be desired with the actual reduction in actual dollars available for training going down substantially in the period between 1980 and 1985. Even the current level of \$22 million d esn't come close to meeting the minimal needs of these programs.

While program funding should be based on a real and identified need, the obvious should not be ignored while these various surveys and studies are being developed. I brought the very same study with me that you showed earlier as being an example of a good study of the needs and how to address them basically being ignored by the administration.

Recently I talked to one university program that had o job listings for the 70 to 80 students they had graduatiarea of vocational evaluation, for instance, just showing need there.

Training programs for ded by RSA basically fall into four case gories: preservice, inservice, long-term and short-term training. While the division between these types of grants has been fairly reasonable. I think it is particularly important that special attention be placed on the inservice and short-term programs.

It is under these two types of programs that training can respond quickly to the changing needs and emphasis and get training quick ly to the people who are providing the direct service to disabled people, and it should be noted, as has been stated earlier, these short-term inservice programs should be readily available to both State VR counselors and to persons employed in rehabilitation facilities.



It also needs to be acknowledged that there are a variety of ways of getting these training programs to the people that need them in addition to traditional according programs. There are some areas of need for training that we have observed over the past several years. One is in the area of training potential counselors to deal with the wide variety of potential funding countee in programs and not just the State/Federal relevant of the diag countee in programs. Within rehabilitation factor

Within rehabilitation factor is once of many spaces of program help to disabled persons. It is and its such as dob Training Partnership Act, developmented discusses to the XX, but a whole gamut of local and State programs as well that they used to be just as well versed in. Counselor to think a bob needs to model more focus on Social Security, SSI, and other incentives in this program so that they can help disabled people 7 or 2

One of our most recent publications is a rocklet that we are providing as a public service called "Social curity Incentives To Work' just to help identify to counselors both within facilities and in other settings that there are at least some incentives to work within the Social Security system: There are needs to improve those, like making sections 1619 permanent, and some other things Mr. Bartlett is well aware of, but we decided at least make a start in making people aware that there are some incentives there already.

We wish to emphasize that there is a continuing need to train persons to do job development and job placement. I think especially we need to note that we need specialists in these areas, and not just counselors who have some training in job placement and job development. We have discovered, especially through the projects with industry-type programs that when you put a person whose only job is to do job development and job placement and put them in a position where they can work directly with clients and directly with private industry, that is where you get very high placement rates with that 1-to-1 type relationship. With that being their only responsibility, not having 8 or 10 other responsibilities they must look after at the same time.

With regard to te nical assistance, I think suffice to say that the situation prior to 1978 was a program at least for rehabilitation facilities which offered probably the lowest cost program within RSA but had some of the highest impact; \$250,000 a year was as high as it ever got. But they were able to provide more than 300 consultations a year and that included the cost of the consulting fee to the experts, as well as their travel. This went a long way in getting information to people very quickly and in places where they could not very easily take advantage of university programs or other types of training programs. This is especially important in rural areas, for instance, where a workshop just can't afford to send somebody to Chicago for a training program.

- They could have someone sent to them quite often to look at a particular problem, and we recommend—we made it more specific in our written testimony—what was considered at the time a technical glitch in the 1978 amendment should be fixed so that they can reestablish a similar program and to expand that program so that it the proactive. In that, we can send experts for instance, into smaller rural places and into smaller facilities to talk about

supported work, talk about transition programs, things like this

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supported work; talk about transition programs, things like this that quite often they only get to read about. They can't get into these other programs where they can get their hands-on experi-ence. This would give them that opportunity. We would be glad to provide additional testimony. One of the areas that we certainly hope that the subcommittee will be looking at as it continues this series of hearings over the next couple of months is h, the area of the providing of services, how are they provided, how might we be able to do it more efficiently and we would certainly be glad to provide testimony in that area when apwould certainly be glad to provide testimony in that area when appropriate. Thank you.

[The prepared statement of Charles Harles follows:]



PREPARED STATEMENT OF CHARLES W. HARLES, ASSOCIATE DIRECTOR, GOVERNMENTAL AFFAIRS, NATIONAL ASSOCIATION OF REHABILITATION FACILITIES

Good morning Mr. Chairman. My name is Charles Harles. I am Associate Director, Governmental Affairs, for the National Association of Rehabilitation Facilities.

The National Association of Rehabilitation Facilities is a membership organization composed of cver 500 rehabilitation facilities and 21 affiliated state chapters. Its stated purpose is to enhance the capacity of facilities to provide quality services to disabled persons. This purpose is achieved through various activities including educational, technical, legislative, public relations and administrative means.

As a voluntary membership organization, NARF provides leadership to rehabilitatic ties. This leadership is particularly exemplified in the f employment programs for handicapped individuals. tional Association of Rehabilitation Facilities oper a national On-Job-Training project for the U.S. Department of Labor and a national Projects with Industry rogram for the Department of Education. Through these innovative programs, the Association has been able to develop a wide range of employment opportunities for handicapped people through skills training at the job site, enclaves in industry and work experience programs.

During the past decade, there has been a major shift in the expectations of handicapped persons, the federal government and service providers on the most app opriate technique for improving the independence and quality of rife for handicapped persons. PL 94-142, The Education for all Handicapped Children Act, the Rehabilitation Act of 1973 as amended, and the Develop-



mental Disabilities Assistance and Bill of Riches Act have integrated disabled persons into the mainstrea and the sty. From the view that handicapped persons could bear be an a protected sheltered environment we have evolved to a compliment to deinstitutionalization, normalization and the least restrictive environment.

This morning I would like to briefly address the issues of training and technical assistance from the perspective of rehabilitation facilities. Both issues are vitally important to the continued improvement in the provision of rehabilitation services.

## TRAINING

Rehabilitation would not be the successful program it is moday were it not for the cadre of trained professionals who provide rehabilitation services. Training programs funder the Rehabilitation Act of 1973 have played an important role in assuring that well qualified persons have been availarie to fill those jobs.

The strength and effectiveness of rehabilitation facilities is dependent upon an adequate supply of appropriately trained and competent practitioners. It is estimated that rehabilitation facilities will need no attract 100,000 - 300,000 new staff by the year 1990. This need for additional personnel is compounded by the Administration's efforts to reduce federal funding available for training rehabilitation personnel.

À recent study by the University of Wisconsin, Stout Vocational Rehabilitation Institute, projects facility manpower needs



through 1990. In 1980, the average facility employed 23 staff in managerial, service and production roles. By 1981, the average facility was employing 26 persons. This 13 percent annual growth rate is not expected to be maintained but the average facility is expected to employ 35 staff in 1985 and 42 staff by 1990. This means 9 more trained staff per facility by 1986 compared to 1981 and 12 by 1990. Despite efforts by the education and rehabilitation communities, the federal funding for training of rehabilitation personnel declined from \$30.5 million in fiscal 1979 to \$19.2 million in fiscal 1983. \$22 million will be spent in fiscal 1985.

Approximately \$1.3 million will be available in fiscal 1985 for training in rehabilitation facility administration and provision of facility training through the regional continuing education programs. In order to meet the manpower needs of facilities during the coming decade, it appears that three major markets will need concentration. These are: the traditional degreeseeking student for which most college programs were developed and which is the major source of new entrant into the facility employment market; the experienced, employed room in a facility seeking advanced training in his/her own stalization or in a secondary area; and finally the long of more term training required by persons needing retraining of an area somewhat slightly unfamiliar to previous levels of experience.

NARP was pleased when OSERS sent its report on training needs to Congress earlier this year that new categories and new emposes was being placed on training rehabilitation facility d: conel. The increased emphasis on job development, placement,



supported work, and transitional programs was also welcomed. There is also a need to recognize vocational evaluation and work adjustment as areas where there is a continuing need for trained personnel to r intain adequate services.

While the Tells is tion of priorities by OSERS is acknowledged, the overall Fupport for training programs leaves something to be desired. Funding for training programs declined from 530.5 million in FY 1980 to \$19.2 million in FY 1983. Even the current level of \$22 million does not come close to meeting minimal needs. In its April report to Congress it was stated that there was inadequate supply and demand data available and that therefore no new training programs would be funded in FY 1986. The Administration's attempts to cut funding to all time lows defies rationale:

While program funding should be based and identified need, the obvious should ... be is tell while surveys are developed and analyzed. Re there were over 1,000 job listings for the 70 to 50 students graduating from one university program that specialized in training vocational evaluators.

Training programs funded by RSA fall into four broad categories. They are pre-service training, in-service training, long-term and short-term training. While the division between these types of grants has been fairly reasonable, NARF thinks it is particularly important that special attention be paid to inservice and short-term programs. It is under these two programs that training can respond quickly to changing needs and new



emphases and gets training quickly to the people who are providing direct services to disabled persons. It should be noted that these short-term; in-service training programs should be readily available to both state VR counselors and to persons employed in rehabilitation facilities. It also needs to be acknowledged that various methods of providing training need to be utilized to bring the training to the most people in the most efficient manner.

NARF is a strong supporter of providing training programs to the rehabilitation field. During the past two years NARF has provided training in the areas of financial management for rehabilitation facilities to help them be more efficient; provided a series of seminars on how to develop Progree Wich Industries Advisory Councils; conducted a national seminar on producing products for state use made in rehabilitation facilities; and produced and distributed thousands of manuals on subjects such as Supported Work models, establishing PWI's, and Wage and Hour compliance. NARF has recently been awarded a major grant by the Administration on Developmental Disabilities that will disseminate information to the rehabilitation field and the business community on how persons with developmenta' disabi'ities can be competitively employed. NARF has recently applied for a training grant from RSA to provided short-term training to facility and state VR personnel to enhance their skills in supported work programs and to encourage greater involvement of advocates, hundicapped individuals and parents in this employment option.

There are some areas of need for training that NARF has observed over the past several years. One is a need to modify



training of potential counselors to deal with a wide variety of potential funding sources and programs; not just the statefederal rebabilitation program. Within rebabilitation facilities VR is one c. many sources of programs to help rebabilitate disabled persons. Programs such as the Job Training Partnership Act, Developmental Disabilities programs and a variety of state programs for persons who are montally retarded or emotionally ill are all utilized as well as private insurance. Counselor training also needs to include more focus on Social Security, SSI and especially the incentives in those programs that help disabled persons work.

We wish to emphasize that there is 7 continuing need to train persons to do job development and job placement. Programs such as PWI have shown that placements can be significantly increased if there are persons whose only job is to work with private industry on jot placement for specific disabled persons. While there is language in the current law identifying these two job categories for special consideration even more emphasis would be he: ful.

This Subcommittee also needs to be aware of a majo: national task force on training that was convened by RSA between 1982 and 1984. That task force, comprised of national leaders in the field of rehabilitation training, made recommendations to RSA on the development of a management system to meet the Congressional mandate to determine manpower needs and to collect data to document those needs. I have given staff copies of this report dated March 21, 1984.

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## TECHNICAL ASSISTANCE

Prior to 1978 technical assistance to rehabilitation facilities was an important form of training. Although the dollars allocated to the program were relatively small, never more than \$250,000, the impact was large. An adverse interpretation of a legiclation change in the technical assistance language effectively ended the technical assistance program.

The 1965 Amendments to the Vocational Rehabilitation Act created a specialized program of technical assistance to rehabilitation facilities. This program was under Section 304(e) of the Rehabilitation Act of 1973. That section of the law provided:

"(e)(1) The Secretary is authorized, directly or by contract with state vocational rehabilitation agencies or experts or consultants or groups thereof, to provide tecknical assistance (2) to rehabilitation facilities, and (B) for the purpose of removal of architectural and transportation barriers, to any public or nonprofit agency, institution; organization or facility."

Under this provision RSA established a list of tionally recognized experts who could be sent to rehabilitation facilities who requested technical assistance through RSA regional offices. RSA would refer the expert to the facility and would pay for the consultation and for the necessary travel.



Consultations were provided in a wide variety of fields. They included contract procurement; plant lavout and workflow; vocaional evaluation and work adjustment; facility accreditation requirements; financial management and accounting; personnel administration; development and marketing of products; production; quality control; industrial engineering; safety; job placement; MIS development; computer utilization; micrographics, wage and hour consultation, and other subjects. The overage cost was less than \$1,000 per consultation, thus allowing more than 250 consultations per year when the program was operational.

The program was effectively ended in 1979 when Section 506 of the Rehabilitation Act replaced Section 304. Section 506 also provided for technical assistance to rehabilitation facilities but changes in punctuation and new language was interpreted to limit the technical assistance to consultations on matters pertaining to barrier emoval. RSA could have utilized Section 12 of the Rehabilitation Act which allows the RSA Commissioner to "Provide consultative services and technical assistance to public or non-profit private agencies and organizations..." However, internal budgetary decisions were made to prevent utilization of this authority.

There is a continuing need to provide technical assistance to rehabilitation facilities. If anything, the world these facilities must operate in has become even more complex. Accreditation requirements are more stringent and more complex, utilization of computers has moved from financial management into programs, and there have been great strides in new program direction such as Projects With Industry, supported work and transitional programs.



While there are training programs and some materials available, they are not always easily accessible to those who need the information. The cost to send staff to training programs is often prohibitive and timing is often a problem. Face to face interaction is much more effective than trying to utilize manuals or training materials which may or may not be appropriate to a particular situation. These factors are especially pertinent to small facilities, often in rural areas.

NARF strongly urges the adoption of an amendment to the Rehabilitation Act which would restore - program of technical assistance to rehabilitation facilities. Not only would facilities once again have access to experts' advice in management, program and technical areas, but new program information and direction such as supported work and transition programs could be better disseminated to the people who are working with severely disabled persons.

This testimony was limited to the issues of training and technical assistance. NARF strongly urges the Subcommittee to hold one of its oversight hearings on the subject of service delivery under the Rehabilitation Act. NARF would like an opportunity to present testimony on that subject to explore how rehabilitation funds can best be used to provide rehabilitation services to those most in need.

Mr. Chairman, thank you for this opportunity to provide testimony. I will be glad to answer any questions you may have or provide additional information to you or your staff pertaining to barrier removal.



Mr. WILLIAMS. Ms. Novak-Krajewski.

Ms. NOVAR-KRAJEWSKI. Good day, Mr. Chairman, members of the subcommittee. My name is Alexa Novak-Krajewski, and J am representing the American Association of Community and Junior Colleges, the Association of Community College Trustees. I am the coordinator for programs for disabled students at Delaware Technical Community College.

The Rehabilitation Act of 1973, amended February 1984, mandates that personnel be specifically trained in providing employment assistance with handicapped individuals through job development and job placement. The question arises as to whether or not State vocational rehabilitation counselors are trained to deal with the specifically targetted population of severely disabled individuals and, if not, what types of training programs are available to such counselors and is the RSA providing sufficient funding to implement such programs?

The guidance information system 1984 data banks indicate that 73 colleges and universities nationwide have graduate level programs in the rehab services. However, they are located in only three specific regions, the Midwest, New England, and the Far West, specifically California. If one is not a resident of one of these areas with a graduate program in rehabilitative services, the outof-State fees are prohibitive.

Title I, section 101 of the act states that the State "contains the plans, policies and methods to be followed in carrying out the State plan, .... to expand and improve services to handicapped individuals with the most severe handicaps." Therefore, one must assume that rehabilitation counselors are trained in these specific areas. Surveys indicate that few State rehabilitation counselors have

Surveys indicate that few State rehabilitation counselors have had training in job development and placement. State agencies cannot offer salaries comparable to private rehabilitation agencies and hospitals. Thus, graduate level rehabilitation service counselors are seeking employment in the private sector.

To illustrate, the State of Delaware currently has 30 vocational rehabilitation counselors serving approximately 5,000 uisabled clients. Of the 30 counselors, only 2 hold master degrees in rehabilitation services; 10 have masters degrees in general counseling, and the other 18 in varied areas of human service bachelor level degrees in criminal justice; social work and psychology.

Since the impetus is towards the rehabilitation and employment placement of severely handicapped individuals, the question arises are State agencies providing the necessary training to upgrade their counselors' expertise and is RSA providing requisite funding to the States?

Delaware is a minimally funded State for RSA moneys. Once rehabilitation priorities are met, a modicum—only approximately 1 percent of its State/Federal budget is allocated for in-service training.

There are experts available to address the complex and new situations surfacing within the rehabilitative area of disabilities. With limited resources, the cost of such expertise is prohibitive. Small States cannot afford to update their counseling staff.

Rehabilitation administrators indicate these areas of concern of supervision of insufficiently trained counselors. Counselors' lack of



knowledge of specialized employment placement; counselors' lack of knowledge interpreting the complexity of a client's medical condition and ability to perform on the job; counselors' lack of knowledge regarding existing funding available to clients for personal transportation needs, housing and attendant care; counselors' inability to provide holistic rehabilitation; and counselors' lack of knowledge of disability referral sources.

How might colleges and universities assist in developing programming for in-service training for rehabilitation staffs? There are approximately 1,200 junior and community colleges throughout the United States serving roughly 8 million full and part-time students.

Junior and community colleges are designed to serve a large demographic cross section of individuals and are conveniently located. Their facilities could easily coordinate and develop in-service programs with State rehabilitation offices and national rehabilitation organizations.

The demographics of the rehabilitation population are ever changing as technological advancements assist the severely disabled in daily living skills, work environment accomodations, and educational and training program access.

Standard college coursework becomes obsolete within a matter of a few years; hence, the most viable form of continuing education in rehabilitation services is ongoing inservice training. Fifty-five percent of all college-bound disabled students begin their college work at community and junior colleges.

Community and junior colleges encompass one-third of the membership of the Association of Handicapped Student Service Programs in Postsecondary Education, better known as AHSSPPE. AHSSPPE has investigated the degree to which rehabilitation counselors are encouraging otherwise qualified nandicapped individuals to attend postsecondary institutions.

Statistics indicate that many counselors are not sufficiently trained in placing such clients. Ohio State University has approved a model project in its graduate school; college of human services to train at the master's level curriculum in disabled student services at the postsecondary level.

Rehabilitation counselors are mandated to serve and place severely disabled individuals. To provide quality rehabilitative services, RSA must increase training funds to States.

Rehabilitative services degree programs are offered by colleges and universities. However, curricular focused on job development and placement are limited.

Overall, RSA funding should be increased to provide State rehabilitation counselors with more competitive salaries.

With an increase in training funds, State rehabilitation agencies, in conjunction with local junior colleges, can develop ongoing inservice programs to serve rehabilitation counselors:

Colleges and universities providing baccalaureate and master degrees in rehabilitation services could utilize junior and community college programs for disabled students as possible internship placements.

Finally, Mr. Chairman, we hope this committee will take a close look at the way States distribute Federal funds to the disabled pop-



ulation and the agencies best able to serve them. Training at the adult level ensures the disabled a stable place in the job market.

Yet, in many States postsecondary aproprictions under the Carl Perkins Vocational Education Act are controlled and monopolized by State educational agencies which channel this support primarily to secondary institutions. Postsecondary institutions, such as community colleges and 4-year colleges and universities, do not receive the funds mandated by Federal law for handicapped services. Thank you.

[The prepared statement of Alexa Novak-Krajewski follows:]



PREPARED STATEMENT OF ALEXA NOVAK-KRAJEWSKI, COORDINATOR, PROGRAMS FOR DISABLED STUDENTS, DELAWAPF TECHNICAL AND COMMUNITY COLLEGE ON BEHALF OF THE AMERICAN ASSOCIATION OF COMMUNITY AND JUNIOR COLLEGES AND THE ASSOCIA-TION OF COMMUNITY COLLEGE TRUSTEES

Mr. Chairman, members of the Subcommittee, my name is Alexa Noval-Krajewski and I am representing the American Association of Community and Junior Colleges and the Association of Community College Trustees: J im the Coordinator of Programs for Disabled Students at Delaware Technical and Community College:

Title III, Part A of the Rehabilitation Act of 1973 as amended through February 22, 1984, Section 304(a) states that: ... "The Commissioner may make grants to and contracts with States and public or nonprofit agencies and organizations, including institutions of higher education, to pay part of the cost of projects for training, traineeships, and related activities designed to assist in increasing the numbers of qualified personnel trained in providing vocational, medical; social, and psychological rehabilitation services to handicapped individuals, including (1) personnel specially trained in providing employment assistance to handicapped individuals through job development and job placement services...."

The question arises as to whether or not state vocational rehabilitation counselors are trained to deal with the specifically targeted population of severely disabled individuals. If not, what types of training programs are available to such counselors and is the Rehabilitation Services Administration providing sufficient funding to implement such programs?

Addressing the area of ava lability of education programs providing Rehabilitative Services curriculum, G.I.S., Guidance Information System (TSC/Koughton Mifflin, Co.) 1984 data banks indicate that 73 colleges and universities nationwide have graduate level programs. Geographically, those 73 programs are concent ated in

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ERIC Full lext Provided by ERIC three specific regions: The Mid-west, New England, and Far-west; specifically; California. If one is not a resident of a state in which a graduate program offers a concentration in Rehabilitative Services, the out-of-state fees are p thibitive. Thus, the availability of programs is limited while many of the programs do not have courses directed towards developing skills in the areas of job deve opment and job placement for handicanced individuals.

Since Title I, Section 101; 5(A) of the Act mandates that the State..."cuntain the plans, policies, and methods to be followed in carrying out the State plan and in its administration and supervision, including a description of the method to be used to expand and improve services to handicapped individuals with the most severe handicaps and a description of the method to be used to utilize existing rehabilitation facilities to the maximum extent feasible ... " therefore, one must assume that rehabilitation counselors are trained in these specific areas. Nevertheless, surveys indicate that few state rehabilitation counselors have had training in job development and placement. State agencies cannot offer salaries comparable to private rehabilitation agencies and hospitals; thus, graduate level Rehabilitation Services counselors are seeking employment in the private sector: Consequently, the numbers of those with degrees in Rehabilitative Services employed by state agencies are decreasing. To illustrate, the state of Delaware currently has 30 vocational rehabilitation counselors serving approximately 5,000 disabled clients. Of the 30 counselors only two hold master degrees in Rehabilitative Services; ten have master degrees in general counseling and the other 18 have bachelor degrees in varied



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areas of human services, such as, criminal justice, social work; and psychology:

The impetus is towards the rehabilitation and employment placement of severely handicapped individuals. Thus the question arises: Are state agencies providing the necessary training to upgrade their counselors' expertise and is RSA providing requisite funding to the states for such staff development? Citing DeliWare as an example, it is a minimally funded state for FSA monies. Once rehabilitative priorities are met, a modicum (approximately one-percent (1.) of its state/federal fiscal budget) remains to provide in-service training to its counseling staff. Utilization of the State of Delaware's Division of Vocational Rehabilitation budgetary figures for fiscal 1984 (FY84) indicates that once service needs are achieved minimal sums are available for in-service training, approximately \$600, per counselor. There are experts available to address the complex and new situations surfacing within the rehabilitative area of disabilities; however, with limited resources, the cost of such expertise is prohibitive. Lacking sufficient funding, most small states cannot afford to update their counseling staff.

Due to nature of most severe handicaps; a counselor must be exceptionally creative in developing job possibilities. Rehabilitation administrators indicate these areas of concern in their supervision of insufficiently trained counselors:

 Counselers lack of knowledge of specialized employment placement (accommodation) of severely disabled qualified applicants.

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- Counselors lack of knowledge interpreting the complexity of a client's medical condition and ability to perform on the job.
- Counselors lack of knowledge regarding existing funding available to clients for personal transportation needs, housing, and attendant care.
- 4: Counselors inability to provide notistic rehabilitation counseling - the client is an individual with family; friends; and personal involvements:
- 5: Counselors lack of knowledge of disability referral sources.

The President's Committee on Employment of the Hand(capped has sponsored a Job Accommodation Network (JAN) to assist employers in providing accommodation for disabled workers. Although rehabilitation counselors have access to JAN, there are no ongoing training programs nor networks for counselors themselves to improve their placement skills. Consequently, RSA should increase its funding for in-service training in State block grants to provide adequate financial support to such staff development programs.

How might colleges and universities assist in developing programming for in-service training for rehabilitation staffs? There are approximately 1,200 junior and community colleges throughout the United States serving roughly 8 million full and part-time students. Since junior and community colleges are designed to serve a large demographic cross section of individuals and are conveniently located throughout the United States, their facilities could feasibly coordinate and develop in-service programs with the guidance of state vocational



rehabilitation offices and national rehabilitation organizations (National Rehabilitation Association and the National Counsel on Rehabilitative Education). The demographics of the rehabilitation population are ever changing as technological advancements assist the severely disabled in daily living skills, work environment accommodations, and educational and training program access: Standard college coursework becomes obsolete within a matter of a few years; hence, the most viable form of continuing education in rehabilitative services is ongoing in-service training programs. Less than ten years ago it would have been rare to see a severely disabled individual, for example, a quadraplegic or a person with cerebra! palsy; successfully completing a bachelor's degree in computer science. Now, this practice is cummon place. Fifty-five percent (55%) of all college-bound disabled students begin their college work at community and junior colleges. Community and junior colleges encompass one-third of the membership of the Association on Handicapped Student Service Programs in Post-Secondary Education (AHSSPPE). AHSSPPE has investigated the degree to which rehabilitation counselors are encouraging otherwise qualified handicapped individuals to attend post-secondary institutions. Statistics indicate that many counselors are not sufficiently trained in placing rehabilitation clients in post-secondary facilities. To address this problem; Ohio State University has approved a model project in its Graduate School, College of Human Services. The model program is offering master level curriculum in Disabled Student Services at the Post-Secondary Level.

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Conclusions and recommendations:

1: Rehabilitation counselors are mandated to serve and place severely disabled individuals; however, funding from RSA is limited for in-service training for these counselors. To provide quality rehabilitative services, RSA must increase training funds to states:

I: Feiderlitätric Jertifes i sick program and offiched by colleges and universities; nowever, curricula focusée ch job dévelopment and placement are limited. Such additional coursework should be implemented in these programs:

3: Overall RSA funding should be increased to provide state rehabilitation counselors with more competitive salaries; thereby, increasing the number of certified renabilitation counselors is its ranks:

4. With an increase in training funds, State rehabilitation agencies, in conjunction with local junior and community colleges, can develop ongoing in-service programs to serve rehabilitation counselors.

5. Universities and colleges providing baccalaureate and master degrees in Rehabilitative Services could utilize junior and community college programs for disabled students as possible internship placements for their students.

To improve the rehabilitation services for our severely disabled citizens, we must provide our rehabilitation counselors with all the necessary skills to accomplish this goal. This should be a joint effort amor: our colleges and universities; RSA,



and State rehabilitation agencies. Funds must be made available from RSA to provide this education. Educators must present relevant and progressive information to their students and inservice participants.

Finally, Mr. Chairman, we hope this Committee will take a close look at the way States distribute federal funds to the disabled population and the agencies best able to serve them. Training at the adult level ensures the disabled a stable place in the job market. Yet in many States postsecondary appropriations under the Carl Perkins Vocational Education Act are controlled and monopolized by State educational agencies which channel this support primarily to secondary school systems. Postsecondary institutions, such as community colleges, often do not receive funds mandated by federal law for handicapped services.

Thank you for considering this testimony.

Mr. WILLIAMS. Thank you very much.

Mr: Bartlett:

Mr. BARTLETT. First. Mr. Harles. I wonder if you would provide a copy of that-two copies of that book, one for the record, and one for my file.

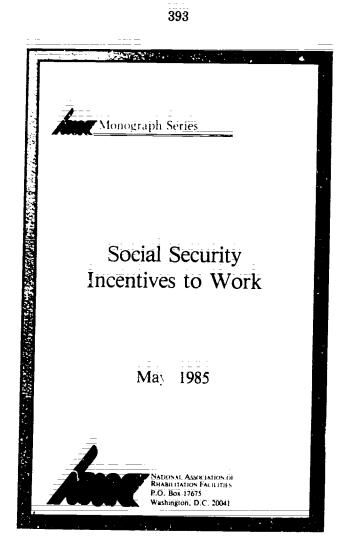
Mr. HARLES. Certainly. In fact, the reason we haven't done so before is that the typesetter left two lines out and we are waiting for the shipment to come back in from the printer.

Mr. BARTLETT. We will be happy to overlook those two lines. But it sounded like a very useful booklet.

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[The information follows:]







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Social Security Incentives to Work

1985 The Sational Association of Rejubilitation Eachities P.O. Box 17675, Washington, J. C. 2004) Published as a Public Service by NARE

. No portion of this monocraph may be depositived without the expressed written consent of the National Association of Rehabilitation Lacinties.



# FOREWORD

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This NARF monograph, Social Security Incomestor Work, wild developed to assist personnel of vocational and medical removing the social security A. Which are intended to encourage Social Security Disability Insurance beneficial work for each of Supplemental Security Income recipients to return to work or to come work force for the first time. It is hoped that this publication will also be the assistance to other rehabilitation professional and advocates to better understat 2 these underuntized incentives to work.

Social Security publications: manuals and training materials were used extensively in preparation of this monograph so that its substance would be in accord with materials prepared by and used by the Social Security Administration. NARF would expecially like to acknowledge the encouragement and assistance of Eleanor Bader, Special Assistant to the Associate Commissioner for Governmental Affairs of the Social Security Administration in the preparation of this monograph.

> James A. Cox, Jr. Executive Director



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# INTRODUCTION

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One of the most frustrating problems facing vocational and medical rehabilitation facilities is the client or patient, who is refluctant to return to or begin work after a rehabilitation program for fear that they will lose federal income support or medical benefits. All too often a rehabilitation counselor is told by a client, "I would like to work, but I can't afford to jeopardize my SSI payment or Medicaid cover ge."

Under current law there are four basic programs that provide income and/or medical coverage for individuals who are disabled.

- These programs are:
- Social Security Disability Insurance
- Supplemental Security Income
- Medicare
- Medicaid
- Individuals could qualify for SSI or SSDI only if and for so long as he or she is, "unable to engage in *any* substantial gainful activity by reason of impairment which is expected to result in death or which has lasted or can be expected to last for a continuous period of not less than twelve months." The law does not, however, provide for partial disability.

Prior to 1980, earnings over the substantial gainful activity level (now \$300 a month) would end the cash payment and eligibility for medical coverage. This was a powerful disincentive for disabled persons to work. If the person was unable to sustain the SGA level, they would have to go through a redetermination process that could take months. In the case of Medicare coverage for SSDI recipients, they would have to wait two years to become reentitled to benefits once they had left the SSDI rolls.

Researchers found that the primary concern of SSI and SSDI beneficines was whether they had enough income to meet living expenses. The second primary concern was whether they would be able to maintain employment once they obtain a job. Fear of losing inedical benefits was the third most prevalent concern.

Congress has been addressing these disincentives to work. The Disability Amendments of 1980 (PL 96-265) amended the Social Security Act to lessen the impact of the disincentives and to encourage SSI and SSDI recipients to work when feasible. These work incentives included allowing deduction for impairment

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related work expense and providing an extended period of eligibility for persons who go to work. A trial work period was previously in the law. The 1980 Amendments also provided for an experimental program allowing SSI recipients to continue receiving SSI cash payments after they begin engaging in substantial gainful activity (SGA) up to the SSI income disregard "breakeven point" which is currently no less than \$735 per month. Even beyond that point, an SSI eligible perion could retain Medicaid eligibility if they continued to need Medicaid services in order to work and if their income was not sufficient to purchase the needed medicail service: These two provisions are known respectively as Section 1619(a) and 1619(b). They were originally passed in 1980 and have been reauthorized through July, 1987.

Section 1619(a) and (b) can be particularly helpful to certain categories of severely disabled persons who are often served in medical and vocational rehabilitation facilities. These persons include the severely disabled individual with high mental and vocational qualifications but high work related expenses; high non-work related living expenses due to disability; and high health care costs. The work incentives can also be very beneficial to individuals with low mental and vocational qualifications which are expected to continue. However, the individual does have the ability to do some work, the work is expected to be of relatively low economic value. These mentally handicapped persons have a high risk of inability to sustain the work over a long period, and the earnings will be at or near the limit for substantial gainful activity.

The work incentives discussed in this monograph are underutilized. Statistics from the Social Security Administration indicate that the level of utilization of Section 1619 has been minimal. At the beginning of 1985, less than 500 SSI recipients were receiving the cash benefits and approximately 5,000 former SSI recipients retained Medicaid eligibility under Section 1619(b). The lack of utilization is due to a combination of lack of knowledge of the incentives and a continuing soncern that returning to work, or working for the first time, will have an adverse effect on eligibility for Social Security Disability and SSI benefits.

These work incentives can be very important in helping a disabled person who has been rehabilitated go to work. Some provisions such as Section 1619(a) allow continued cash benefits after the disabled person goes back to work. The trial work period allows an SSI or SSDI recipient an opportunity to try working without jeopardizing cash benefits or eligibility. Extended eligibility allows immediate reinstatement if the work experience does not work out.

The rehabilitation facility is an important point of contact for SSI and SSDI recipients. It is at the rehabilitation facility that the recipients most often receive the services which may enable them to work. The rehabilitation courselor and other facility personnel need to be aware of incentives that will help disabled persons join and rejoin the work force.

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The material in this monograph is intended to give rehabilitation facility staff an overview of the incentives to work in the SSDI and SSI programs. It is not a technical or detailed manual. A list of reference materials and how to obtain supplemental information is included.

In addition to understanding the basic provisions of the work incentives, it is very important that facility staff establish a good working relationship with the local Social Security Office. Information reported to the Social Security office will determine how the incentives apply in a given situation. All local Social Security offices are being required to participate in a training program dealing with incentives and a new Social Security pamphlet entitled "Disability Benefits and Work" is available to the public at any Social Security Office.





## 1. BASIC PROVISIONS OF SSI AND SSDI

### Social Security Disability Insurance Program

The Social Security Disability Insurance program (SSDI) provides monthly cash benef. for workers under age 65 who become disabled. Coverage for the Social Security Disability Insurance Program is basically the same as for the Social Security Old Age Survivors Insurance (OASI) program. However, there are differences in insured status and administration of the programs.

A percentage of the Social Security taxes paid by workers it all cated to the Disability Insurance Trust Fund. This is the source of funds for monthly benefits paid to the disabled worker and dependents and for administrative expenses of the program. In addition, the revenue derived from the taxation of disability benefits is also deposited in the Trust Fund.

There are four types of disability beneficiaries:

- 1) Disabled Worker
- 2) Spouse Benefit
- 3) Child's Benefit
- 4) Disabled Child's Benefit

Note that many clients receive SSDI benefits because they were disabled prior to age 18 or they are the son or daughter of an insured parent who has retired, become disabled or died.

To receive disability benefits, a worker must have the requisite number of quarters of coverage. Workers age 31 or over who are not blind must have 20 quarters of coverage during the preceding 40 quarters. Workers under age 31 must have been covered for at least one half of the quarters since they reached age 21. However, a minimum of six quarters is required.

The amount of SSDI benefits is based on the earnings and length of employment of the worker. Benefits may be reduced if other federal state and local benefits are being received.

Disability determinations are made by state agencies which make determinations following guidelines and regulations issued by SSA. SSA may review state determinations and under the 1980 amendments must review non-permanently disabled persons every three years. Benefits may be terminated if there has been medical improvement in the person's condition and the person is able to engage in substantial gainful activity (SGA).





### Supplemental Security Income

Supplemental Security Income (SSI) was added to the Social Security Act in 1972 as Title XVL SSI provides monthly cash payments to aged, blind and disabled needy persons. There are nationally uniform federal eligibility standards. SSI replaces state welfare programs to the same group of eligible persons.

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SSI recipients must meet certain income and resource limits to become eligible for benefits. The regular Federal SSI benefit standard for an individual for 1985 is \$325 a month and \$448 for a couple. States may supplement the regular federal SSI payment standard. The result is often a combined state-federal payment which can yary from state to state. Individuals who are in a public hospital or other public institution where most of the bill is paid by Medicaid, the monthly federal SSI payment is reduced to \$25 to allow for small personal expenses while they are in the hospital or institution. There are complex regulations which take into account the living situation, income disregards, in kind support, resources and deeming of income to determine the monthly payment level.

While many, if not most, SSI recipients are covered by Medicaid, states have three options on how to cover recipients.

- 1) Automatic eligibility through agreement between SSA and the state.
- 2) Automatic eligibility but with separate Medicaid application.
- State imposed Medicaid eligibility requirements that are usually more restrictive than federal criteria.

Contact should be made with the appropriate state agency to determine which method is used in your state.

### Definition of Disability

While eligibility criteria differ greatly between Social Security Disability insurance beneficiaries (Title II) and Supplemental Security Income recipients (Title XVI), the definition of disability is the same for both programs. The Social Securty Act sets out a unique definition of disability.

The statute provides in essence: That an individual must have a medically determinable impairment which has precluded or can be expected to preclude any substantial gainful activity (SGA) for twelve months or terminate in deatil. Further, the impairment must not only prevent a person from doing his/her past work, but also prevent him/her from doing any other substantial gainful work that excise in the national economy. The statute specifically requires consideration of an individual's age, education; and past work experience in determining disability; however, it precludes consideration of any matters that go to the issue of employability, e.g.; job openings, or whether the person would be hired if applied for the job. In essence, the critical issue is whether the impairment and the individual's age, education, and past work experience precludes the performance of SGA. This



means that when past work is precluded the primary focus of the disability definition is shother an individual can 20 work and nor whether the person can ger work. The Social Security Administration uses a five step sequential process in deter-

maning whether there is a disability for both SSDI and SSI purposes.

- Step 1 Determine whether the individual is working, and does it constitute substantial gainful activity.
- Step 2 If the individual is not eligaged in SGX, determine whether the individual has a severe impairment which causes a significant (estriction in performing work related functions).
- Step 3 It a severe impairment is present see it the impairment is listed in SSA regulation and or whether it meets the duration requirement (12 months) and level of seventy.
- Step 4 Determine whether the individual can do work which he she has previously done.
- Step 5 If the person cannot do previous work, determine whether he she can engage in SGA based on residual functional capacity for work and vocational factors such as age, education and prior work experience. If the person is determined not to be able to engage in SGA at this stage then the disability is allowed.

### Substantial Gainful Activity

It is important that the concept of substantial gainful activity (SC(A) is understood since it is used in determining whether a disability exists and also plays an important role in several of the work incentives.

The primary consideration in determining whether work activity is SGA is the countable earnings derived from the employment. The current countable earnings guideline representative of SGA for nonblind employees is earnings averaging over \$300 per month (called the primary guideline). There is also a secondary SGA guideline for employees which is currently \$190 per month of countable earnings. The significance of the SGA secondary guideline is that earnings below the secondary amount are generally presumed not to be SGA. For earnings between the primary amount (\$300) and the secondary amount (\$190) it is necessary to consider certain nonmonetary criteria to determine if the work is SGA.

The nonmonetary criteria involve two texts,

- Test of Comparability Does the work compare to that done by animpared individuals in the community orgaged in the same or similar occupations for their livelihood and
- 2 Test of Worth Is the individual's work clearly worth more than the primary earning: euideline (\$300 per month)\*



For individuals employed in a sheltered workshop or similar rehabilitation facility, the SGA secondary guideline is of little significance. If their earnings are below the SGA primary guideline (\$300 or less), the earnings are generally presumed not to be SGA:

By reason of specific legislation in 1978, there is no second, ry guideline for the blind under Title II and there is a larger SGA earnings guideline for the blind. It is currently \$550 per month and the guideline increases with the Consumer Price Index. The blin ... under Title XVI, are not subject to the SGA tests.

In determining countable earnings of employees for SGA purposes, any subsidies provided by an employer plus impairment-related work expenses (IPWE) are deducted from gross earnings.

Impairment related work expenses can be deducted from gross earnings before determining countable earnings for SGA purposes. The Social Security Administration also allows deductions of subsidies from gross earnings. A subsidy will be found to exist when wages exceed the value of services performed. Subsidies will be found to exist where an individual requires unusual supervision or assistance in order to perform work or where individual productivity is not used to determine wage level.

In some instances periods of employment above the SGA level can be considered an unsuccessful work attempt (UWA). To qualify as a UWA, the work must have been of 3 months duration or less and been discontinued or markedly reduced because of the impairment or removal of conditions essential to further performance, such as special hours, equipment; or other assistance on the job. With additional qualifications the unsuccessful work attempt can last up to 6 months.



### II. SOCIAL SECURITY WORK INCENTIVES

#### TRIAL WORK PERIOD

### Who is Eligible?

SSI recipients and SSDI beneficiaries are potentially eligible for a trial work period. It does not apply to SSI recipients based on blindness or to SSDI beneficiaries who do not serve a waiting period.

#### Basic Provisions of a Trial Work Phriod

The trial work period allows a beneticiary to work for mile consecutive or nonconsecutive months without endangering eligibility for benefits of the impairment does not improve during this period. The trial work period offers an opportunity to measure the effectiveness of reliabilitation services, the recipient's ability to work, and maintain a job. The trial work period can begin with the month of entillement to benefits and ends with medical recovery or the completion of 9 (nine) months of service. The service months need not be consecutive. Any work and earnings during this nine month period are disregarded in determining whether or not the disability has ceased. However, evidence of medical improvement, during the nine month period may be considered which could result in the discontinuance of benefits. Only one trial work period is allowed for each period of disability. For purposes of the trial work period, "work" is defined as periorming a service as an employee or as a self-employed individual for remuneration or gain.

Generally, only months in which earnings are over \$75 gross wages count as trial work months. If self employment is involved only months in which there are more than 15 hours of work and \$75 in gross earnings will count toward the trial work period.

Earnings are assented to the months when the service was performed, and not when the pay was received. Impairment related work expenses and subsidies are not deducted from earnings to determine service months during a trial period:

#### How This Provision Will Help Clients of Rehabilitation Facilities

Most disability claimants are allowed the nine month trial work period which allows employment without affecting their disability status so long as their impairment remains disabling during that time. This trial work period can be useful for recipients during rehabilitation services to see if they can become gainfully employed for an extended period of time as a result of the services without a loss of



benefits. Only after completion of the trial work period will the work be evaluated for purposes of determining whether the recipient is engaged in substantial gainful activity (SGA).

Unless properly monitored, the Social Security Administration may consider sheltered employment to be counted toward the trial work period if the worker is earning more than \$75 per month. If the disabling condition has not changed and if the sheltered work differs significantly from competitive work in that a higher degree of staff supervision is required; then the shaltered work should not be considered trial work.

The determination should be requested so that the client's benefits will not be Jeopardized later, protecting your client from suspended benefits during an evaluation.

Does the condition of impairment still exist?

2) Can the work be performed competitively without the staff supports?

If the answer to number one is yes and the answer to number two is no, immediately ask for an appeal and benefit reinstatement. Kemember, if the decision is not favorable, all money received during appeal time must be paid back.



# EXTENDED PERIOD OF ELIGIBILITY

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#### Who is Eligible?

 SSI and SSDI recipients are generally eligible for the extended period of eligibility for benefits.

- The extended period of eligibility connot be used by beneficiaries:
- · whose disability ceased before December 1, 1980; or
- whose disability has medically ceased; or
- · who do not complete trial work period; or
- · who have already received an extended period of eligibility.

#### Basic Provisions of the Extended Period of Eligibility

The extended period of eligibility is intended to encourage disabled persons to work after completion of the nine month trial work period. The extended period of eligibility is for fifteen months beyond the nine month trial work period. If income exceeds SGA during the fifteen month period, benefits under SSI and SSDI will cease. However, if carnings fall below SGA during the fifteen months, then benefits will be reinstated during those months with no need to redetermine eligibility. It should be remen bered that the nine months to use up the nine trial work period it could take more than nine calendar months to use up the nine trial work period months. However, the fifteen month extended period of eligibility is fifteen consecutive months following completion of the trial work period.

The term disability takes on new meaning under the extended period of eligibiliity since a person may engage in SGA, but may still be considered disabled. This sate concept applies to payments or Medicaid eligibility under Section 1619. SSA will evaluate recipicits in the fifteen months of extended eligibility to determine whether they have a "disability impairment."

A cleabling impairment is an impairment or combination of impairments which, of itself, is so severe that it meets or equals the level of severity on the inedical listings or when considered with the person's vocational factors, would recall in a finding that the person continues to be disabled were it not for his or her earnings. However, for widows, widowers and surviving divorced spouses eligible for Title II disability benefits, the impairment must meet or equal the level of severity of the medical listings. Vocational factors are not considered in such cases:

There are differences between the SSI and SSDI programs as to when the extended period of eligibility ends. For SSDI recipients it is the earlier of:



- the second month following the month when the impairment is no longer disabling; or
- after the nine month trial work period, and after the fifteen consecutive months following the trial work period — the second month following the earliest month that the recipient engages in SGA.

For SSI recipients it ends with the earlier of:

- the month preceasing the month in which the impairment is not disabling; or
- the month preceding the first month of SUA after the fifteen months extended ed period of eligibility and nine month trial work period.

Once SGA is engaged after the fifteen months following a trial work period, a new application and determination of disability is required for SSL: benefits. Only a redetermination of disability is required for SSI.

# How This Provision Will Help Clients of Rehabilitation Facilities.

The extended period of eligibility is intended to encourage work beyond the trial work period. Clients and parents can be assured that their benefits will be reinstated during the fifteen month period if they fall below SGA, unless they have recovered from the disabling condition. Remember that the reinstatement will be immediate since eligibility has already been determined.





### SECTION 1619 (a) & (b)

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### Who is Eligible?

Only certain SSI recipients are eligible for Section 1619 benefits. The program description includes qualification criteria for each program.

#### Basic Provisions of Section 1619:

Prior to 1981, a disabled individual could qualify for Supplemental Security Income (SSI) only if and for so long as he (she, "is unable to engage in any substantial gainful activity by reason of impairment which can be expected to result in death or which has lasted or can be expected to last for a continuous period of not less that, twelve months." If a recipient carned more than \$300 a month (SGA), the individual could not become eligible for SSI, or if already a recipient, would cease to be eligible.

The Social Security Disability Amendments of 1980 (P.L. 96-265) included a provision entitled Section 1619 which provided for a demonstration program allowing a SSI recipient to retain SSI benefits and Medicaid eligibility while earning above the SGA level. Section 1619 is an experimental provision which, will expire June 30, 1987. There is a strong possibility that Congress will extend the program or make its provisions permanent. The purpose of Section 1619 is to see whether continuation of eash payment and/or Medicaid will be an incentive to work.

### Section 1619(a) - Special SSI Cash Benefit

The purpose of Section 1619(a) is to protect and continue the SSI cash payment of a disabled recipient whose work above the SGA level would normally end basic SSI eligibility even though he or she remains severely impaired. Without this protection, a recipient would lose the benefits the month after the second month of earning SGA level following a trial work period. Under Section 16(9(a) a recipient could continue to receive an SSI cash payment with restructions only for the increase in earnings until the individual reached the break even point. Thus, instead of losing cash venefits when the SGA level is reached, some cash benefits are continued as an incentive to continue working.

To qualify for Section 1619(a), the individual must:

- be under age 65; or
- continue to be medically impaired; or
- have been eligible for a regular SSI cash payment for the prior month; or



- not be blind (SGA test does not apply to them under current law); or
- meet all other SS: eligibility criteria such as countable income and resources, institutionalization, etc; or
- not be in a trial work period.

The special 1619(a) payments will negate the need to use the extended period of eligibility since benefits will continue beyond the trial work period even though the individual has exceeded SGA. If, however, the individual becomes ineligible for the regular or special cash benefits during the 15 months following the trial work period, the extended period of eligibility provision can be used to reinstate regular SSI benefits without a new application.

The special SSI cash benefits under SSI stop when:

- · eligibility under the regular SSI program begins; or
- the individual fails to meet any non-disability criteria; or
- the individual recovers medically; or
- the provision expires June 30, 1987 (There is a strong possibility that the provision will be made permanent by Congress).

The special cash benefits under Section 1619 are calculated in much the same way as regular SSI benefits except there is no cuttoff of benefits once the \$300 per month SGA limit is reached. For example, as of May 1, 1985, the federal benefit rate (FBR) for an individual is \$325 per month and \$488 for an eligible couple. Under section 1619, individuals with countable income can earn up to \$735 in a month and still receive some federal SSI benefits. An eligible couple could receive up to \$1,016 per month. These amounts would be increased in states that provide supplementary benefits.

### Section 1619(b) - Extended Medicaid Coverage

Section 1619(b) provides extended Medicald coverage for individuals who lose their SSI payments due to their earnings but, who, nontheless, need continued Medicaid coverage to work.

To qualify for Section 16i9(b) the individual must:

- be under 65; or
- be blind or severely dirabled; or
- have been eligible to receive a regular SSI cash payment or a special cash benefit under Section 1619(a) in the prior month; or
- need Medicaid in order to continue working. Use of Medicaid within the past twelve months or expected need during the next twelve months must be documented; or
- not be able to afford medical care without assistance. A threshold earnings





level is set for each state to determine the point at which the individual theoretically does not need Medicaid. Even if the individual's earnings exceed that level, SSA must determine if the individuals actual expenses are higher than the average.

# How This Provision Will Help Clients of Rehabilitation Facilities

Section 1619 is considered to be the most beneficial to work incentive clients in rehabilitation facilities. It allows higher earnings for recipients, therefore encouraging them to work or to accept pheement. The continued eligibility for Medicaid even after their earnings exceed the level allowed for continued SSI payments is especially helpful in placing severely handicapped persons into supported or competitive work situations.

Even though all eligible disabled persons can take advantage of Section 1619(a) and (b), the provisions are especially helpful to certain groups of disabled persons. Section 1619(a) can be used most effectively by disabled persons who have some, but limited earning capacity. Often persons with severe mental impairment can work, but usually at levels below the breakeven point. Section 1619(a) will allow them to earn at much higher levels of income while retaining their SSI cash benefits and in-kind benefits that often are dependent on SSI status.

Concurrently, Section (619(b) can be very helpful to severely physically disabled persons who have the ability to earn levels of income in excess of that allowed under SSI on Section (619(a), but who need continuing medical services in order to work.





# IMPAIRMENT RELATED WORK EXPENSES

### Who is Eligible?

SSD1 and SS1 recipients can deduct impairment related work expenses (IRWE) from earnings for SGA determinations. SS1 recipients can exclude IRWE's from earned income for the purpose of determining countable earned income, assuming the person was eligible under the federal income test if working when they first ap,ily.

SSA allows deduction of impairment-related work expenses in order that the extra expenses disabled persons incur in order to work will be taken into consideration for purposes of SSI and SSDI eligibility and for determining countable income in determining SSI benefit levels.

In order for IRWE's to be deductible, the individual must be disabled and the item or service must be needed by die individual because of their disability. The individual must have actually paid for the services or items. Reimbursed payments or payments in-Find are not deductible.

. While there is no definitive list of services or items that are deductible, the following list of examples may be helpful:

- attendant care services; or
- durable medical devices; or
- prostheses; or
- · work-related equipment needed to accommodate the impairment; or
- residential modification; or
- non-medical appliances where there is a medical need; or
- drugs and medical services needed to control disabling conditions; or
- transportation.

Expenses of a recurring nature will normally be deducted for the month the expense was paid. For nonrecurring one-time payments or downpayments, deduction may be made in the month paid or prorated over a twelve month period.

### How This Provision Will Help Clients of Rehabilitation Facilities.

Many SSI and SSDI recipients are reluctant to consider working because the costs of medicine, medical devices, attendant care, or special transportation often outweigh the earnings that they could make or substantially reduce real earnings.

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The allowance of impairment-related work expenses will be a significant factor for some SSI and SSDI recipients in accepting rehabilitation services and accepting employment:





# PLAN FOR ACHIEVING SELF-SUPPORT

#### Who is Eligible?

SSI recipients or persons applying for SSI are eligible for this program.

### Basic Provisions of a Plan for Achieving Self-Support.

A plan for achieving self-support (PASS) permits exclusion of specified income and resources needed to help an individual enter or return to employment. Income and resources set aside under a PASS are not counted in computing an individual's SSI payment or when establishing eligibility. Monies saved under a PASS can be used to obtain training, education, or occupation related equipment, or even be used to start up a business.

The Social Security Administration will approve a PASS when it will help the individual to establish or retain SSI eligibility; provide an increase in the SSI payment; assure retention of Medicaid eligibility; or prevent denial or suspension based on excess income or resources.

The individual seeking approval of a PASS must be physically and mentally capable of pursuing the vocational objective before SSA will approve the PASS. The person applying for a PASS must be disabled and under age 65. He/She must be interested in employment and be willing to participate in SSA approved training. SSA considers VR clients, individuals already in training pograms, marginaliy employed persons, and person inquiring about rehabilitation services, to be among the best candidates for a PASS.

The PASS must be in writing with a feasible occupational objective, and a specific plan for disbursing savings relating to the occupational plan. The funds to be used for a PASS must be clearly identified and separated. A PASS must be achieved within a reasonable period of time. The basic period of a PASS is eighteen months from the date of SSI eligibility or when a PASS was first discussed. An additional eighteen months may be granted if warranted. Another twelve months may be added for needed education under the PASS.

The PASS may be developed by the individual, by SSA or by another organization such as a rehabilitation facility or workshop. SSA will work with a counselor or other representative of the client in developing a PASS where appropriate.

### How This Provision Will Help Clients of Rehabilitation Facilities.

This provision may be helpful when a client in a rehabilitation facility has resources or savings that make them ineligible for SSI benefits. The PASS would





allow the client to establish eligibility for SSI (assuming he she meets other eligibility criteria) while working toward employment. The rehabilitation facility can develop the PASS and assist the client in working with SSA and other agencies in fulfilling the PASS.

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### TREATMENT OF INCOME FROM SHELTERED EMPLOYMENT

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Prior to the 1980 Amendments to the Social Security Act, income from sheltered employment which was part of an active rehabilitation program was not considered earned income for purposes of determining SSI payments, and therefore, did not qualify for the earned income disregard (**S65** a month plus one-half of additional earnings). This had the effect of requiring benefits as if the income were unearned, even though it was from the productivity of the disabled worker.

Beginning in October, 1980 the law provides that remuneration received for revices in a sufficient workshop or work activities center will be considered earned income and therefore qualify for the earned in some disregard.

It is important to note that suffered work does not necessarily constitute substantial gainful activity (SGA) nor does it necessarily constitute a trial work period.

# BENEFITS WHILE IN VOCATIONAL REHABILITATION PROGRAM

### Who is Eligible?

SSI and SSDI recipients and beneficiaries.

### Basic Provision of Benefits While in VR Program

Under most circumstances, VR clients who are SSI beneficiaries or SSDI recipients will continue to receive their cash benefits while they are enrolled in VR programs. If there is compensated work involved in the program, the individual can take advantage of Section 1619(a) if earnings result in substantial gainful activity.

There is a special provision that allows SSI and SSDI benefits to continue for a recipient who *unexpectedly* recovers medically and thus would otherwise become ineligible because the disabling condition no longer existed. The special provision allows continued benefits if they are participating in an approved state vocational rehabilitation program.

This provision is intended to consider only those exceptional cases where the disabled individual is not expected to medically recover during the rehabilitation process. SSA can continue an individual's benefits and VR funding in those instances when the disabling condition improves and results in a medical cessation before the person is prepared vocationally for an immediate return to work.



# CONTINUED MEDICARE COVERAGE UNDER SSDI

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### Who is Eligible?

SSDI beneficiaries are eligible for extended Medicare eligibility.

#### Basic Provisions of Continue fon of Medicare

Medicare ent lement ends with the last month an individual receives Social Security disability checks. But if payments end because of work activity and the person is still disabled, Medicare can continue for up to twenty-four months after either the last month benefits was received or after the end of the fifteen-month extended period of eligibility, whichever is later.

If a worker becom a disabled a second time within five years after Social Security disability checks stop for any reason, Medicare can resume the same morth as monthly benefits if he/she formerty had this coverage. If the person previously did not complete a twenty four month waiting period for Medicare, any months for which monthly checks were received during the first period of disability can count toward meeting this requirement in the second period of disability. This provision also applies to disabled widows, widowers and persons disabled before age 22 who become disabled again within seven years after payments ended.

There are some cases where a person will be eligible for Medicare and Medicaid at the same time. This can happen when a disabled child or adult has Medicare eligibility through a parent or spouse, but also meets the means test for Medicaid.



# EXPERIMENTAL AND DEMONSTRATION PROJECTS

Section 505 of the 1980 Sc cial Security Act provides that the Secretary of the Department of Health and Human Services *shall* develop and carry out experiments and demonstration projects designed to determine the relative advantages and disadvantages of various alternatives. These are designed to encourage disabled beneficiaries to return to work. Other projects that could be funded could include alternations and conditions that would facilitate new forms of rehabilitation and result in savings to the trust fund.

This authority has not been used often by Social Security. As of April, 1985, three projects have been funded. One involves a transitional program for mentally retarded SS1 beneficiaries. Another is a placement program for SSDI beneficiaries based on a Projects With Industry model. The third is a project to keep SSDi and SSI recipients on the job, even though they have serious intestinal disabilities requiring special feeding programs.

E-guilation is currently pending before Congress to make the authority for experimental and demonstration projects permanent.



# Glossary of Terms

Continuation of Medicare Coverage — This is a period of twenty-four additional months of Medicare entitlement in cases where a Title II beneficiary's disability benefit entitlement ends following the EPE because of the performance of (or demonstrated ability to engage in) SGA.

Continued Payment of Benefits to Individuais Under Vocational Rehabilitation Plans (Section 301) — This provision applies to both Socia. Security benefits and disability benefits. It is the only work incentive that applies to a person who is no longer medically disabled. Section 301 of the 1980 Disability Amendments provides for continuation of payments after the physical or mental impairment ceases, if the beneficiary/recipient is participating in an approved state vocational rehabilitation plan. The Social Security Administration must determine that following the plan will significantly increase the likelihood that the person may be removed from the disability roles.

Extended Period of Eligibility (EPE) — This provision applies to SSDI and SSI benefits. The extended period of eligibility permits the reinstatement of benefits without a new application if disability impairment continues and SGA is discontinued within the fifteen consecutive month period immediately following the trial work period.

Impairment Related Work Expense (IRWE) — This is applicable to SSI and SSDI and provides that the cost to the individual of certain impairment-related work services and items that are needed in order to work can be deducted from earnings in determinations of substantial gainfull activity. They will also be excluded from earned income for the purpose of determining an SSI recipient's monthly payment amount, but not basic eligibility.

Medicaid — Medicaid, authorized under Title XIX of the Social Security Act, is a federal-state matching program providing medical assistance for low-income persons who are aged, blind, disabled, or members of families with dependent children. Within Federal guideline:, each state designs and administers its own program. Thus, there is substantial variation among the States in terms of persons covered, types, and scope of benefits offered, and amounts of payments for services.

Medkare — Medicare, authorized under Title XVIII of the Social Security Act, is a nationwide health insurance program for the aged and certain disabled persons. It consists of two parts, the hospital insurance (art A) program and the supplementary medical insurance (part B) program.



Most Americans over age 65 are entitled to part A coverage. Persons under age 65 who are receiving Social Security disability benefits are eligible for part A coverage after a two-year waiting period.

**OASI** — The old-age survivors insurance (OASI) program provides monthly benefits to retired workers and their dependents and to survivors of insured workers. Old-age retirement benefits were provided for retired workers by the original Social Security Act of 1935, and benefits for dependents and survivors were provided by the 1939 amendments.

Plan for Achieving Self-Support (PASS) — This provision applies only to the SSI program. Under a plan for self-support, a disabled or blind individual is permitted to receive earned and unearned income, and accumulate resources over a reasonable period of time in order to obtain occupational training and education, purchase occupational equipment, establish a business, etc., thereby encouraging the individual to become financially self-supportive.

<u>SSPI</u> — The Social Security Disability Insurance Program (SSDI) provides monthly cash benefits for disabled workers under age 65 and their dependents. Benefit amounts are related to the past earnings of the insured worker.

SSI — The Supplemental Security Income (SSI) program is a federally administered income assistance program authorized by Title XVI of the Social Security Act. Established by the 1972 amendments to the Act and begun in 1974, SSI provides monthly cash payments in accordance with uniform, nationwide eligibility requirements to n œdy, aged, blind and disabled persons. The SSI program replaced the former Federal grants to the States for old-age assistance, aid to the blind and aid to the permanently disabled.

Substantial Gainful Activity (SGA) — This is applicable under both titles and is the performance of significant physical and/or mental activities in work for pay or profit, or in work of a type generally performed by pay or profit. Work may be substantial even if it is performed on a part-time basis, or even if the individual does less, is paid less, or has less responsibility than in previous work. Work activity may be gainful if it is the kind of work usually done for pay, whether in cash or in kind; or for profit, whether or not a grofit is realized. SGA is determined by an employee's earnings, and a self-employed individual's earnings and/or activity.

**Trial Work Period (TWP)** — This provision applies to Social Security and SSI beneficiaries. A beneficiary's work in nine calendar months (not necessarily consecutive), regardless of magnitude, will not be used in determining that disability has ceased.





### Resources

There are several C.S. Government publications that offer additional detail on the background, procedures and requirements of the work incentives discussed in this monograph. Most of them are available for sale through the Government Printing Office, Department 33, Washington, DC 20402. You must know the title, publication no. and price for each publication. Payment by check must accompany the order. Phone orders may be charged on VISA or MasterCard. The phone number is (202) 783-3238. Calls can be made between 8:00 a :n. and 4:00 p.m. (EST) Monday through Friday.

- Social Security Handbook (Eighth Edition) SSA Publication No. 05-10135.
   \$9.00. A 435 page book describing all programs under the Social Security Act.
- Title 20 Code of Federal Regulations, Parts 400-499, Revised as of 1984.
   \$9.00. This volume contains all of the regulations for the Social Security Administration.

The following publications are available directly from the Social Security Administration. Request for copies of these publications should be made to the Office of Disability, Social Security Administration, Baltimore, Maryland 21235.

- Work Incentives for the Disabled and Blind Under the Social Security and Supplemental Security Income Programs: A Training Aid for Vocational Rehabilitation Counselors. Social Security Publication No. 64-015. May, 1985.
- Disability Evaluations Under Social Security: A Handbook for Physicians. Social Security Publication No. 79-16089.

The following Social Security pamphlets are usually available at local Social Security offices. If unavailable contact the Office of Disability at the address given above.

- "If You Beceme Disabled" (January 1985 edition) Social Security Publication No. 05-10029.
- "A Guide to SSI" (March 1985) Social Security No. 05-11015.
- "Your Social Security" (January 1985) Social Security Publication No. 05-10035.
- "Disability Benefits and Work" (May 1985) Publications number not available.





Mr. BARTLETT. You represent essentially the private rehabilitation agencies?

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Mr. HARLES. Nonprofit.

Mr. BARTLETT. Nonprofit. What percentage—and I would also like to ask this of Mr. Cholette of Easter Seal—what percentage placement in competitive employment do you generally run, your agencies?

Mr. HARLES. There are both simple and complex answers. You have to look at particular programs within facilities. Some are geared toward placement, others-for instance, State agencies will buy large amounts of vocational evaluation services where the intent is not placement but only to provide that service. The overall placement rates range anywhere from 10 to 25 percent of all people served for any purpose. Those programs that are geared toward placement have very high placement rates.

For instance, most of the projects with industry programs are in nonprofit rehabilitation facilities and there you have placement rates averaging over 75 percent.

Mr. BARTLETT. If you were to be permitted or if SSI or SSDI were to be permitted to enter into a contract with you for placement services only and pay you for that, would you be able to handle that, placing SSI recipients, and if so, do you have any sense as to what-a range of what your costs are for placements?

Mr. HARLES. In fact, we have a proposal before Social Security right now suggesting that they use some of their demonstration money and authority to provide direct placement to either State agencies or rehabilitation facilities for placement and it will be paid out of trust funds and they are currently considering that.

I think one of the things that they are waiting on is passage of renewal of the demonstration authority.

Mr. BARTLETT. Could you send me-both for the record and to me a copy of just a summary of that proposal?

Mr. HARLES. Sure.

Mr. BARTLETT. The highlights of it.

[The information follows:]





NATIONAL ASSOCIATION OF REHABILITATION FACILITIES P.O. Box 17675. Washington, D.C. 20041 • (703) 556-8848

James A. Cox, Jr., Executive Director

April 19; 1985

The Honorable Martha McSteen Commissioner Social Security Administration Department of Health and Human Services 6401 Security Boulevard, Room 900 Baltimore, MD 21235

Dear Ms. McSteen:

In recent months representatives of the National Association of Rehabilitation Pacilities (NARF) have met with officials of the Social Security Administration to explore a concept which we believe could reinvigorate the Beneficiary Rehabilitation Program for SSDI beneficiaries. This concept is reviewed in the attached Paper. "A Demonstration Proposal by National Association of Rehabilitation Pacilities for Alternative Referrals and Services to Social Security Disability Beneficiaries."

As you will note, the plan offers a means for significantly expanding rehabilitative services to SSDI beneficiaries to facilitate their return to gainful employment without increasing outlays from the SSDI Trust Fund and, in fact, producing savings for it.

A participating rehabilitation facility would have an incentive to follow the beneficiary after completion of a rehabilitation program so long as a portion of its contingent compensation is at risk. Such continued involvement with and support of beneficiaries would improve the prospects for permanent employment.

We believe that it is desirable to field test this approach through a demonstration project. We propose to identify and coordinate the involvement of a group of approximately 12 rehabilitation facilities; representing both geographic and programmatic diversity; to participate in auch demonstration project utilizing a standard contract to be developed as well as a set of instructions to guide relationships between participating facilities and SSA District Offices.

Such\_a demonstration project would be undertaken under Section 505.of the Social Security Disability Amendments of 1980, Section 1110. of the Social Security Act (42 U.S.C. 1310) or similar authority.





The concept outlined in the attached paper offers potential benefits for the rehabilitation community, the SDI Trust Fund and, most importantly, SDI beneficiaries. This same process could be modified for SSI recipients with savings to the general revenue fund. I would like to meet with you to discuss this idea and means for implementing it. I will contact your office about an appointment.

James A. Cox, Jr. Executive Director Sincerely,



A DEMONSTRATION PROPOSAL BY NATIONAL ASSOCIATION OF REHABILITATION PACILITIES FOR ALTERNATIVE REPERRALS AND SERVICES TO SOCIAL SECURITY DISABILITY BENEFICIARIES

This proposal is advanced by the National Association of Rehabilitation Pacilities (NARF). NARF is the national membership organization of medical and vocational rehabilitation facilities. Its members provide therapeutic, educational, training and job placement services to people with mental, physical and emotional disabilities. Its membership includes more than 400 institutional members and 20 affiliated state chapters. The proposal which follows has been developed and/or reviewed with the assistance of a representative sample of NARF's membership.

The purpose of this proposal is to establish the means for providing rehabilitation services to enable SSDI beneficiaries to return to gainful employment and thereby drop off the SSDI rolls. The proposal makes an explicit connection between termination of benefits and the payment for rehabilitation services by the Social Security Administration. It also makes an explicit connection between payment for rehabilitation services and follow up to assure that persons remain in employment to the greatest extent possible. The proposal contains elements which are drawn from current practices of private insurers, particularly insurors of workers compensation liabilities, who actively promote rehabilitation of disabled persons as an alternative to payment of long term cash assistance.



### A. Background

The Social Security Amendments of 1965 authorized the use of Social Security Trust Funds to pay for rehabilitation services for disabled beneficiaries.

Such assistance became known as the Beneficiary Rehabilitation Program (BRP). The purpose of the BRP was to make available rehabilitation services for Social Security Disability Insurance (SSDI) beneficiaries to facilitate their return to substantial gainful activity. This program had two objectives. The first was to enable SSDI beneficiaries to experience the rewards of increased self-sufficiency. The second was to reduce cash outlays from the SSDI Trust Fund. The BRP provided funds from the Trust Fund through the Rehabilitation Services Administration (RSA) to state vocational rehabilitation agencies to be used by the state agencies for the provision of rehabilitation services to SSDI recipients. Funding was authorized as a percentage of the cash benefits paid to SSDI beneficiaries in the previous The program grew to over \$100 million in PY 1980 for the year. BRP.

In November of 1980 the General Accounting Office released a report ön the BRP, entitled, Improvements Needed In Rehabilitation. Social Security Disability Insurance Beneficiaries, GAO (HRD81-22). Based on an extensive assessment of records of SSDI beneficiaries who had participated in the program the report found that many reported "rehabilitations" were people who were expected to recover under any circumstances



and that much of the "savings" to the Trust Fund reported by SSA and RSA were overstated. GAO found that even with these failings the program showed a nominally positive cost/benefit ratio of 1:1.15.

This ratio reflects the actual costs of services delivered and benefits derived from such services, calculated to be the present value of future program benefits through age 65, when the beneficiary would no longer be covered by the SSDI program and would become a regular Social Security beneficiary. This rate of return for Trust Fund expenditures was regarded as marginal in view of the generous assumption used to calculate benefits. The combination of this report and the reassessment of social programs in 1981 led to the enactment of legislation making radical changes in the BRP.

As amended in 1981 and 1984; whe BRP now authorizes the use of Trust Fund monies to reimburse the cost of rehabilitation services in the event of successful rehabilitation or if a person medically recovers while receiving services or fails to cooperate without good cause in the receipt of services. A successful rehabilitation is defined as nine months of continuous substantial gainful activity. In the event services are provided and the recipient of them does not reach this level of employment the state VR agency is not reimbursed from the Trust Fund for the cost of the services. In light of substantial pressure on VR funds this system has the effect of sharply reducing the attention given to SSDI beneficiaries.





The 1985 Budget estimated that BRP expenditures in the current fiscal year will be less than \$6 million. Actual expenditures in PY 1983 were less than \$4 million. The requirement in current law for successful rehabilitation of beneficiaries as a precondition for payment of the cost of rehabilitation services from the Trust Fund guarantees that this program will be minimal in scope.

The prospects for rehabilitation of a SSDI beneficiary are a function of several things, including the nature of the disabling condition, the motivation of the individual, the professional competence of the service provider and, in some cases, the state of the economy which may determine the job opportunities available at the end of the services. Under present law the risks of any or all of these uncertainties falls upon the state vocational rehabilitation agency and/or service provider facility since there is no assurance of payments of services at the time they are rendered.

### B. SSDI Program

The PY 1986 Budget estimates that in that fiscal year benefits through the SSDI program will be approximately \$19.6 billion. Approximately 2.6 million disabled people receive benefits. Currently the average monthly benefit under SSDI is about \$460. Rehabilitation of even a small percentage of people now on the rolls would effect a substantial savings to the government while; of course, adding the contribution of those rehabilitated to the economy.



#### C. Criteria Used in Developing this Proposal

In considering ways of making the BRP effective NARF regarded two points as fixed. The first is that any such program could not result in an increase in federal outlays. The second is that any such program would have to be administratively simple, with the twin objectives of keeping administrative costs to a minimum and operating with maximum larity for the beneficiaries. The following proposal responds to both considerations.

#### D. Direct Referral

The GAO report referenced above was critical of the role of state vocational rehabilitation agencies in the administration of the BRP program. It recommended that the Social Security Administration experiment with the direct referral of SSDI beneficiaries to rehabilitation facilities for evaluation and, if appropriate, services. In 1980 the Congress, in Section 505 of the Social Security Disability Amendments of 1980 (P.L. 96-265) authorized the Social Security Administration to undertake demonstration projects to test means for rehabilitation of SSDI beneficiaries.

A key to a successful cost effective program for rehabilitation of SSDI beneficiaries lies in the identification of the right candidates. This entails a well focused effort to evaluate a given beneficiary's potential for rehabilitation and restoration to substantial gainful employment. Not every SSDI beneficiary

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can return to work even with an optimum rehabilitation program. Selection of those persons with potential for gainful employment and concentration of services on them is critical. Host vocational evaluation capacity in the country is located in rehabilitation facilities. Direct involvement of the trained professionals who represent this capacity in the identification of candidates for the BRP is critical.

Therefore it is proposed that a demonstration project include direct referral of SSDI beneficiaries by SSA to rehabilitation agencies.

#### E. Financing

The second element of this proposal deals with the financing of rehabilitation services. As noted above it is assumed that any change in the BRP would only be financially and politically feasible if it did not result in an increse in federal outlays. The current financing mechanism for these programs guarantees a very limited program. It provides only for the payment of costs and then only in successful cases. Inevitably some services will not result in a successful rehabilitation. The cost of any such "failures" must be borne by state agencies and/or facilities. Since reimbursement from the SSDI Trust Pund is only for the cost of services in successful cases (and there will inevitably be some unsuccessful ones) the program in the aggregate offers no incentive and, in fact, is a disincentive to providing rehabilitation services to SSDI beneficiaries. Any new program



must be based on an explicit connection between expenditures for rehabilitation and savings to the SSDI Trust Fund.

To meet this objective, it is proposed that the present system be modified to permit the Social Security Administration to enter into contracts with rehabilitation facilities and other qualified entities for the provision of rehabilitation services to SSDI beneficiaries and that the compensation paid for such services be contingent upon the beneficiaries served achieving substantial gainful employment. It is proposed that facilities be compensated, not in relation to their own costs or charges, but rather based on the savings generated for the SSDI Trust Fund. Such payments would be made to the facility only when benefit outlays are reduced or terminated and would be made only so long as the beneficiary remained off the rolls, not to exceed five years.

It is proposed that payments to facilities be made as a declining percentage of the benefits payments which, in the absence of a successful program of rehabilitation services, would have been paid to the SSDI beneficiary, in accordance with the following schedule:

|      | _      |             |
|------|--------|-------------|
| Year | One:   | 95%         |
| Year | Two :  | 90 <b>8</b> |
| Year | Three: | 85%         |
| Year | Four:  | 808         |
| Year | Five:  | 75×         |

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Under such an arrangement facilities would bear the risk for identification of potential candidates among SSDI beneficiaries, evaluation and success in rehabilitation. The federal government cannot lose since it would never pay to a rehabilitation facility funds which would not otherwise have been paid to a SSDI beneficiary:

A participating rehabilitation facility would have an incentive to follow the beneficiery after completion of a rehabilitation program so long as a portion of its contingent compensation is at risk. Such continued involvement with and support of beneficiaries would improve the prospects for permanent employment.

It is helpful to consider the mechanics of such an arrangement. The average monthly cash payment to an SSDI beneficiary is about \$460. Such payments are adjusted periodically to reflect changes in the cost of living. For purposes of analysis the following assumptions are made: this level of benefits is held constant, a beneficiary receiving services is employed and dropped off the rolls; he or she stays off for five years, and the payment rate for the facility is as stated above. Under these assumptions, over five years the facility would be paid the following amounts:

> \$ 5,244 4,968 4,692

ERIC Prulitext Provided by ERIC

4,416 140 \$23,460

Since these payments would be received over five years their current value would be substantially less. At a 10% discount rate the right to receive these payments over five years has a value at the start of that period of about \$17,500. The Social Security Act allows a beneficiary a nine-month trial work period before there is a cessation of benefits. Coupled with a period for services this means that payments to the facility would star: not less than a year after the initiation of services. This would reduce the value of these potential payments at the time services are initiated (assuming a 10% discount rate) to not more than \$16,000.

To determine that the provision of services is warranted, the costs and risks of such services would have to be assessed by a facility against this potential compensation. Such risks include, at least, the following:

- The risk that the benficiary will not achieve substantial gainful activity.
- The risk that the beneficiary will not stay off the rolls for the full five years.
- 3. The cost of services to be provided.





- The cost of monitoring the beneficary over the five-year period and any followup services that may be needed.
- The carrying cost of the services (although the foregoing analysis assumes a 10% value of money in measuring present worth of future payments).

If a program of this type is to be effective it will require facilities to be willing to take these risks while seeking to minimize them. Early identification of the candidates for a rehabilitation program is a major consideration, as is the integration of vocational assessment with the initial eligibility determination for the applicants for SSDI beneficiaries. It is recognized that certain beneficiaries have been determined to qualify for SSDI with the expectation that their disabling conditions will abate and, therefore, that benefits are under any circumstances will be of short duration. The Social Security Administration should have authority to exclude from the BRP persons in this category or, alternately, to provide for shorter period of compensation to participating rehabilitation facilities in such cases.

A system of this type would require facilities to be extremely careful about the people accepted for services as well as to determine that anticipated future payments, reduced to present value, would warrant delivery of such services. Facilities would





be at risk for the success of services, but with a potential reward if they do so.

In November 1983 the Social Security Administration published a statistical analysis of SSDI beneficiaries. entitled; Characteristics of Social Security Disability Insurance Reneficiaries, SSA Publication No. 13-11947. This report contains the most current public information on the characteristics of SSDI beneficiaries. It is based on a sample of disability decisions made during 1977-1979 and includes data by sex, age, occupation, diagnosis, mobility and state of residence.

Attached as Exhibit A is a table extracted from this report showing the number and percentage distribution of disabled worker claims allowances by age and diagnosis in 1979 based on a sample of claims allowed. In assessing the potential for rehabilitation of SSDI beneficiaries it is pertinent that 35% of approved claims were for people less than 49 years of age. Of these, 39% (14.7% of the total) were under 35 years of age. Rehabilitation of any significant number of such SSDI beneficiairies would produce great savings for the Trust Fund.

F. Relationship to Vocational Rehabilitation Program

The contingent fee concept outlined above is proposed as a supplement to rather than in lieu of the current mechanism for



providing rehabilitation services to SSDI beneficiaries. Accordingly beneficiaries should continue to be eligible for sponsorship under the rehabilitation program administered by state rehabilitation agencies and such agencies should continue to be reimbursed form the SSDI Trust Punc for successful rehabilitation which they sponsor. It is presumed that the state vocational rehabilitation agency and/or a participating facility would not qualify for both the contingency fee and reimbursement from the Trust Pund as currently authorized and that selection between these alternate modes of sponsorship would be made when services are initiated. Further, it is presumed that a state agency would not qualify for the contingent fee arrangement if rehabilitation services for the beneficiary were financed with federal funds under the Rehabilitation Act or similar authority:

#### G. <u>Medicare Eligibility</u>

Under current law an SSDI beneficiary becomes eligible for the Medicare program 24 months after a positive determination of disability. For disabled persons such coverage is very important. NARF proposes that such Medicare coverage be continued during the five-year work period upon which the contingency fee is predicated.

#### H. <u>Referral Mechanism</u>

It is proposed that participating facilities have access to medical records and other information associated with disability



determinations and reevaluations of SSDI beneficiaries. On the basis of joint determination between SSA personnel and participating facilities SSDI beneficiaries determined to have rehabilitation potential would be referred to such facilities for evaluation and, ultimately a determination as to whether services are indicated:

1. Means for Implementation

This proposal can be implemented through a demonstration project under the authority of Section 505 of the Social Security Disability Amendments of 1980 (42 U.S. \$1301) or Section 1110 of the Social Security Act (42 U.S.C. \$1310).

NARF, at no cost to the government, would provide ā representative group of rehabilitation facilities in different parts of the country to enter into contracts with SSA as described above. The Disability Determination Service of state agencies in these areas and SSA office would be advised to provide information to them necessary to make the decision to determine candidates for services. NARP requests that a person be designated by SSA to coordinate the development of this proposal into a concrete plan which reflects any concerns the agency may have and identifies the operational requirements from SSA's perspective.





NARP Contact: James A. Cox, Jr. P. O. Box 17675 Washington, D.C. 20041 (703) 556-8848



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IABLE 12. -- Diagnostic group and division: Sucher and percentage distribution of disubled-worker claims allowences, by age and sex, 1979

| Disgrostic       | later+          |                       |               |           |                | Age+2/                  |                   |                                       |                |
|------------------|-----------------|-----------------------|---------------|-----------|----------------|-------------------------|-------------------|---------------------------------------|----------------|
| group and        | <b>Netionel</b> |                       |               | ber       | · ·            | <br>Pe                  |                   | i i i i i i i i i i i i i i i i i i i |                |
| division         | code+1/         |                       | Under         |           | SO and         | Percentage distribution |                   |                                       |                |
|                  |                 | totel                 | 75            | 75-49     | Over           | Total                   | 3                 | 21-41                                 | 90 and<br>Over |
|                  | tol             |                       |               |           |                |                         |                   |                                       |                |
|                  |                 |                       |               |           |                |                         |                   |                                       |                |
| Tetal main       | <b>P</b> ***    | 408,600               | 10,817        | 87, 142   | 265,721        | 100.0                   | 13.7              | 21.3                                  | <b>H</b> .0    |
| Infec & parse    | 001-129         | 2,684                 | 112           | 144       | 1,418          | 100.0                   |                   |                                       | <br>51. 7      |
| Intest Info d    | 18 001-009      | - 30                  | 0             | 15        | _15            | 100.0                   | 19.4              | 21.1                                  | 12.2           |
| Tuberculosis     | 010-018         | 743                   | 74            | 216       | 454            | 100.0                   | 0.0               | 49.1                                  | <b>\$0.1</b>   |
| Resp tuberc      | 011-012         | 623                   | <b>14</b>     | 184       | 501            | 100.0                   | <u>9.9</u><br>9.4 | 29.0<br>29.8                          | 11.1<br>11.1   |
| Necp1eene-       | 140-239         | 95,013                |               |           |                |                         |                   |                                       |                |
| In buccal cavi   |                 |                       | 3,000         | 11;412    | 40,337         | 100.0                   | 1.9               | 20.8                                  | 92.8           |
| In disgt orga    |                 | -4,000                | -19           | - 302     | 1,486          | 100.0                   | 1.0               | 20.2                                  | 70,1           |
| In respir sys    |                 | 10,071                | 354           | 1,454     | .7,859         | 100.0                   | 3.5               | 10.4                                  | 78.0           |
| In ton/skiv/sr   |                 | 18,079                | -166          | 2,785     | 12,540         | 100.0                   | -1.1              | 10,3                                  | 80.0           |
| Rn Jone          | 170             | 7,843                 | 124           | 2,010     | 5,151          | 100.0                   | -8.0              | 21,4                                  | 65.7           |
| Hin ::annetv/sel | -               | 754                   | 207           | 185       | 264            | 100.0                   | 27.4              | 24,4                                  | 4.2            |
| Hn ikin          | 111-113         | <u>\$74</u>           | 106           | 107       | 251            | 100.0                   | 20.3              | 31,8                                  | 47.9           |
| In Groupt        | 174-175         | - <b>95</b> 1         | 161           | - 344     | - 447          | 100.0                   | 14.3              | 31.7                                  | 47.0           |
| In genitic ave   |                 | <u>8,811</u>          | <u>149</u>    | 1,252     | 4,089          | 100.0                   | 3.0               | 24.1                                  | 72.9           |
| Other & unap #   |                 | 6,872                 | 692           | 1,214     | 5,044          | 100.0                   |                   | 17.1                                  | 14.2           |
| In brain         | 191             | <b>6</b> ; <u>470</u> | . 411         | 1,528     | 4,261          | 100.0                   | 10.1              | 23.8                                  | 85,9           |
| In lyaph/heans   |                 | 2,503                 | - 338         | 721       | 1,445          | 100.0                   | 12.0              | 20,8                                  | \$7.7          |
| Leuksenta        | 204-207         | \$. <u>77</u> \$      | 1,011         | 1,225     | 3,469          | 100.0                   | 10,7              | 21.2                                  | 0.1            |
| Senign neuplag   |                 | 1,400                 | 240           | 402       | 731            | 100.0                   | 10.1              | 20,7                                  | \$7.2          |
| Other meanings   | a 990.994       | <u>10</u>             | 125           | 106       | 397            | 199, 0                  | 17.4              | 28.4                                  | 16.2           |
|                  | • <****         | 951                   | 203           | 100       | 411            | 100.0                   | 27.7              | 19.8                                  | 11.1           |
| l'Met nutr & m   | t 240-279       | 14,278                | 1,530         | 3,324     | 9,414          |                         | 4818              | <b>33</b> ° 3                         |                |
| Dis of thyroid   | 2//0-246        | _ 201                 | _1            | 42        | - 230          | 100.0                   | 10.0              | 23.3                                  | <b>65.9</b>    |
| Die ether ende   | 290-259         | 9,631                 | 825           | 2,181     | - 120<br>F,625 | 100.0                   | 0.0               | 14,5                                  | 78,9           |
| -Diabetes with   |                 | 9,342                 | ĪÄ            | 2,041     | <u>5,454</u>   | 100.D                   | 1.0               | 21,0                                  | <b>H</b> .6    |
| Nutrit det       |                 | - 233                 | - 1           | 55        | 171            | 100.0                   | 9.1               | 21.0                                  | <u>11</u>      |
| Other mish di    | 270-279         | 4,102                 | 100           | 1,120     | 2,200          | <u>100.0</u><br>100.0   | _3;3<br>14,3      | 23.4<br>27.8                          | 73.4<br>50.2   |
| lood/bid ftein   | 200.980         | <br>("MA              | <br>B4T       |           |                |                         |                   |                                       |                |
| Aniela           | 280-284         | 1,250                 | 343           | 297       | 844            | 100.0                   | 27.4              | <b>\$9.8</b>                          | 48.9           |
| Other discases   | 204-209         | 922<br>_ 329          | 24)<br>99     | 210<br>11 | 463            | 100.0                   | 21.5              | 22.4                                  | 50.2           |
|                  |                 | - • •                 | ••            | ••        | 140            | 100.0                   | 30.2              | 24.8                                  | 48.0           |
| intol-disorders  |                 | 46, 624               | <u>40,759</u> | 13,004    | 14, 104        | 100.0                   | 40.2              | 27.9                                  | 31.9           |
| Paychoses        | 290-299         | 22, 185               | 11,789        | 5,992     | 8,423          | 100.0                   | 10.1              | 25.8                                  | 23.4           |
| Senilo peych     | 290             | . 499                 | _0            | . 25      | 473            | 100.0                   | 0.0               | °8,1                                  | H.1            |
| Alcoholic payo   |                 | - 355                 | 21            | 79        | 256            | 100.0                   | 11.1              | 22.3                                  | 11.5           |
| Schizophrente    | 295             | 10,862                | 10,519        | 4,323     | 1,950          | 100.0                   | 82.6              | 25.4                                  | -11,0          |
| Alfect psych     |                 | 3,524                 | - 695         | 1,062     | 1,767          | 100.0                   | 19.7              | 30.2                                  | BO. I          |
| Neuroses/nonpsy  | 900-316         | 15,450                | 3,142         | 5,066     | 1,629          | 100.0                   | 19.0              | 32.0                                  | 46.2           |



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TABLE 13.++Diagnostic group and division: Number and percentage distribution of disabled-worker claims allowances, by age and sex, 1978 (Continued)

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| Plagnostic                                    |                     |              |            |              |                                | Age+2 /       |               |              |                      |
|-----------------------------------------------|---------------------|--------------|------------|--------------|--------------------------------|---------------|---------------|--------------|----------------------|
| Proup and                                     | -Inter-             |              |            |              |                                | -             |               |              |                      |
| division                                      | netionel<br>code+1/ |              |            | Der          | ··                             | P1            | Incentade     | distribut    | 100                  |
| 44 - 8 - 9 - 90 - 90 - 90 - 10 - 10 - 10 - 10 | 0000-1/             |              | Unune      |              | 50 and                         |               | Under         |              | 50_and               |
|                                               |                     | Total        | 75         | 25-49        | ÖVÖT                           | Total         | 25            | 25-49        | Over                 |
| 41cohol lan -                                 | 703                 | 1,027        |            |              |                                |               |               | · · ·        |                      |
| Drug depending                                |                     | ·19          | 14         | <b>34</b> 2  | 572                            | 100.0         | 14.2          | 33.8         | \$1,9                |
| Nontal retard                                 | 817-319             | 7,99         | 0<br>3,847 | 15<br>1,943  | - 0<br>1,000                   | 100.0         | 0.0           | 100.0        | _0.0                 |
| Norv evil & sence                             | 900.980             |              |            |              | ·                              | 100.0         | 50.6          | 25.6         | 22.0                 |
| infl-dig-of and                               |                     | 30,934       | 7,051      | 7,975        | 18, <u>705</u>                 | 100.0         | 26,7          | 24.5         | <b>10</b> , <b>1</b> |
| Hered & dogen                                 | 2:0-337             | - <b>848</b> | 102        | 202          | - 243                          | 100.e         | 13.7          | 40.0         | 37,5                 |
| Pack In. dia                                  | 233                 | 4,915        | 401        | \$74         | 3,538                          | 100.0         | 1.1           | 19.0         | 72,0                 |
| Other dis/cns                                 | \$40-345            | 1,749        | 11         | 174          | 1.542                          | 100.0         | -0,7          | -9.9         | 89.3                 |
| Nutt octoresta                                | 340                 | <b>1,50</b>  | 3,852      | 2,873        | 2,890                          | 100.0         | 40.2          | 29.4         | 20.2                 |
| Paralysis                                     | -                   | 3,254        | 1,202      | 1,244        | 808                            | 100.0         | 21.5          | 20.2         |                      |
| Teltupey"                                     | 313-344             | 1,570        | 177        | <u>414</u>   | 329                            | 100.0         | 52.9          | 20.3         | 20,0                 |
| Dis per_mery                                  | 245                 | 2,843        | 1,408      | - 823        | - 612                          | 100.0         | \$3.3         | 22.0         |                      |
| Dia of eya                                    | 720-339             | 4,001        | 687        | 1,013        | 2.270                          | 100.0         | 47.2          | 28.4         | 23,2<br>54,1         |
| Elevene                                       | 340-379             | 1.011        | 1,001      | 1,586        | 4,011                          | 100.0         | 19.9          | 19.7         |                      |
| Catanact-                                     | 265                 | - 744        | 50         | - 15         | 602                            | 100.0         | 1.5           | 17.2         | <u>80.</u> (         |
|                                               | 364                 | 1,110        | 10         | 144          | ₩Ö                             | 100.0         | -0.9          | 14,1         | 80,7                 |
| B1 Indhees                                    |                     | . 944        |            | -99          | - 384                          | 100.0         | 20.2          |              | D4.2                 |
| Pis der 8 net                                 | 300-343             | 3,730        | f,006      | \$73         | 1,897                          | 100.0         | 24.9          | 14.2         | \$7.2                |
| Necr loss                                     | 101                 | 2,791        | M          |              | 1,219                          | 100.0         | 23.9          | 27.3<br>22.2 | 90.8<br>47.8         |
| Circulatory ays                               | 210-450             | 114, 895     | 2.400      | 19,918       | 92,910                         | 100.0         |               |              |                      |
| Act meante fy                                 | 310-345             | t <b>i</b>   | 0          | 7            | 7                              | 100.0         | 1.1           | 17.0         | <b>10.1</b>          |
| Cre rhousts h/d                               | 293-398             | -1,820       | 189        | 043          | 1,212                          | 100.0         | <u>0</u> .0   | 9.9          | 10.1                 |
|                                               | 401-405             | 12,614       | 140        | 1,921        | 10,294                         |               | 9.3           | 24,4         | 66,4                 |
| Essent hyper                                  | 401                 | 8,420        | 126        | 1,006        | 4,995                          | 100.0         | 1,9           | <u>19, 9</u> | <u>85'</u>           |
| -Hypertens-h/d                                | 402                 | 9,323        |            | 425          | 4,442                          | 100.0         | 2.1           | 10.4         | <b>11,1</b>          |
|                                               | 410-414             | \$3,183      | 14         | 11,429       | \$4,499                        | 100.0         | ę.7           | 11.7         | 87.6                 |
| Acute el                                      | 410                 | 2,994        | 3          | 856          | 2,435                          | 100,0         | 0.1           | <u>17.6</u>  | <u>.</u>             |
| Angling pact                                  | 413                 | 2,302        | 11         |              | -1,925                         | 100.0         | 0,1           | 10.0         | 84. <b>3</b>         |
| Oth the lat h/                                | 414                 | \$7,405      | 133        | 10,125       | 40,740                         | 100.0         | 1.2           | 18,1         | <u>[]</u> ,          |
| Other_forme_IVd                               | 420-429             | 10, 149      | 411        | 1,724        |                                | 100.0         | 0.1           | 11,0         | <b>81,4</b>          |
| Cardle ayop                                   | 475                 | 1,389        | 329        | 373          | <b>F</b> ,010<br>- <b>92</b> 3 | 100.0         | 4.1           | 17.0         | 79.0                 |
| <u>Heert failure</u>                          | 420                 | 2,849        | 115        | 427          | 2,106                          | 100.0         | <u> 10, 1</u> | <u>21.2</u>  | 91. <u>i</u>         |
| 111-defined tv/d                              |                     | 3,892        | 104        |              |                                | 100.0         | 4,4           | ł#, ł        | <b>79,4</b>          |
| Carabrovaac dis                               | 420-430             | 10,294       |            | 2 875        | 2,990                          | 100.0         | 2.0           | 18,2         | 81.0                 |
| Coreb honorrhy                                | 434                 | 679          | 30         | 140          | 12,924                         | 100.0         | 4.1           | 10,4         | 79.3                 |
| Carab throubsu                                | 433                 | 1 614        |            | -90          | 503                            | 100.0         | 4,4           | 21,9         | 74,1                 |
| Coreb Gabol (ap                               | 434                 | 1.911        | -70        | 289          | - 487                          | 100.0         | <b>6</b> ,9   | . 14.0       | <u>71.5</u> ··       |
| - 111-def-cerve- a                            | 478-437             | 9,374        | 342        | 1,540        | 1,649                          | <u>100</u> .0 | 7.9           | 14, 3        | <b>\$4,0</b>         |
|                                               | 420                 | 2,548        | - ()       | 7,299<br>346 | 7,430                          | 100.0         | 3,7           | 10,6         | 79.8                 |
| Dis_arins/capii /                             |                     | 6,896        | 183        |              | 2,154                          | 100.0         | 2.7           | 12,1         | 83.8                 |
| Atherosciers                                  | 440                 | 2,900        | 20         | 870          | \$ <u>191</u> 2                | 100.0         | 2.4           | 14,9         | 85.Q                 |
|                                               | 111-442             | - 394        | - 10<br>   | 224          | 2,455                          | 100.0         | 1.0           | 1.1          | 11.2                 |
| Biter dis cire d                              | 11-659              | 3,745        | 202 _      | 101          | 440                            | 100.0         | 9.1           | 19, i        | 47.0                 |
|                                               |                     | *****        | •W _       |              | 2,364                          | 100.0         | 5.4,          | 10. t        | 78.5                 |
| •                                             |                     | 1            | - 1        | 46           |                                |               |               |              |                      |
|                                               |                     | •            | - 4        | 70           |                                |               |               |              |                      |
|                                               |                     |              |            |              |                                |               |               |              |                      |



TABLE-13,--Diagnostic group and division: Number and percentage distribution of disabled-vorker claims allowances, by age and sex, 1979 (Continued)

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| • • • •                                                            |             |                         |                    |              |                  |                |                     |                     |                     |
|--------------------------------------------------------------------|-------------|-------------------------|--------------------|--------------|------------------|----------------|---------------------|---------------------|---------------------|
| Diagnoet Ig                                                        | Inter:      |                         |                    |              |                  | Age+2/         |                     |                     |                     |
| group and                                                          | nelionel    |                         | Na                 | iter .       |                  |                |                     |                     |                     |
| divig fan                                                          | code+1/     |                         | Under              |              | to and           | · · · · ·      | rcoritage (         | 01827 IQUX          |                     |
| -                                                                  |             | Total                   | 75                 | 28-41        | Over             | totāt          | Under<br>25         | 71-49               | 10 m                |
|                                                                    |             |                         |                    | -            |                  |                | •*                  | 49-48               |                     |
|                                                                    |             |                         |                    |              |                  |                |                     |                     |                     |
| Pileb & three                                                      | 411         | 1,109                   | 67                 | 270          | 432              | 100.0          | Ī.7                 | 22,1                | 11.1                |
| 444,175,384-949                                                    | 460-819     |                         |                    |              |                  |                |                     |                     |                     |
| <ul> <li>Antipersonal state</li> <li>Antipersonal state</li> </ul> | 460-487     | 28,919                  | 420                | 3,337        | 21,784           | 100.0          | 1.1                 | 1 <u>7, 1</u>       | 85.3                |
| ( Lapase pull                                                      | 410-410     | 110                     | 0                  | 14           |                  | 100.0          | 0.0                 | 12,8                | 87.2                |
| State of the second state                                          |             | 22,804<br>1,689         | 133                | 2,812        | 19,257           | 100.0          | 1.1                 | 12.1                | ŪŪ.Ū                |
| -: TY/pel                                                          | 492         | 4,902                   | 10<br>- 14         | <u>791</u>   | <u>1,200</u>     | 100.0          | 0.6                 | 17.2                | 82.2                |
|                                                                    | 493         | -1,030                  | 171                | \$54<br>\$55 | 4,414            | 100.0          | 0.3                 | 11,1                | <u>00.5</u>         |
| Car Bouth MBD                                                      | 496         | 12,575                  | H                  | 1,39         | 1,243            | 100.0          | 11.1                | 21,2                | 41.0                |
| Presson & ath                                                      | 100-108     | - 209                   |                    | - <b>69</b>  | 12, 141<br>- 330 | 100.0          | 0.1                 | 10.0                | <b>17</b> . N       |
| Olmer dis resp                                                     | 810-819     | 2,218                   | 74                 | (23          | 1,719            | 100.0          | <u>0.0</u>          | <u>15.1</u>         | 4.1                 |
| · · · · · · · · · · · · · · ·                                      |             |                         |                    |              |                  | 100.0          | 3.3                 | 10, 1               | 77.6                |
| Digettive tys                                                      |             | 9,449                   | 913                | 2,648        | 5,001            | 100.0          |                     |                     |                     |
| Dis orei/sg/jau                                                    | \$20-\$2\$  | 0                       | .0                 |              | 0                | 100.0          | 1.7                 | 21.0                | 11.3                |
| Dis ees/st/Dand                                                    |             | 1,317                   | 11                 | 375          | 921              | 100.0          | 0.0<br>8.3          | -9.0                | 0.0                 |
| Hernis-and-ovty                                                    |             | \$44                    | - 0                | 138          | 407              | 100.0          |                     | <u>22.4</u><br>78,3 | (1.)                |
| Enter & colit                                                      |             | 1,222                   | 425                | 24.7         | 547              | 100.0          | 34.2                | 20.3<br>1.1         | 14,7                |
| <u>Citur dis Intes</u>                                             |             | - 149                   | +14                | - 296        | 429              | 100.0          | 12.4                |                     | 44,2                |
| Oth die die eys                                                    |             | 8,451                   | 304                | 1,172        | 3,525            | \$00.0         | 1 <u>1.5</u><br>1.0 | 24,9<br>70,6        | \$1,2<br>\$5,6      |
| Che fly dia                                                        | <b>B</b> 71 | 4,293                   | 190                | 1,218        | 2,880            | 100.0          | 4.6                 | 28.3                | 47.1                |
| Conitourinry bys                                                   | M0.476      | -<br>• •                |                    |              |                  |                |                     |                     |                     |
|                                                                    | NO-349      | <u>3,443</u> -<br>1,083 | <b>999</b>         | 797          | 2,007            | 100.0          | 19.0                | 23.0                | M.O                 |
|                                                                    | 190-591     | 909                     | 41 <b>9</b><br>173 | 427          | 1,020            | 100,0          | 22.2                | 22.1                | 15.1                |
| • • • · • · · • · • · • · • · • · • · •                            | 000-000     | 140                     | 24                 | 202          | <b>1</b> 1       | 100.0          | 17,3                | 25.5                | 87,2                |
|                                                                    | 810-614     | 104                     | 0                  | 33           | -82              | 100.0          | 17.8                | 27.9                | <u>W, 1</u>         |
| Dis fon pol org                                                    |             |                         | tě                 |              | 182              | <u>100</u> . Q | .0.0                |                     | 98.5                |
| tth f <b>in</b> . Th                                               | 617-429     | 247                     | n                  |              | 0<br>1 <b>20</b> | 100.0          | 100.0               | -0.0                | 0.0                 |
| · · _ · · · ·                                                      |             | -                       |                    |              |                  | 100.0          | 11.7                | 22.4                | <b>N.</b> 7         |
| Coup prog birth                                                    | 630-676     | 14                      | - <b>Ť</b>         | 1            | Ö                | 100.0          | 41.1                | \$1.\$              | 0.0                 |
| Skin & Indepton                                                    | 800-709     | 1,710                   | 210                | itt          | <b>961</b>       | 100.0          | 10, D               | 20.1                | <b>N</b> ,3         |
| Recularies ant                                                     | 710-731     | 71,014                  | 1,402              | 18,952       | 47,642           | 100.0          |                     |                     |                     |
| Arthropeth                                                         | 710-719     | 27,919                  | 1,126              | 4,44         | <u>**</u> (***   |                | 10.4                | 22.8                | 47,4                |
| Dis com 118                                                        | 710         | 4,653                   | KH I               | 478          | 893              | 100.0<br>100.0 | -1,7<br>M. 4        |                     | · · <u>11,5</u> .   |
| Phone arth                                                         | 714         | 8,598                   | 652                | 1,912        | .1,912           | 100.0          | 21. <u>3</u><br>7.6 | 28.6                | 75,5                |
| Di teoir th                                                        | 715         | 12.697                  | 154                | 875          | f1,667           | 107.0          | 1.2                 | 22.4<br>"A 4        | 69,8<br>0110        |
| 0th arth                                                           | 718         | 1,207                   | -17                | 336          | 1,474            | 100.0          | <b></b>             | <u>-0.1</u><br>47.4 | <u>91.9</u><br>77,3 |
| -Oth dis jnt                                                       | 719         | 1,611                   | . 1 <b>1</b> 1     | - \$25       | - 914            | 100.0          | 10.0                | 31.3                | H,1                 |
| Dorsopathies 1                                                     | 20-724      | 32,814                  | 3,364              | 8,912        | 20,234           | 100.0          | 10.3                | 11.4                | 62.2                |
| Spundylas<br>Disc: dis                                             | 721         | 10,413                  | 107                | 1,220        | 9.072            | 100.0          | -1.0                | 11.1                | 87,1                |
| Oth beck die                                                       | 722         | 18,371                  | 1,201              | 8,254        | 7,918            | 100.0          | 14.3                | 34.2                | 51.5                |
| B                                                                  |             | 5,750                   | 940                | 2,109        | 2,671            | 100.0          | 10.4                | 37.2                | 44,1                |
| D10 0011 110                                                       | 729         | 2,955                   | 373                | 113          | 1,809            | 100.0          | 12.4                | 28.1                | 61,2                |
|                                                                    |             | 1,208                   | 326                | 446          | \$24             | 100.0          | 18.8                | 37.0                | 44,5                |



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Mr. BARTLETT. Mr. Cholette, I had wanted to ask you also about the competitive placements.

Mr. CHOLETTE. I can only speak for the State of New Hampshire. We do handle the projects with industry for the State and with a State with less than a million people, we placed 177 disabled people into permanent employment last year. I don't know what the costs would be of handling the SSI, but I could probably research that and send it to you.

Mr. BARTLETT. You could do it? You are equipped to do it?

Mr. CHOLETTE. Yes. Definitely.

Mr. BARTLETT. If you were redrafting this act, the reauthorization of the Rehabilitation Act, what things would each of you include to provide for increased private sector involvement in rehabilitation?

Mr. Cholette, you expressed disappointment at the actual implementation of private sector involvement. Would you include percentage requirements? Or how would you approach it if you were in our shoes?

Mr. CHOLETTE. Well, I think we suggest that, for instance, priority be given to State agencies who would include the private sector and their continuing education, preservice education, and continuing education. We think that getting the providers—at least a task force under RSA where you had private providers and State agency representatives just to form a task force, to exchange ideas and be always current as to what was happening in the field. This has been done away with and now it is a hit and miss situation if someone is interested or they are not that they get together.

I think there are several things of this nature which I have included in the presentation.

Mr. BARTLETT. Your testimony was extremely helpful, Mr. Harles,

Mr. HARLES. Just a couple of quick points. Probably a substantial increase in projects with industries. That has proven, I think, itself now to be a very effective program and I think it needs to go from what is still more of a demonstration level in terms of funding and its place within the Rehabilitation Act to a much broader program, both in terms of how it is set up and in terms of its funding.

I think that we need to see a reemphasis on the innovation and expansion part of the act that has been basically, again, dormant for several years now. It was through those dollars, it went to the States and, in turn, primarily to private, nonprofit rehabilitation agencies to develop new methodologies to come up with some innovative approaches to new and old problems.

I think we need to see a reemphasis on that right now that States are relatively strapped in terms of not having any discretionary money available. I think we need to maybe point out in the act that there doesn't need to be some money carved out for that type of activity.

The same thing is true for discretionary programs in general, that there is where we did get a lot of the innovation, new ideas, new ways of doing things, and we pretty much lost that over the past several years.

Mr. BARTLETT. Mr. Dew, one final question. You testified—if I could overly simplify, one of the points of your testimony was that

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51-316 0 = 86 = 15

you are not overly impressed with new technologies of teaching, that is, satellite linkups and such as that, but you testified essentially back—and I am over-simplifying——

Mr. Dew. Gee, I hope I didn't say that.

Mr. BATTLETT. That there is no substitute for the classroom. My question would take in the issue of technology and taking technology out of teaching techniques, but I want to inquire as to what extent trainees are exposed to technological advances and their implications for the employment of disabled persons. So leaving aside using technology for teaching, do we need to improve on teaching technological availability for the disabled?

Is that an area of priority in your judgment?

Mr. DEW. Yes. I would certainly think sc. We talk about rehabilitation engineers and we know that they are certainly not being produced and trying to take engineers and make them rehabilitation engineers is certainly one route, but, no, I think that would certainly be a high area of priority.

Mr. BARTLETT. So you would increase that as a priority?

Mr. Dew. Oh, yes.

Mr. BARTLETT: Particularly rehabilitation engineers.

Mr. DEW. Could I just clarify my comment about the satellite because I don't mean to say that there is not a place for that, there is. One of the concerns I have is that we quite often get into this it is either this or this. In rehabilitation today there are no easy answers. It is a combination and I just hope that with the committee's guidance and leadership and everyone in this room that we just kind of force all of us to kind of work closer together to build on what we have and not take from each other.

I think that was my point.

Mr. BARTLETT. Thank you.

Mr. WILLIAMS. Mr. Cholette, many people see the organizations which you represent as prime examples of the successful contributory volunteer-like effort to assist folks. As you know, both because of changing philosophies and the Federal deficit, the Federal Government has looked more and more to volunteer efforts or private contributions to assist in some of the Nation's providing of services to those who need it.

Inasmuch as you, I might say, work both sides of the street, what is the appropriate Federal role the rest of this decade beyond?

Mr. CHOLETTE. Well, I think two major areas. On nink we have to continue the partnership between private and public. If we lose that by taking away all of the money, we are not going to get it back in contributions.

Second, we are fighting an uphill battle in trying to raise some basic contributed income. As you know, the third-class postal subsidy is very much in jeopardy; and for every penny of increase to a third-class nonprofit mailer, it will cost \$1 million worth of services that Easter Seal societies across the country are providing today.

that Easter Seal societies across the country are providing today. Now, if you take that away from us and take away the other part of the bargain, there will be nothing left. So we can do our share, I think, in the world of contributed income, but it, too, has its limitations.

Tax reform is affecting that, too, as you know. We don't know what is coming there.



Mr. WILLIAMS. Neither do we. Nor does anyone at the White House know what to expect.

Ms. Novak-Krajewski, you mentioned in your testimony that due to the nature of most severe handicaps a counselor must be exceptionally creative in developing job possibilities. Is it the judgment of your association that the current university-based rehabilitation counselor training programs are sufficiently preparing counselors to do that?

You are shaking your head no, for the record. Tell us, you did delineate what you thought was some concerns in your testimony, but it you would expand on those, I would appreciate it.

Ms. Novak-KRAJEWSKI. Having been in the field for about 9 years, I have heard of two universities that do excellent training and job placement and development. Those happen to be George Washington and the University of Wisconsin. Obviously there are only two that have a primary curricula focus in those areas.

Of the others, they are weak in those areas. It may be a small composite of a general counseling course in rehabilitation. There has not been an emphasis in what I have seen of rehabilitation counselors to be trained in specific areas of job development and placement with severely disabled individuals.

We obviously have to see the severely disabled individuals haven't been in the forefront, except for the last 5 years. So it is basically opportunities are opening for the disabled and education kept up within these. So there is a lack of service there.

Mr. WILLIAMS. I must close this hearing. Again, we appreciate all of you being with us and sharing your good counsel, and this hearing is adjourned.

[Additional material submitted for the record follows:]



PREPARED STATEMENT OF ROGER P. KINGSLEY, PH.D., DIRECTOR, CONGRESSIONAL RELA-TIONS DIVISION, GOVEENMENTAL AFFAIRS DEPARTMENT, ON BEHALF OT THE AMERICAN SPEECH-LANGUAGE-HEARING ASSOCIATION

The American Speech-Language-Hearing Association (ASHA) welcomes the opportunity to submit a statement to the Subcommittee on Select Education as part of the record of oversight hearings on the Rehabilitati. Act of 1973; as amended. As the major professional association concerned with rehabilitation of persons with communication handicaps, we are pleased that the Subcommittee has focused attention on a vitally important but inadequately implemented part of the Act--the Rehabilitation Training Program.

ASHA represents over 43,000 speech-language pathologists and audiologists nationwide, including many who provide rehabilitation services to handicapped adults. Among the relevant employment settings our members work in are hospital-based speech and hearing clinics, rehabilitation agencies and comprehensive outpatient rehabilitation agencies (including National Easter Seals and thited Cerebral Palsy facilities), state vocational rehabilitation agencies; and home health agencies.

# Evolution of the Rehabilitation Training Program

Having heard testimony from public officials, including state directors of vocational rehabilitation, representatives of national organizations, and disabled individuals receiving services in the rehabilitation system, the Subcommittee is already aware of serious problems in the Rehabilitation Training Program. The objectives of this statement are to (a) discuss the failure of the Rehabilitation services Administration (RSA) to fulfill requirements established by Congress in the Rehabilitation Act Amendments of 1984 (P.L. 98-221); (b) elaborate on the univertified ack of support for training personnel in the field of speech-language pathology and audiology; Cid (c) make several recommendations for modifications in the Rehabilitation Act.



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The Rehabilitation Tokining Program and ion 10% of the Rehabilitation Act of 1973, as amended) supports training in the bload range of established professional rehabilitation fields identified in the . h.bilitation Act inclusing rehabilitation medicine, speech-langurge pathology, audiology, physical therapy, occupational therapy, rehabilizetties counseling, interprefers for the deaf, and personnel to train the blind. Because rehabilitation focuses on the unique needs of handicapped indivituals, successful outcomes are largely dependent on professional service providers with appropriate training and skills. Long-term fraining accounts for the majority of the Rehabilitation Training Program, while the remainder of the hudget is devoted to continuing education programs which enuine that personnel already in the fiel maintain up-to-date techniques and skills enabling them to respond to changing priorities and needs within the rehabilitation program. Established by Congress in the Vocational Rehabilitation Amendments of 1954 (P.L. 83-565) to provide for the preparation and maintenance of a qualified work force, the Rehabilitation Training Program was expanded in 1973 (P.L. 93-112) to meet the demand for more specialized personnel qualified to work with persons suffering from a variety of disabling conditions and to improve the skills of those already engaged in rehabilitation of the handicapped. Section 304(b) of the Rehabilitation Act of 1973, as amended, stated that

In making such grants or contracts; funds made available for any year will be utilized to provide a balanced program of assistance to meet the medical vocational, and other personnel training needs of both public and private rehabilitation programs and institutions; to include projects in rehabilitation medicine; rehabilitation hursing; rehabilitation counseling; rebabilitation social work, rehabilitation psychiatry, rehabilitation psycholog iphysical therapy, occupational therapy, peech pathology and addology, workshop and facility administration, prosthetics and orthotics, special defined providing services to blind and deaf individe personnel in providing services to blind and deaf individe personnel to



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Because the sterute did not explicitly Jeffne "balanced program," considerable discretion was left in the hands of RSA to determine levels of support for the various rehabilitation fields. Training priorities were established on the basis of factors other than the actual need for different kinds of rehabilitation services. In 1980, a report concerning the impact of rehabilitation training support on the service delivery system found that "RSA does not use data on the characteristics of existing rehabilitation personnel for planning purposes."<sup>1</sup> The report concluded that "there has heen no way to systematically estimate the demand for rehabilitation personnel in many of the established disciplines other than by contacting professional organizations."<sup>2</sup> However, for many years, RSA has shown liftle interest in utilizing information on training needs from many professional associations, including ASMA. The Committee on Education and Labor recognized this problem when it reauthorized the Act in 1973:

A variety of government and private studies over the last several years have provided evidence of major manpower shortiges in rehabilitation fields such as speech-language pathology, audiology, rehabilitation medicine, physical therapy, occupational therapy, prosthetics and orthotics. The Committee has no evidence, however, that present training grant allocations are base upon objective findings of personnel shortages.

The Committee recognizes that documentation of rebabilitation personnel needs, updated annually; is the most objective and cost-effective means of justifying the allocation of training funds across discipling lines. Currently, there is no method to systematically distribute these grants according to findings of manpower shortages. Allocations can be made without necessary study and evaluation consistent with identifying needs for trianing or shortages in personnel. (House Report No. 98-137, p. 21)

<sup>2</sup><u>Ibid</u>., II-7.

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<sup>1</sup> Juk International Corporation, " issment of the impact of Rehabilitation Training Grant Support 12 S- Ed Areas of Academic and Sorr-Academic Training on Improving the Effectiveness of the Vocational Rehabilitation Service Delivery System." Final Report submitted to PSA/OSERS (December 1980), II-5.

#### Rehabilitation Training in Public Law 98-221

During the last reduthorization of the Act; this Subcommittee examined the status of Rehabilitation Training and drew two important conclusions. First, that serious personnel shortages exist in rehabilitation fields including speech-language pathology and audiology. Second, that the system for allocating training funds was inadequate in that it did not those on the amelioration of personnel do these.

Finding the manne: a training funds were allocated to be inadequate; the House and Senäte authorizing committees included changes which were intended to ensure effective use of personnel preparation funds. One amendment requires targeting of specific areas of personnel shortages. In order to eliminate arbitrary allocation of funds and to ensure that the awarding of grants is based on demonstrated used, another amendment requires that:

"The Commissioner shall\_prepare and submit to the Congress, simultaneously with the budget submission for the succeedior fiscal year for the Rehabilitation Services Administration, "eport setting forth and justifying in detail how the unds for the fiscal year prior to such submission are by professional discipline and other program areas. The contribution such submission personnel shortages, by funds proposed for the succeeding fiscal year will be allocated under the President's budget proposal, and how the findings of personnel shortages justify the allocations." (P.L. 98-221, Section 133(d))

Since enactment of this amendment, RSA has demonstrated little interest in implementing new procedures for determining personnel needs and basing funding allocations on objective findings. Last year, the agency contracted with David Roberts, Ph.D., of the Department of Educational and Counseling Psychology at the University of Missouri-Columbia to conduct a study of



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rehabilitation personnel meeds. Results of the National Rehabilitation Manpower Needs Assessment (1984) were presented at a briefing in Washington, D.C., on September 13, 1984, and published in April, 1985. The data reported are incomplete - a fact that was acknowledged by RSA officials who attended the briefing. A major reason for the incomplete data was they not all of the professional rehabilitation disciplines were adequately represented in the study. For instance, this Association, representing a significant segment of the rehabilitation der community, was not included on the Advisory Committee and was insulted during the planning phase of the study. As a result, speech-language pathology and audiology training programs were inadequately represented when the survey was done. Despite problems with the manner in which the study was conducted, it did produce more data than were previously available concerning the rehabilitation workforce, particularly relating to personnel shortages and Rehabilitative Services (05:06) on ided to not include any of the findings in its "Congressional Report" on He militation Training program allocations that was sent to Congress a sell of this year. 4 This report only alludes to the findings when it states that:

<u>Cirrently</u> available rehabilitation personnel supply and demand data and other information were reviewed to determine whether that data and information could be used to deter ine appropriate Fiscal Year 1985 and 1986 allocation levels in a uniform and reliable manner. This review indicated this adequate re habilitation personnel supply and demand data are not or rently available to permit the identification of personnel protones in a consistent and uniform manner.



<sup>&</sup>lt;sup>3</sup>C. David Röberts and Michael V. Oliveri, <u>National Rehabilitation Manpower</u> <u>Needs Assessment</u>, University of Missouri-Columbia (April 1985).

<sup>40.5.</sup> Department of Education, Office of Special Education and Rehabilitative Services, "Congressional Report: Fiscal Years 1985 and 1986 Relabilitation Training Program Allocations" (April 1985).

With the rejection of the initial study, RSA has recently contracted with Advanced Technology, incorporated, to develop a system for collecting data to estimate shortages of rehabilitation personnel and for making fund allocation decisions. OSERS officials have indicated that it will take at least another two years before valid data relating to rehabilitation personnel shortages are available.<sup>5</sup> we do not believe that delaying the first real report until the FY 1988 budget submission is what Congress intended when the amendment was passed requiring the Commissioner to provide reports at the time of the Department's budget submission for the succeeding fiscal year. The Senate Appropriations Committee restated its position in the Report accompanying the FY 1985 L, HHS, ED Appropriations bill:

The Committee is concerned that it has not been provided adequate documentation by RSA on how rehabilitation training funds are to be allocated to meet shortages of specific skilled personnel categories. A review of the actual training expenditures by RSA reveals a wide disparity in funding of various professional areas including seemingly disproportionately small amounts for major professions such as physical therapy.

The Committee notes that section\_133(d) of the recently enacted Public Law 98-221 reduires the RSA Commissioner to Submit with each year's budget request a justification of past and requested training expenditures in terms of shortage areas. The Committee strongly supports this provision and looks forward to receiving the first such report together with the fiscal year 1986 budget request. (Senate Report No. 98-544, p. 167)

The "Report" that RSA submitted to Congress last month falls far short of what the authorizing committees had in mind when they added the annual rehabilitation which there study to the Act. In fact, RSA acknowledges that "adequate rehabilitation personnel supply use domand dat one not currently available to permit the doublication of personnel supply to a consistent



<sup>5</sup> Based on conversations with staff of the Office of Special Edwards on and Rehabilitative Services (Apr.) 18 and June 11, 1985).

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manner," and therefore fiscal wears 1985 and 1985 allocation funds by discipline and protram area are and Will not SE based on objective data. BSA is continuing the practice of allocating training funds in a non-objective manner - exactly the practice Congress wanted to reform when it amended the Act. What all this amounts to is a disregard by the Pehabilitation Services Administration of the congressional mandal contribuished in Pil; 98-221 and a continuition of budget allocations that are not linked to findings of personnel meeds and shortages.

### Rehabilitation Training and Speech-Language Pathology and Audiology

The arbitrary decision-making concerning fund locations in personnel training has meant a continuous decline in support for speech-language-bearing programs and the total elimination of new training grants for these programs in the current fiscal year. (See Appendix A) RSA has neither provided evidence of a decline in the rehabilitation needs of adults with communication diporters not of a sufficient workforce (provide rehabilitation services to this population. (In the contrary, dara supplied to RSA by Dr. Roberts, along with demographic trends; give strong indication of a growing need for more speech-language pathology and audiology services. This need is amplified in a statement on "Rehabilitation Services and Personnel Needs for the Communicatively Handicapped," which was prepared for Dr. Roberts, who indicated that it would be appended to the <u>National</u> <u>Rehabilitation Manpower Needs Assessment</u> report. (See Appendix B)



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<sup>&</sup>lt;sup>6</sup>Madeleine C. Will, Assistant Secretary for Special Education and Rehabilita tive Services, testimony before the Subcommittee - Select Education (July 17, 1985), p. 2.

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Although this statement did not ippear in the final published report, it had been sent also to officials in the Office of Special Education and Rehabilitative Services. Yet, when the notice on Rehabilitation Long-Term Training Program allocation dows published in the <u>Federal Receister</u> on February 27. 1955, new funding for speech-language pathology and audiclosy program was omitted. Two verus ago, RSA decided to eliminate new funding for this projection, promptic, Congress to include a provision accompanying the FY 1984 CHEV, 55 Sparopriations Act (P.C. 98-139) which required a maintemance of funding support at the FY 1983 level of \$292,000. (Senate Report 98-247, p. 42)

In testimony before this Subcommittee on July 17, 1985; the Addistant Secretary for OSERS; Madeleine Will, res. "ed to the Chairman's quistion about current fund allocations by stating that her office was "in a holding pattern" due to inadequate personnel data and; therefore, that RSA was continuing to support the different professional areas. However, in the "Congressional Report" referred to earlier; there is no explanation as to why support for a major rehabilitation discipline - speech-language pachology and audiology - is being eliminated.

We are further concerned that RSA has been indicating to ASHA members contacting the agency that there are no new funds available because ASHA did not provide documentation to justify allocation of funds to the profession. Clearly, it was not the intent of Congress to require ASHA or any professional association to conduct studies that would demonstrate personnel needs and justify funding support. The Congressional requirement is that:

In addition to consulting the various training disciplines, state agencies, and others, in regard to training needs, the Committee expects the Commissioner to de clop objective procedures for gathering and assessing the information it receives. The Committee further expects that funds for the study and evaluation of manpower needs in fiscal year 1984 will not



be drawn from rehabilitation training program allocations; rather, the source for the necessary funding should be the salaries and expenses accounts of the Department. (Senate Report No. 98-168; p. 17)

This Association has, in fact, made every effort to provide RSA with information regarding workforce needs in the field of speech-landwage mathology and audiology. However, this information is apparently below disregarded as are data from the Roberts' study demonstrating a shortage of trained speechlangwage pathologists and audiologists? Our formal request made nearly four months ago for a review of the FY 1985 fund allocation decision has received no response from either the Assistant Secretary for OSERS or the Commissioner of RSA.<sup>8</sup>

#### Recommendation: Rehabilitation Personal Study

ASHA believes that the later contained in P.L. 98-221 and accompanying committee reports is quite clear regarding reports and justifications from RSA concerning the allocation of training grants. The Commissioner should fully explain his agency's failure to carry out these requirements in the law.

The timing of the Initial report was not entirely clear from the legislative history of P.L. 98-221. However; the Intent of Congress that BSA submit annual reports is not oper to question. The Senate Labor and Human Resources Committee Report on the Penabilitation Amendments of 1983 referred to "a study and evaluation of stepseer needs in <u>fiscal year 1984</u>..." (Senate Report V2. 98-168, p. 77, emphasis added). The House Education and Labor



<sup>7</sup>R-berts, National Rehabilitation Manpower-Needs Assessment, pp. 19-22, 4\*.

<sup>&</sup>lt;sup>B</sup>Letter from Dr. Frederick T. Spahr, ASHA Executive Director, to Madeleine Will (April 2, 1985).

Committee Report stated that "the amendment requires the Commissioner to provide to Congress <u>annually</u>, at the time of the Departmental budget submission, a report of the finding, of personnel needs... that justify the allocation of present and proposed training funds." Also, "the Committee recognizes that documentation of rehabilitation personnel meeds, <u>updated</u> <u>annually</u>, is the most objective and cost effective means of justifying the allocation of training funds across discipline lines." (House Report No. 98-298; p. 22; emphasis added)

Appatentity, committee report language has not provided sufficient motivation for RSA to comply with the amendment. It may be necessary to clarify the statute and, to this end, ASHA recommends a simple amendment to Section 304(c):

The Commissioner shall <u>annually</u> prepare and submit to the Congress, simultaneously with the budget submission for the succeeding fiscal year for the Rehabilitation Services Administration, a report...

#### Recommendation: Qualified Rehabilitation Personnel

In the last reauthorization of the Act, Congress amended Section 304 to include an emphasis on the need for "qualified" rehabilitation personnel. The Commissioner is supposed to determine training needs for qualified personnel and ensure that training grants and contracts be awarded for the purpose of assisting in increasing the authors of qualified personnel. Both authorizing or mittees stated that what is means of qualified" in this definition "in mittees stated that what is means of appropriate state and/or national certifying boards..." (Senate Report No. 98-168; p. 17; House Report No. 95-137, p. 22, and House Report No. 98-595).

ASHA strongly supported the addition of the term "dualified" and we believe that the change will contribute to the training of professionals who will be more able than in the past to provide appropriate rebabilitation services.

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We believe that the training of qualified personnel could be further enhanced by requiring that programs receiving Rehabilitation Training grants meet state and professional standards. Such a requirement was added to the Special Education Personnel Development Program in the Education of the Handicapped Act Amendments of 1983 (P.L. 98-199). Applied to rehabilitation personnel preparation, this would focus funding support on programs that have met state and national standards of quality education and training. ASHA recommends that Section 304 of the Rehabilitation Act he amended to include a provision requiring that:

The Commissioner shall ensure that applicant institutions, in order to be awarded rehabilitation training grants, shall meet both state and professionally recognized standards for the fraining of qualified rehabilitation personnel.

# Special Education - Rehabilitation Transition: Professional Training Needs

Cooperation between special education and vocational rehabilitation was strengthened when the two federal offices were placed under the same assistant secretary level office when the Department of Education was established in 1980. The new Office of Special Education and Rehabilitative Services (OSERS) was created to foster improved linkages between special education and rehabilitation agencies at state and local levels. It was generally assumed that coordination between the two program areas would be initiated by mational leaders and filter down to the lower levels where programs are actually implemented. The 1992 annual report of the National Council on the Handicapped recommend the development of an individualized career Development Plan (ICDP) which would be based on the Individualized Education Plan (ICP) and the Ind. thus the rehabilitation Plan (IWRP).9

9U.S. Bepartment of Education 2 Annual Report of the Nat Shal Council on the Handicapped (March 1983) . 40-43.



Recognizing the importance of improving training of students who are in transition between school and work, home and independent light; Contross estiblished Section 626 of the Education of a consignaped Act. "The Secondary Elucation and Transitional Services for Handloopped Youth" program, is designed to:

"strenkthen and contribute education, training, and related services for handicapped wouth to a sist in the transition a process to post-secondary education, or adult services..."

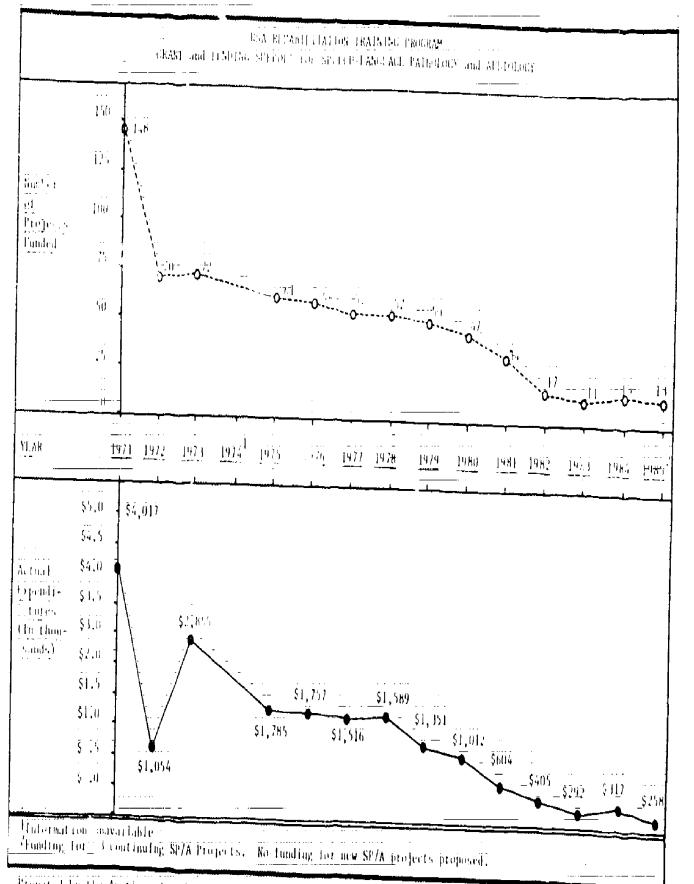
Despite coordination at the national level, educational and rehabilitation agencies remain apparated in the bureaucratic structures of most state and local governments. Ou diffications for professionals serving the handicapped are different and graving programs tend to focus on either education or robabilitation, resurgers in service providers who are inadequately equipped to work with or population or the other.

We would recommend that attention be given to this deficiency in the reauthorization of both the Rehabilitation Act and the Education of the Handicapped Act. For instance; the definition of "qualified" professional could be amended to include a requirement for at least some preservice training ing in both special education and rehabilitation. Also, inservice training programs in each field could be modified in scope and content incorporate information and practical instruction relating to the other field. The need for rehabilitation professionals to be equipped with skills for working with kriduates of Special education programs is greater than ever since the first Ra. of students is now emerging from the schools and entering rehabilitation programs.

ASEA apprectates the Committee's consideration of our glows and becommendations regarding the Rehabilitation Training Program. A look torward to working with Committee members and staff on the readibiofization of the Abr.



APPENDIX A



Prepared by the American Speech-Language-Hearing Association, Covernmental Affairs Department, May 1985





#### APPENDIX B

#### REMABILITATION SERVICES AND PERSONNEL NEEDS FOR THE COMMUNICATIVELY HANDICAPPED

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As in any professional service area; vocational rehabilitation services are only as good as the personnel who provide them. Personnel who specialize in the rehabilitation of handicapped individuals must receive quality training and must be trained in numbers adequite to ensure accessibility for persons in regions throughout the country and with a variety of disabling conditions. Congress has recognized these needs by making rehabilitation training an integral part of the overall federal-state vocational rehabilitation program. Authorization is provided for states and public or nonprofit agencies ind organizations; including institutions of higher education; to fund projects to increase the number of personnel trained in providing vocational and social rehabilitation services to handicapped individuals. Section 304(b) of the Rehabilitation Act of 1973, as amended, states that

"In making such grants or contracts, funds made available for any year shall be targeted to areas of personnel shortage which may for clude projects in rehabilitation medicine, rehabilitation nursing, rehabilitation counseling, rehabilitation social work, rehabilitation psychlatry, rehabilitation psychology, hysical therapy, occupational therapy, speech pathology and audiology...

The Rehabilitation Training section was Strengthened in the Rehabilitation Act Amendments of 1984 (P.L. 98-221) by placing new emphasis on the need for "qualifies" personnel, and by requiring RSA to systematically distribute training funds on the basis of findings of personnel shortages and analysis of personnel needs. This latter amendment requires RSA to provide Congress annually, along with its hudget request, a report on the findings of personnel needs (including inservice and continuing education needs) that justify the allocation of present and proposed training funds.

# Service Needs for the Contractively Handleapped Population

The ability to commune tesh a necessary skill in almost all walks of life, The portance f alignets communication ability in inferpersonal relation , educated and itional pursuits is underlable. It is signifies and the provides in the united States. These disorders are prevaled and the united States, and are groups, although speech and the inference of the more commonly found in children and hearing disorders are more prevalent in the elderly population, becoming to U.S. Censes at for 1980, there were approximately for million speech and language the provider sould over 18 million bearing timpaired persons in the nation.<sup>2</sup>

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However, as a result of an increase in the number of surviving handleapped infants and the disproportionate growth in the aging population, both types of bandleaps are projected to increase dramatically during the rest of this century and beyond. By the year 2025, it is estimated that there will be ever 3.6 million speech language impaired and 32.6 fillion hearing impaired Americans. It has been estimated that ampri solits are 18 to 79, seven to eight percent suffer, from some\_degree.of lawar of loss. The annual deficit in earning power among the hearing handleappe is estimated at over one and one-quarter billion dollars.

1...Due to confidentification and underrepeting of speech and language impairments to the USS: population; prevalence of these disorders is less certaid: 'However, it is generally assumed that there may be 10 million individuals; including both children and adults; who suffer from speech and language impairments.

As a result of congenital impairments, accidents, and severe illness, the number of persons with speech, language and bearing disorders is constantly growing. As the communicatively ha dicapped population increases, so does the demand for well-trained speech-language mathologists and audiologists to provide services in rehabilitation settings.

Nost speech and language disorders can be corrected when appropriate diagnoses and treatments are available and are provided. Although bearing is usually irreversion many hard-of-hearing (as opposed to deaf) indivican also be helpe. If professional rehabilitation and the use of hearing aids. Because to its to communicate effectively is so important in the work environment and the communicative disorders have such a high potential for successful repertied of the programs designed and funded to serve this population are very cost-effective.

RSA. ted that in fiscal year 1982; 226;924 individuals were rehabilitated through the federal-state program. Yet, despite the significant potential for rehabilitation; relatively few persons with speech; language and heating impairments baye been served. Only 20;300 of the individuals rehabilitated in 1981 had communication disorders, including 7;700 deaf; 10,800 hard-ofthearing; and 1,800 with speech and language impairments.<sup>6</sup> Over one and one-half million Americans are prevented from working as a result of communication disorders including result of addition disorders; and among the estimated 16.5 million people with a partial work disorders.

A final point here is that communication impairments are often related to severe handicapping condition. Like Parkinsonism; cerebral palsy; and multiple sclerosis. Individual rehabilitation programs for persons with these neurological conditions frequently include the services of scorch; language and rearing professionals. About one in five stroke parients have communication problems and need specialized rehabilitation in order to regain the use of



potentially eligible to receive republication services, a portaut criterion is the capacity to benefit from such services. In this context, it is important to note that persons with moderate and server communication (Hörders can often be rehabilitated to a degree that enable they to function effectively in day-to-day activities.

# Rehabilitation Personnel Heeds in Speech-Language Pathology and Audiology

In a 1979 report prepared by the HEN-HRA Bureau of wealth Manpow - for the Senate Committee on Labor and Human Resources and the House Committee on Interstate and Foreign Commerce (new Energy and Converce), serious Shortages were found in the availability of speech-landwage pathologists and audiologists. Using conservative estimates of Prevalence of communication disorders and data three or four times more speech pathologists are needed and approximately four that the supply of speech pathologists and audiologists...it appears that the supply of speech pathologists and audiologists is not adequate to meet either current or future demands and needs.

A similar conclusió i was reached in a report prepared for the Health Resources Administration Bureau of Health Professions in 1980. This report available audiological services, a problem that "may become even more acute as demand for services increases to meet requirements to provide audiological aid Report also found evidence of servicus maldistribution of audiologists and speech-language pathologists.

A 1984 study found that the undersupply of personnel in "speech/language communication was a "serious national need."10 Losking to the future; a Department of Labor study has estimated that becamen 1978-1990; an average of services to communicatively in "fildren, idults and senior fildrens. By 1990; at least 60,000 speech-la athologist and audiologists will be children Act, the Rehabilitation Medicate, Yedicate and other federal and second highest projected rise to bely the remeasures a 87.5 percent increase, the and social service occupations."



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- Notes
- 1. Senate Committee on Libor and Human Resources, Report No. 98-168, pp. 16-17.
- U.S. Bureau of the Census. 1982a Preliminary Estimates of the Population of the United States: 1970 to 1981.
- 3. U.S. Bureau of the Census. 1982b Projections of the Population of the United States: 1902 to 2050.
- N-t'onal Institute of Neurological Diseases ind Stroke, <u>Human Communication</u> <u>and It's Disorders: An Overview</u>. U.S. Department of Health, Juc tion and Welfare (1970);
- Rehabilitation Services Administration. Office of Special Education and Rehabilitative Services, <u>Annual Report to the President and the Congress of</u> Federal Activities Related to the Administration of the Rehabilitation Act of 1973, as amended (1982), pp. 8-9.
- Rehabilitation Services Administration, Office of Special Education and Rehabilitative Services, <u>Annual Report to the President and Congress on</u> <u>Pederal Activities Related to the Administration of the Rehabilitation Act</u> of 1973, as amended (1981).
- 7. National Center for Health statistics, Health Interview Survey (1977).
- Bureau of Health Manpower, Healt: Pesources Admin. stration; <u>A Report on</u> <u>Allied Health Personnet</u> (November 1979), p. SIV-5.
- 9. <u>Analysis of Geographic Distribution of Health Manpower Types Not Covered by Current Shortage Area Crit 18, pared for Bureau of Health Professions; Health Resources Administration by Applied Management Sciences; Inc. (1980), volume 11, chapters 4 and 5.</u>
- Instinct for the Study of Ecceptional Children and Youth, Department of Special ducation, College of Education, University of Maryland, <u>Personnel</u> to Eoi ste the Handicapped in America (1984).
- Occupational Projections and Training Data, Bureau of Labor Statistics, U.S. Department of Labor, (1980).





# PREPARED STATEMENT OF THE NAVAJO NATION

#### INTRODUCTION

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These comments are presented to be included in the record of the hearings conditioned by the Subcommittee on Select Education of the House Education and .... Committee regarding the authorization and amendment of the Rehabilitation Act of 1973. The comments particularly concern the provision of vocational rehabilitation lunds to Indian tribes to operate vocational rehabilitation programs.

The Navajo Nation is, at this writing, the only Indian tribc dir tly operating a vocational rehabilitation program or receiving funds for that purpose. It is anticipated, however, that this year one or more additional tribal programs will be funded by the U.S. Department of Education. The Navajo Nation is concerned that arm instration of the program under current legislation will encourage the continued underfunding of this activity by the Department of Education and will make it extremely difficult for other Indian tribes to operate vocational rehabilitation programs or for tribes such as the Navajo Nation to maintain the programs they have established.

#### PROVISIONS OF EXISTING LAW

The Navajo Nation operates a vocational rehabilitation program pursuant to Section 130 of the Rehabilitation Act of 1973 as amended by the Rehabilitation Amendments of 1978. Section 130 provide, that the Department of Education may make grants to the governing bodies of Indian tribes located on federal or state reservations to pay 90% of the cost of providing vocational rehabilitation services to hardicapped American Indians residing on such reservations. The grants are to be made in the form or a contract, to which sections 5,6.7, and 102(a) of the Indian Self-Determination and Education Assistance Act, P.I. 93-638, apply. The proposal must be developed in consultation with the state reviabilitation program and must offer services comparable to the rehabilitation services offered by the State.

Funding for grants to Indian tribes for relabilitation services is provided for in Section 100(b) (3) of the Act. That subsection provides that in addition to the other subs authorize' to be appropriated under the relabilitation act, there is authorized to be appropriated up to 1% of the basic state appropriation for making grants to Indian tribes. In fact, there has never been an appropriation under this section which came even close to 1% of the state appropriation. The appropriation for state programs in fiscal year 1984 and in fiscal year 1985 was over one billion dollars. The appropriation for Indian v ational numbilitation





was car; \$715,000. The existing law does not mandate any floor under the appropriation for Indian vocational rehabilitation. It does not address the question of continuity of funding. As will be discussed in this testimony, this inadequacy in the existing law has both discussed the development of more tribally-operated vocational rehabilitation programs and jeopardized the continued operation of the one existing Indian program.

The existing law makes no provision for tribally-operated programs to participate in many of the additional, supplementally funded programs available to state vocational rehabilitation provises. These include funding for staff training, for independent living and for advocacy services. As a result, it is more difficult for a tribally operated program to meets its mandate to provide services comparative to those provided by a state program. The Navajo vocational rehabilitation program has had to obtain staff training either out of the basic grant funds or through training conducted by state programs, usually in Arizona. The program has also been unable to develop needed independent living resources.

Finally, the existing law makes no provision for tribal programs operated supplementally to a state program. It privides only for a tribal program which replaces the state effort for the reservation population. Indeed, Section 130 provides for a redure ion over a three-year period in funds received by the state for the population inved by the tribal program. This feature of the existing law may have discouraged Indian tribes from oplying for funds since tribes are unable to provide the full range of services needed in a self-sustained program. Many tribes might be unwilling to take a step which could jeopardize the access of tribal merviers to the state program. While the Navajo Nation has a large enough copulation to support a full service vocational relabilitation program, other tribes might benefit more from a program which complements and interfaces with the state effort.

# HANDICAPPED NATIVE AMERICANS AND REMABILITATION

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The situation of handrcapped Native Americans throughout the country reflects a number of differences from the rest of the handicopped population. The incidence of many handicapping conditions is greater among Native Americans. The relative distribution of different handicapping conditions is different from the general population. The access to rehabilitation services of handicapped Native Americans is less than the general population. The rate of acceptance by rehabilitation programs is lower, as is the rate of rehabilitation for those accepted for services. These characteristics will be discussed below and in supplemental material which is presented to this Committee as background inform ..., \*



The Navajo Nation expresses its appreciation tc, the Native American Research and Tral ing Center at Northern Arizona University for making is information on the incidence of handicapping conditions and

A report prepared by the Native American Research and Training Center at Northern Arizona University indicates that the overall incidence of disabling conditions is 1 1/2 times higher among Native Americans than among the general population. Despite this higher incidence of handicapping conditions, disabled Native Americans are only 60% as likely as disabled members of the general population to be successfully rehabilitater . Native Americans are less likely to apply for rehabilitation survices. If they apply, they are less likely to be accepted into the caseload. If accepted into the caseload, they are less likely to be rehabilitated.

Within the categories of handicapping conditions among persons Within the categories or nancicapping conditions among persons accepted for vocational rehabilitation caseloads, Native Americans have reported higher incidents of 'sability than the general population in regard to accident', injury c: the eye (1:28 times the general popula-tion); injuries to be spinal cord (1:13); infections of the ear (1:03); arthritis (1:17), accident loss of limb (1:11), dental conditions (1:61) and end stage renal failure (1.98). These figures actually underestimate the amount of trauma-caused disability, since accidents are the leading cause of death and traumatic hospitalization among Native Americans.

Leading the causes of disability, and highly implicated in many of the other disabilities reported for Native Americans is alcoholism (3.21 times the average for the general population). "Other character disorders" are also reported at higher than the national average (1.16). handicapped population to have a secondar, disability. This disability is most likely to be classified as alcoholism.

It those disabilities which appear with greater frequency among Native Americans, the rate of rehabilitation is often less than the rate for the general population. For example, 61.7% of those with cases of accidental eye injury from the general population are successfully rehabilitated. Only 53% of the Native Americans with this disability accepted for services are rehabilitated. 73% of those from the general population accepted for services with accidental loss of limb are successfully rehabilitated. For Native Americans with this condition, the rate of rehabilitation for those accepted for services is only 58.3%. Persons accepted from the general population for services because of alcoholism show a rehabilitation rate of 52.6%. For Native Americans; the rehabilitation rate is 37%.

One of the most common reasons given in rehabilitation services reports for the failure to accept Native Americans into the rehabilitation caseload or for the failure to successfully rehabilitate is the inability to locate the client after the initial contact. A report of

rehabilitation of Native merican handicapped available to the Navajo Nation for this testimony Conclusions drawn from data are those of the Navajo Nation.



the Rehabilitation Services Administration for cases closed in 1978 indicates that 25% of the Native American cases were closed out because of the failure to locate the client, compared to 15% for the general population. This figure reflects, among other things; the geographic isolation of the Native American client and the concentration of services in the more settled, urban areas. It also reflects the gulf of language and culture betweer the disabled Native American and the rehabilitation service providers in the larger society:

What these figures and reports demonstrate is that the Native American population has a greater need or rehabilitation services than does the general population. Yet, those services are less available to Native Americans, particularly those living on reservations, than to the general population. A recent article published in <u>American Rehabili-</u> tation (Jan/Feb/Mar 1985), concluded:

"Evidence indicates that (federally funded health care agencies) — i.e., Rehabilitation Services Administration, Special Education, Administration on Aging -- have neither served the Indian handicapped and disabled on a scale commensurate to their needs, nor formally approached tribal entities to resolve jurisdictional, cultural, linguistic and other barriers that impede service delivery:" ("Handicapping a d Disabiing Conditions in Native American Populations," by Jamil L. Toubbeh)

The Rehabilitation Services Administration in its report on the RSA-300 data for fiscal year 1978 also concluded:

"The Indian population on reservations, including

the disabled population, are not conveniently located for easy participation in general Federal and State programs; ... If there is any single, important step that RSA should consider in order to improve VR services to Native Americans, that step is developing ways to take VR to the reservation Indians. It is not lightly that they will or even can come to VR in highly significant numbers."

EXPERIENCE OF THE NAVAJO VOCATIONAL REHABILITATION PROGRAM

The most successful example of a vocational rehabilitation program aimed at serving Native Americans is the Nava's Vocational Rehabilitation Program. At this writing, NVRP is the only vocational rehabilitation program directly operated by an Indian tribe. It is anticipated, however, that in the coming contract year one or more additional tribal



programs will be funded by the Department of Education. The Navajo Vocational Rehabilitation Program was established in 1975, utilizing VR funds from the states of Arizona, New Mexico and Utah. The program first received funds under Section 130 of the Rehabilitation Act in FY 1982 (appropriated in FY 1981). The program began with a staff of 5 and a caseload of less than 75. It now has a staff of 18 and a caseload of more than 450 active files. Rehabilitations have grown from 32 to more than 72 and are increasing.

Utilizing a professional Navajo staff, the Navajo Vocational Rehabilitation Program has been able to is effective in serving its Native American clients in many areas where state VR programs have been found lacking. The Navajo Vocational Rehabilitation Proc am has counsellors located in each of the five Agencies of the reservation. These Navajo counsellors are bilingual, able to serve both Navajo speaking and English speaking clients. They are located proximate to Tribal, BIA and Indian Health Service agency service centers, facili- tating such processes as receiving referrals, receiving supportive health services, referring to job training opportunities, and similar supportive processes.

The Navajo program is able to interface with the local secondary schools, and in fact operates a school-to-work program under an additional grant. The program is able to seek placement for clients in the available employment in the reservation area. The program has effectively integrated Native healing services who the rehabilitation process. At the same time, the program does wordinate with state 'R appropriate:

The program has, however, experienced some difficulties as a consequence of its special status. Since the Navajo Vocational Rehabilitation Program is not treated as a state VR ingram, the program is not eligible to receive staff training funds, independent living funds and advocacy fully for which state VP programs may apply. These limitations, while they have not crippled the p. gram, have limited its ability to obtain appropriate training for staff, to establish independent living arrangements for clients or to establish reservation-wide advocacy services. State advocacy services are as limited for onreservation handicapped persons as stat: VF services. In order to obtain training, NVRP has made arrangements so its staff can "sit in" on a space available basis in training conducted by the Arizona VR program. This is not as satisfactory an alternative as training directed at the specific needs of the Navajo program.

Most critically, the program has been plaqued by financial uncertainty. When the Navajo Vocational Rehabilition Program was first funded through Section 130, funds were earmarked for the Navajo program. This solved the problem of the Navajo program for a time. However, the earmarking of funds for the Navajo program meant that no funds were available for other tribes to establish vocational rehabilitation pro-



grams. In addition, the Navajo program had to return to Congress each year seeking either an earmatking of funds or an increase sufficient to fund more than one program. Also, the Navajo program did not share in the cost of living increases which applied to the state programs. The Congress received \$650,000 in FY 1982, 1983 and 1984. In FY 1984, Congress appropriated \$715,000 for FY 1985 with unquern in the recent of the conference committee identifying these funds is a mailer to find the Navajo program at its then current level with an increase for inflation. \$715,000 was again appropriated in F 1981 is the interbut any language indicating that the funds which are increase for program.

The funds appropriated in FY 1964 for FY 1985 we have a subcompetitive bid in an RFP. Since time was short that we is the only qualified bidder and received the last spectral tribes. The funds appropriated in FY 1985 for FY 1986 have a so to be put out to competitive bid. This time several tribes have put an attractions. Total Section 130 funds sought in this year's application. Accord 52 million: As a consequence, the Navajo Vocational Rehabilitation of the funded. This situation creates two untenable scenarios. Fither an established program with a proven track record of serving Native American clients will be seriously impaired because other tribal programs are funded or other tribes will have gone to the work and effort of developing VR proposals which cannot be funded because the Navajo VR program requires the full appropriation. Neither scenarios serves Indian people;

As a consequence of this situation, the Navajo Nation has sought a supplemental appropriation for Fi 1985 of \$715,000 for Section 130 VR projects. This would allow a full funding of the Navajo Vocational Rehabilitation Program while allowing the Department of Education to fund additional tribal programs from among those who have submitted appl.ations. At this writing the Senate has included appropriate language to accomplish this in the 1985 Supplemental Appropriations Bill and that language is being reviewed by a House-Senate conference committes. The Navajo Nation is seeking additional funding in the FY 1986 appropriation, together with language distinguishing the funds intended for established orograms from funds intended for new program starts:

## RECOMMENDATIONS FOR LEGISLATIVE CHANGE

The present situation is very unsa stactory. Congressional staff are understandably weary of the annual fort to save the Navajo Vocational Rehabilitation Program. So is the Navajo Nation. The current law, as it is being implemented, appears to offer no way in which the program can enjoy the funding stability which state VR programs take for granted. In addition, the levels of funding sought for Section 130 programs each year by the Department of Education are totally inadequate to meet the need for Native American vocational rehabilitation services. The Navajo Nation believes that a fundamental change in the law is



required that would:

- a. assure more adequate furthing for Indian vocational rehabilitation programs;
- provide some stability in the funding levels of established Intian TR programs;
- c. allow Indian VR programs to apply for the supplemental state VR programs for which state VR programs are eligible; and
- c. provide for tribal <u>programs</u> that complement and s plement state VR programs as well as for VR programs that provide separate and comparable services.

The Navajo ' tion will be providing to the Subcommittee on Select Education recommended wording that could accomplish the above goals through one or more approaches. For purposes of this testimony, we will simply discuss how the above goals could be accomplished.

In the first place, if Congress withes to encourage tribally-based programs to meet the needs of unserved and underserved disabled Indians, it is essential to establish a floor for Section 130 funds as well as a ceiling. The current law provides that Congress may appropriate no more than 1% of the state allocation for Indian vocational rehabilitation programs. In fact, nowhere near this amount has ever been appropriated; we would recommend that the law be amended to phase in 1% funding for Indian vocational rehabilitation programs over a four-year period.

Additionally, specific lang age is needed requiring that funding be applied first to maintaining existing Indian VR services and then to new programs and special projects. This is needed not only by the Navajo Vocational Rehabilitation Program but by any Indian VR program that may become established under the current or amencial law. It is wasteful of administrative resources to be constantly subjected to funding uncertainty. It would be wasteful of program resources to cut the funding for services to an existing group of clients.

Specific language is required which will assure that tribal vocational rehabilitation programs may apply for the same supplemental and support funds that state programs can a <u>bly</u> for, particularly funds for staff training, independent living and advocacy. These supplemental programs can add greatly to the quality of the tribal program.

Section 130 needs to be amended to allow tribal organizations authorized by the tribal governing body to apply for VR funds. This is necessary both to permit the operation of a tribal VR program by a tribal corporation and to allow several tribes together to develop an intertribal organization to provide VR services to more than one tribe.



Such an arrangement could be particularly useful to smaller tribes or pueblos which could not operate a full service program by thenselves. In addition, Section 13 needs to be amended to permit tribes to develop VR programs which supplement or complement state VR programs. Such a change would be particularly valuable for tribes which do not have the size necessary to support a full service VR program but which need tribal VR services to assist tribal members in making the best use of state resources. As stated above, these state resources often do not effectively extend to the reservation population. Clearly some kind of service located within the tribe is required even to make the best use of state resources.

Finally, language is needed to specifically reference the obligation of the state to serve disabled populations located on-reservation and to cooperate and coordinate with tribally-operated vocational rehabilitation programs. As stated above; this population has greater service needs and fewer services than the rest of the disabled population. VR programs must be required to address the disabilities from which Native Americans disproportionately suffer, including the disability of alcoholism.

#### CONCLUSION

The suggestions made in this testimony are intended to bring to the attention of Congress the seriousness of the providing adequate vocational rehabilitation services to National propulations and to propose solutions through the developmine of tribally-based vocational rehabilitation program the experience of the Navajo Vocational Rehabilitation program the experience of the Navajo Vocational Rehabilitation services a tribally-operated program of vocational rehabilitation services that unless change is made in the current law it will be difficult if not impossible to develop more effective tribal vocational rehabilitation programs.

[Whereupon, ät 12:25 p.m. the subcommittee adjourned subject to the call of the Chair.]



# REAUTHORIZATION OF THE REHABILITATION ACT OF 1973

# TUESDAY: AUGUST 27, 1985

HOUSE OF REPRESENTATIVES. SUBCOMMITTEE ON SELECT EDUCATION, COMMITTEE ON EDUCATION AND LABOR;

Bozeman, MT

e subcommittee met, pursuant to notice, at 9:30 a.m., in room Strand Student Union Building, Montana State University Boze an, MT, Hon. Pat Williams presiding.

Me ibers present: Representatives Williams and Bartlett.

Stat present: Celinda Lake, majority legislative associate; and Bol Silverstein, majority counsel.

r. WILLIAMS. I want to welcome each of you to the fourth in a series of hearings the Subcommittee on Select Education has been holding on the reauthorization of the Rehabilitation Act of 1973.

We nave been hearing from a variety of national groups in Washington, DC, representing consumers, Federal and State administrators, private providers of the rehabilitation system, counselors, and others about the effectiveness of the current rehabilitation program and the future challenge of the system.

Vocational rehabilitation is, as you know, the major Federal jobrelated effort serving persons with disabilities and providing support services to allow people to work.

Vocational rehabilitation has made a major contribution to keeping people self-sufficient and independent. For all of us concerned about the Federal deficit, we are encouraged by the cost effectiveness of the vocational rehabilitation effort which returns, according to the best analysis I have been able to identify, returns \$10.80 to the Treasury for every \$1 spent on those services.

However, the unmet need is enormous. Disabled people suffer between 50 and 80 percent unemployment. Despite our successes, we have a long way to go in this State-Federal partnership to develop the most comprehensive and effective program.

Today, we are particularly interested in hearing from the persective of people who work with vocational rehabilitation and about its priorities, organization, and leadership.

Montana is a lightly populated State which can mean unique demands for rehabilitation cutreach and differences in the profile of the disabled population.

I am very concerned that the Federal rehabilitation program be designed to meet the needs of our State and others like us. Our hearing today is at a university, Montana State University in Boze-



man: It is particularly appropriate for us to examine how the rehabilition system and the education system are meeting the needs of disabled students who have benefited from the first gene: tion of the Education for the Handicapped Act but now need assistance with higher education and job placement.

Finally, we will be exploring the challenges the rehabilitation system faces for job placement and independent living with changes in technology and demography.

With me today is Congressman Steve Bartlett-from Texas. Steve is the ranking minority member on our Select Education Committee. Steve is serving his second term in Congress. He represents the Dallas area in Texas. I find Steve to be a prudent conscientious legislator of great assistance to our committee, and I am delighted; Steve that you are with us today in Montana.

Mr. BARTLETT. Thank you, Mr. Chairman. It is a pleasure to be here.

I want to begin by thanking the chairman for the opportunity to have this hearing and the opportunity to participate. As you all know, rehabilitation issues and disability issues are bipartisan kinds of issues both here in Montana and fortunately in Washington. I am very appreciative of the leadership the chairman, Pat Williams, has displayed in this area when he volunteered to serve as chairman of this committee.

- During his long years of service on the Education and Labor Committee, he has displayed a great deal of leadership and know! edge of and interest in disability issues.

It is a particular pleasure as one who is from Texas to be in Montana for this hearing. There are those in Texas who believe that Montana was once part of Texas. I have detected that sentiment probably not shared in this room. We also think of Texas being the land of the Big Sky, although at elevation 900 feet in Dallas, are not as close to the Big Sky as we are here in Bozeman. Net there so, I think that there are a lot of similarities, in terms of the tances particularly, that Texais and Montanans share.

The one similarity that I know we share, and what makes the more appreciative than anything else in this field hearing, is an understanding—and both of this field hearing and that the other hearings that the chairman has held, is an understanding that the answer: o many of the dilemmas of the Nation's problems, particularly in rehabilitation issues, do not reside within the bounds of the Potamac River in Washington, DC.

I met, i is to the ch. rman's credit, this subcommittee's credit, that in connecting the Rehabilitation Act, that we are setting out to be the contract of the containing of the Washington mindset and to come to the contract and this issues to people from other States in fact to discover to there are a lot of things that Montanans in the rehabilitation area have to teach.

If we could just find a way to export the knowledge and the expertise of the people in this room to Washington, DC, I think the act and the rehabilitation movement in the country as a whole would be far better off.

The Rehabilite Act itself, enacted in 1921, is singularly the most successful proce of Federal legislat — that anyone has ever devised. It will be reauthorized, no doubt about that. In spite of its



success, it is to the credit of the chairman that this subcommittee is taking the extra effort and is willing to ask those questions as to how the Rehabilitation Act can; already successful, be improved as we go into the latter part of the 1980's and 1600's. How can we meet the number of employment, higher technology, and medical technologies and other bry throughs?

In particular, some of the specific areas that I will be interested in asking about would be the opinion is of the people who—of the rather formidable list of witnesses that we have; in terms of the matching grants, as to whether the 80 percent Federal and 20 percent State grant is still the right ratio, or whether that ought to be increased on the State side to try to increase the leverage: as to whether the formula and the distribution formula among States is fair.

As you know, the formula is based strictly on a State's population and per capita income without regard to other kinds of factors, such as remoteness or distance factor that we have here in Montana and many places in Texas.

I will be interested to see how well. in your opinion, the increased mandate of 1983 to serve the severely disabled first how well that has worked, and whether it has worked well, z = 1 what additional mandates Congress either could add or should readove in the area of severely disabled, where on the name of all were z = 59 percent of all those served are severely disabled

I am interested in a number of other are i particular, the area of independent living, both as it relates to independent living centers, which I think are one of the real success stories in the last several years; how independent living centers can be improved; and specifically how we can put into the entire process the overriding concept of independent living and full employment, and how we can put that into the rehabilitation process.

In the area of employment, one of the things that I think everyone in here will focus on is the question as to how we can break out of that 84 percent unemployment rate that disabled persons now suffer on a national average. What are the barriers? Is it transportation, is it insurance, is it Social Security, all of the able persons?

In conclusion, I feel this is a hearing in which we are all free to think together of ways in which the Rehabilitation Act can and out it to be improved to make a support it it at a support

ought to be improved to make a successful act work even better. Thank you, Mr. Chairman.

Mr. Wittiams. Thank you very much. Steve.

Despite the size of Texas, about which I am alongs impressed, history will demonstrate that Montana was, in fact, no er part of Texas:

Steve has been impressed since he has come here, and although I know he can't say it to his constituents he is beginning to doubt, since he saw Montana, particularly this western half that Texas is indeed the largest State in the Union, because he said, "My God, you have so much land out here you stack it." If we leveled it out, Steve, Texas would be part of Montana.



That is the good thing about being chairman. You get the mike and don't have to give it back. There will be no response at this time.

Our first panel today is administrator of the rehabilitation services division, department of social and rehabilitative services, State of Montana, Bob Donaldson, and the supervisor of visual services division of the department of social and rehabilitative services of Montana, supervisor, Maggie Bullock. If both of you will come forward, please.

# STATEMENTS OF BOB DONALDSON, ADMINISTRATOR, REHABILI-

TATIVE SERVICES DIVISION; DEPARTMENT OF SOCIAL AND REHABILITATIVE SERVICES; STATE OF MONTANA; AND MAGGIE BULLOCK, SUPERVISOR, VISUAL SERVICES DIVISION, DEPARTMENT OF SOCIAL AND REHABILITATIVE SERVICES, STATE OF MONTANA

Mr. DONALDSON. Mr. Chairman, members of the committee, I a... Bob Donaldson, the administrator of the rehabilitative services division for the State of Montana.

It is a privilege to appear here before you and to present testimo ny as to the act itself and the unique needs that arise because of a rural State and that type of thing.

I have been with the Vocational Rehabilitation Program in Montana for 30 years. I have been administering the program for the past 10. With me, as Representative Williams said, is Maggie Bullock, who supervises, the visual services program, acts its staff functioning with special projects, facilities, special funding, both State and Federal sources of funding.

In the last census the total number of disabled in Montana between age 14 and 64 was about 41,000 folks. About 8,000 folks being blind or visually impaired, the other 33,000 having other physical or mental disabilities.

In 1985 the State Vocational Rehabilitation Program served approximately 8,000 clients; placed back into gainful employment about 800. This was at a service cost of \$866 per recipient, and as Representative Williams stated, a return of about \$10 fr each dollar that was spent.

Sixty-four percent of those rehabilitated in gainful employment by the program were severely disabled by definition. I think they are fairly reflective of a small program. By that I mean the size of the program in comparison with New York or California.

In a large and rural State, and the need and the inability of this State, as in many of the other States, to serve the remaining 34,000 of the group that we are not presently providing VR service to or the countless cover disabled who need and require independent living services before a vocational goal, or before reaching their level or the ability to remain independent in their life.

There are n.any barriers to providing rehabilitation or social service in States like Montana. One of these barriers is inclequate data: The data we have available is just not correct or current. We base estimated needs, on national formulas that are developed through studies conducted, generally speaking by large Eastern States or large eastern university systems.



They do not take into account the extensive area, or the fact that in some States, like Montana, there are Indian reservations with little or no date for programs like ours to access.

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During the 1985 legislative session in Montana, there was a great deal of input from providers of service, applicants, consumers, other interested people that the needs of the disabled were not being, as they felt, adequately served. Needed services that were not available, and were not provided through the vocational rehabilitation program because you weren't talking about gainful employment.

At any rate, the legislature did pass enabling legislation, some funding was given, which was used to match the independent living grant, rehabilitation grant, and we are providing some services, and will attempt to meet some of the needs to get data to support wherever we should be going with independent living rehabilitation such as in the act and such as in State law.

The ethnicity of the States like this, we have 12 Indian tribes in Montana. Native Americans account for about 5 percent of the State's total population. About 60 percent of these live on seven reservations: According to Federal data, and from working out here, I do believe it, the disability rate is about one and a half times higher on a reservation than it is in one of our downtown communities or elsewhere in the State, for many reasons, none of which I care to go into, because some may or may not be founded on fact:

They are not too accessible to health services, prekinds of services. We are trying to increase our outreach to them. The other is professional staff. As in many States, Montana tries to obtain the best qualified staff we can.

Here we are talking about staff such as rchabilitation counselors, your staff who actually provide the one-to one counseling service and placement, other special types of service, such as orientation mobility specialists that work with the blind, rehabilitation teachers that work with the blind.

There are schools throughout the country, Eastern Montana-College in Billings does have a master's level program in training rehabilitation counselors. Most of the universities that train people in rehabilitation teachers are back east.

We have had a certain amount of trouble filling some of these slots mainly because a lot of the profession always prefer a center type or city type atmosphere. You are still working with people helping people, but you are working in more of a building office structure, 8 to 5 o'clock, Monday through Friday, as opposed to spending 6 hours driving to Glendive, MT, to spend 1 hour working with maybe a very needy client, somebody that really needs that service. So some won't apply. Some people, they get here, feel that because of their training, because of their background, and I can see it both ways, that maybe 6 hours in a car is a total waste of time when they have these skills to offer.

By the same token, States like Montana, Utah, many other States, including parts of Texas, you do have people out in some of these areas that need the service and they are entitled the same level of qualification of staff as the people living in Dallas or Missoula, MT.

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We have attempted to fill openings in some of our areas. Miles City is one for a rehab teacher. Some of our staff in these special fields where they have unique skills to offer the disabled do travel an ungodly distance, and I think Maggie will go into some of that.

Also, your central office staff here, your administrative staff, do have to handle many different kinds of administrative kinds of duties. Any additional central office function is parcelled out to somebody that already exists.

The economic factors I have kind of touched on. The extensive travel, that does increase both costs of travel, the costs of staff time to providing service, the outreach abilities of a program like this, and I do see this as one of our responsibilities to provide outreach to contact people promptly in their own community, their home.

But with the size of the caseloads and travel involved, the other aspects of that is where you get service. So if you are talking about unique training or unique surgical procedure, if you live in eastern Montana, say Sidney, Glendive, you tend to go to Minneapolis. If you live in Billings, it is apt to be Salt Lake or Denver. If you live in western Montana, it is more apt to be Seattle.

More and more the larger communities are providing many of the type, particularly in the medically related, and I am certainly not making any kind of a pitch to build any unique heart cardiac center in Glendive or anything like that. But some people will always have to go to service because of that particular service, because the skills are there.

It does mean that probably more than we would like, certainly, we are doing a lot of our contact or outreach three on the mail, so that instead of personal contract, maybe we are writing and arranging with them, if they can, to meet us some place 100 miles away where we can have two or three come, which gets into the next area, which is transportation.

Only our major cities in Montana have bus service, or public transportation, and between Montana cities, again, if you get into eastern or northern Montana, the public transportation is fairly limited. Then you run into whether you rent a plane or spend an overnight.

If you take the bus for commercial transportation, you are apt to spend 2 days to get to a spot in the State to see two or three people. Again, staff do do that, and there is no particular solution to that problem, but I felt the committee should understand that.

The other issue I want to discuss to some extent is the attitude of the conservative "I want to do it myself" kind of a thing, and "I'll handle this," which some of it, of course, is good and it is healthy and that, but when you do have somebody who is all of a sudden a paraplegic, or has to really limit what he can do and has to do, you do have to come in and provide whatever services are available.

With that, I will close my presentation and turn this over to Maggie Bullock.

[Prepared statement of Walter R. Donaldson follows:]

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PREPARED STATEMENT OF WALTER R. DONALDSON, ADMINISTRATOR, REHABILITATIVE Services Division, Department of Social and Rehabilitative Services

I am Walter R. "Bob" Donaldson, Administrator of the Rehabilitative and Visual Services Divisions, known as the Voc Rehab program of the Department of Social



and Rehabilitation Service in Montana. I have seen the Administrator since 1974, having been the Assistant Administrator and Supervisor of Field Services prior to that. I have participated in service Jelivery to Montana's disabled citizens since 1955 when I began my carcer with Voc Rehab as a counselor. Providing the other part of Montana VR's testimony is Maggie Bullock who, during the past fifteen years, has supervised special federal and state funds administered by Voc Rehab and supervised the Visual Service program the past four years.

It is a privilege to appear before this committee and discuss with you our perceptions of special rehab needs existing in rural areas and whether they can be met; and how the federal-state partnership has evolved and what changes if any, should be made.

41,000 individuals or 8.1% of Montana's 498,060 residents between 16 and 64 are eligible for VR services. Approximately 8,000 of those are blind and visually impaired and 33,000 reflect other disabilities. In federal fiscal year 1985, 7,051 of these people were served by both of Montana's VR divisions, 798 or 11% were rehabilitated at an average cost of \$866 service dollars and at an average return of \$9.80 to Montana's economy for every public dollar invested. 695 of those served were industrially injured as were 182 of those rehabilitated. 64% of those rehabilitated met the definition of severely disabled as stated in the Rehab Act of 1973.

These statistics are reflective of a small VR program in a large rural state and the need but inability to serve the remaining 34,000 people who require VR services and the countless other disabled who require independent living services before a vocational goal can be considered.

Ruralness implies the following barriers and Montana's attempt to (not always solve), but to at least deal with these barriers.

## INADEQUATE DATA

In Montana as in ot ier rural state there exists a lack of a comprehensive needs assessment or system or collecting data on rural disabled individuals. Estimates of n ed are oftentimes based on national formulas that do not account for extensive territories, sporse populations, and Indian reservations. Prior to and during the last session of Montana's 1985 legislature, consumers, providers and professionals in a united front, effectively presented the needs of all the disabled, especially the severely disabled. As a result of those efforts the umbrella agency, of which the VR program is a division, is tentatively hoping to undertake a needs survey, the results of which will be presented to the next legislature.

### ETHNICITY

Twelve tribes of Native Americans account for 5 percent of Montana's total population. Over 60% of the state's Native Americans live on 7 reservations. According to an analysis of federal Rehab Services Administration data, the rate of disability, of the Native American is one and a half times the rate reported for the rest of the population. We believe Native Americans are among the poorest population in America today.

If an individual has no money, then access to transportation is not possible. No transportation leads to limited, if any, access to those communities where medical, educational and social services are housed. (Example: Someone living 40 miles from a post office without transportation and no money to pay for a ride will probably not pick up mail but once or twice a month.) Unfortunately, with budget cuts most human services' primary vehicle for notification is the United States Postal Service. Consequently, many individuals never get services because they don't keep appointments, and services are not delivered because it is "assumed" they are not needed or wanted based on "no response". Very few Native Americans have telephones.

#### PROFESSIONAL STAFF

Because of the itinerant nature of professional level jobs (i.e. rehab supervisors, counselors, orientation and mobility specialists and rehab teachers) recruiting of qualified staff has been difficult. Itinerant in a rural area is different from itinerant in a large city. In a large city much travel implies home every night for traveling staff. Staff covering rural Montana are often "on the road" a minimum of a week at a time, sometimes having to travel a full day to reach one client. Graduates of rehab counselor training programs and instructional service programs are trained principally to work at eight to five jobs in clinic settings. An example of difficulties in recruiting staff, is taking a year and a half to fill an Orientation & Mobility spe-



cialist position in Great Falls (population 57,000) and a year to fill a counselor position in Miles City (population 10,000), both at competitive salaries nationwide.

To alleviate the qualified staff recruitment problem we are beginning to convert professional level positions to training assignments and providing the academic and practical training to upgrade the individual to the credentials required for the profession.

Also in rural states like Montana, administrative staff typically assume a variety of repsonsibilities, i.e. wear many hats. In Montana's state office of VR, six professional staff (with two Administrative Assistants and one clerical person), everyone assumes multiple responsibilities in our attempt to comply with the requirements of the Rehab Act and Administer two separate VR divisions.

#### ECONOMIC

Because of the extensive travel involved in contacting disabled people living in areas of Montana other than the major cities, the cost of providing services and rehabilitating cisabled Montanans is much greater. For example we have an orientation and mobility specialist stationed in Great Falls with a caseload at any one time cf 55-75 visually impaired and blind adults. Until we are able to recruit a qualified professional to relieve her of a part of her territory (which includes the five (5) northern counties of Eastern Montana), she is responsible for traveling 56,036 miles a year covering the area from Great Falls to the North Dakota border and down to White Sulphur (see the map in attachment A outlining her territory—a territory comparable to the state of Ohio and part of Pennsylvania). She is limited to a travel budget of \$4,300 for the year. The real cost of providing services and rehabilitating a person in her area must include the price of her time and travel as well as the cost of delivering services, which often cannot be followed up personally but once a month or once every other month or by mail or phone. Other ways we are attempting to solve this temporary shortage of professional staff are to: (a) occasionally provide her relief utilizing other staff covering other areas; or (b) training volunteers or depending on county health nurses to assist in service delivery (However this is not being done extensively.)

# TRANSPORTATION

Transportation is a very costly portion of delivering services to clients and supervising the VR program by Helena state office staff. Only the larger communities of Great Falls, Billings, Helena and Missoula have public transportation systems. Many outlying communities in Montana are accessible only via car so that residents (disabled or not) are dependent on friends or family members to transport them to services, typically available only in the larger communities. However certain services such as some vocational diagnostic services are being provided by private nonprofit rehabilitation organizations using mobile units. One private non-profit corporation in eastern Montana provides a mobile evaluation unit that covers the 17 eastern counties or 90,000 square miles. Also, other organizations such as Job Service and county welfare departments provide itinerate VI; staff office space to meet with disabled folks in outlying areas. Not to be ignored are the many home visits made by VR staff.

# ATTITUDES

I cannot reference a study that demonstrates the relationship between rural attitudes and rehab. However, VR counselors that travel those areas will tell you that because physical prowess and self reliance characterize the rural culture, rehab services are sometimes viewed as alien—something to be avoided. Professional VR staff (counselors and instructional staff) are also viewed with a first impression of "How come you think you can do this better than me?" Rural people have a tendency to "make do" with what they have, such as the lady living along the sparsely populated Montana-Canadian border who was using a broom as a cane to assist herself with mobility until our staff offered to order her an appropriate cane. We try to reinforce this self reliant attitude while encouraging them to try new ways and new products, especially new technologies.





CONTRACTOR

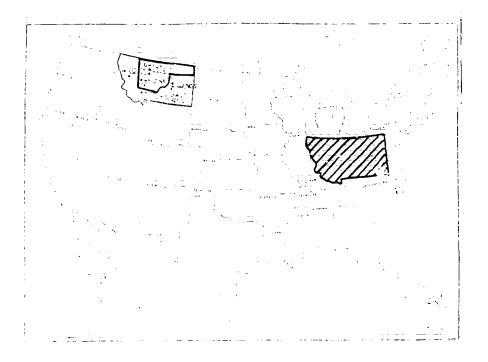
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Ms. BULLOCK. Good morning, Chairman Williams, Mr. Bartlett.

I would like to continue on with our testimony and tell you some of the ways we have tried to overcome the barriers for ruralness talk to you a little bit about the Federal-State partnership.

Montana VR currently has nonwritten agreements with many other private and public agencies to work together on behalf of disabled individuals. As you know, agreements are only as good as the people implementing them.

Because there are so few people, relatively speaking, administering human service programs in rural States, communication among the different agencies tends to be more open and administration of such programs tends to be a lot more accessible, and this is the case in Montana.

We have what we think are four outstanding examples of agreements orgoing right now. One of them is cooperating on a project with the AFL-CIO to reemploy individuals displaced from the work force because of a disabling illness or injury.

Another rgreement we have is with the job service and training division of the Department of Labor in Montana, and that is to be a program operator for the Job Training Partnership Act.

We receive a grant of approximately \$410,000, and served about 300 disabled Montanans, and we have in the past year put back into competitive employment approximately 79 people.

Since the fell of 1984, we had an agreement with the Office of Public Instruction and the Montana Developmental Disabilities Authority, and have participated with them in an inner agency transition team to better coordinate the efforts to move severely disabled young adults from secondary education into the world of work.

These three agencies are also submitting an application for special projects discretionary dollars to fund a support employment rural demonstration model.

The last agreement that I would like to talk about, and it is not-these are not the only four agreements we have, but we wanted to mention them. We have recently undertaken a public education or public relations campaign that will include special efforts to work with many private organizations and persons such as the chambers of commerce, local legislators, rehab facilities, consumer groups, and independent living organizations.

The State-Federal partnership. In addition to serving all disabled people with a full range of services to place them in gainful employment, the history of the State-Federal voc-rehab program is characterized by a partnership.

With our Denver regional office, the State-Federal partnership has been strong in spite of not being able to meet personally with one regional office person but once or twice a year because of their in decuate travel budgets the past 4 years.

As a matter of fact, today is the first day in 5 years that our Denver Regional Commissioner has been in Montana.

The Montana VR relationship with Washington, DC, has never had to be a particularly close one because the chain of command is typically and effectively been through Denver. Also, prior to 1981 we were always well heeled, so to speak, with regular influences that would come from that office, and these were known as informational memorandums or policy directives, and they were in all



areas of the administration of the VR program. and in all areas of service delivery for the VR program. Now, those issuances have decreased by at least half, and the ones that have been issued the past 4 years have typically been on the learning disabled, job placement transitions, and supported employment.

Our Denver regional office has always provided technical assistance, legal opinions, and interpretations of Federal intent which have held us in good stead through Federal and State audits and in our relationships with consumers.

While we strongly feel that our Washington, DC, Federal leaders are well intentioned, we also feel that they have very narrow perspectives. They are characteristically also very slow in advertising dollars and just generally providing the necessary tools for implementing programs, whether those tools are State plan format or whether they are Federal regulations or program policies or directives.

As in example, the new State plan for voc-rehab was due July 1 of this year, and the preprint format on which to submit the plan did not arrive until August 8, 1985.

Another example is the independent living State plan. That preprint arrived in May 1985 and that was for 1985 dollars, and Montana's plan was not approved until the middle of July. To date we still have no policy directives at all on the independent living dollars.

Most of our testimony has centered around the voc-rehab program, and that is the primary mission of the agency This program, which is 65 years old at the Federal and State level, is one of the most, if not the most, cost effective human service program, which you have heard in the other hearings.

When the program is criticized by consumers and others, typically it is because of a lack of resources or it is because we can't serve people unless they are vocationally handicapped with a potential to go back into remunerative work. We are very aware of the needs of the disabled who are so severely impaired that they do not presently have any potential for employment.

Montana  $\hat{V}R$  is aware of 426 of these individuals, as a matter of fact, who were close to severe for voc-rehab in Federal fiscal year 1984.

A 2-year-old survey by a human service organization in western Montana has revealed that a rising number, about 690 of those people in Montana, are very severely disabled and are head injured. The intensity and constancy required in delivering independent living services to meet the needs of those folks and other severely disabled require at least two things.

One is more money than the \$96,000 appropriated for each State, and the second thing is more training and technical assistance, especially through our regional office staff in very specialized areas.

If this is in fact the decade of the disabled, as our President has proclaimed, we in human services, like VR, have to stay abreast with medical science and with technology, which is allowing victims of severe injuries to survive

We feel because of the flexibility inherent in the language of the rehab act, we do not recommend the amending or rescinding por-

tions of it. We feel it is mode! legislation and car accommodate the needs of all the diasabled as they are surfacing today.

However, unless Washington, DC, leadership possesses the knowledge and experience to sustain VR as a national program implementad according to congressional intent, this very effective program could become a very insulated State program with as many operational modes as there are States.

However, because the needs of all the disabled are national in scope, requiring a sharing of information and ideas among all States, and because all necessary resources do not exist in each State, a strong Federal presence is required to maintain and oversee the National Service Delivery System.

We also strongly recommend two things. One is that jcb descrip-tions delineating VR knowledge and experience for Washington, DC, RSA physicians be a Federal requirement as it is a regional and State office requirement, and the second thing is that the technical assistance responsibility of the regional office staff be returned to them.

Thank you.

# [Prepared statement of Maggie Bullock follows:]

# PREPARED STATEMENT OF MAGGIE BULLOCK, SUPERVISOR, VISUAL SERVICES DIVISION, DEPARTMENT OF SOCIAL AND REHABILITATIVE SERVICES

Implicit in our rural attitude of self reliance is a pride that drives us to overcome the above stated barriers in the following ways: (1) Coordinating and cooperating with other public and with private organiza-

tions both inside and outside of Montana;

(2) Nurturing the state and federal partnership in a way that we are most comfortable with and confident in, i.e. through the Denver Regional office that boasts a staff of 10 people with 160 years of VR experience and knowledge among them. That 160 years of VR experience and knowledge has been in private and public, medical and non-medical, administration and services delivery. I would like to take a few minutes to talk about each of these.

### A. AGREEMENTS

Montana VR currently has written agreements with the Veteran's Administration, the Office of Public Instruction, the Developmental Disabilities authority, Vocational Education, Job Service, the Montana Association of Financial Aid Officers. and private rehabilitation organizations. We have unwritten agreements to work together on behalf of disabled individuals with Social Security, rehab facilities, con-sumer groups, independent living organizations, the Department of Labor's Wage and Hour and Workers' Compensation authorities. These agreements basically pro-vide for our agencies to work together on behalf of disabled Montanans of working age and approaching working age. As you know, agreements are only as good as the people implementing them. Because there are so few people (relatively specking) administering human service programs in rural state, communication among the dif-ferent agencies tends to be more open and administration of such programs tend to be more accessible. Such is the case in Montana. Four outstanding examples of this are:

Montana VR's good working relationship with AFL-CIO. We are currently co-operating on an AFL-CIO project to re-employ individuals displaced from the work force because of a disabling illness or injury.
 Montana VR is a Job Traning Partnership Act p ogram operator for the Bal-ance of State Private Inductor Courted.

ance of State Private Industry Council. We are spending \$410,000 of JTPA dollars (with none of it going for administration) serving approximately 300 disabled Mon-tanans placing 79 into competitive employment at an average wage of \$5.21 an hour

(3) Since the fall of 1984 the Montana Office of Public Instruction, Montana VR and the Montana DD authority have participated in an intervency transition team to better coordinate efforts to move severely disabled young adults from secondary education into the world of work. These three agencies are also submitting an appli-



cation for the Special Projects discretionary dollars to fund a Supported Employment rural demonstration model.

(4) The Montana VR agency has recently undertaken a public education/public relations campaign that will include special efforts to work with many private organizations and persons such as Chambers of Commerce, local legislators, rehab facilities, consumer groups, and independent living organizations.

## B. THE STAT "EDERAL PARTNERSHIP

The 65 year history of the state-federal vocational rehabilitation program is characterized by:

(1) Continuous expansion to inlcude all mental and physical disabilities to be served and a full range of services;

(2) A constant mission of rendering employable; disabled persons who are handicapped as far as securing and holding a job; and

(3) A federal-state partnership implicit in the years of bipartisan Congressional interest and support shown by increasing the appropriation to meet the needs of vocationally handicapped individuals of employable age.

The first two characteristics have been well defined and upheld these 65 years. With our Denver Regional Office the state-federal partnership has been strong in spite of not being able to meet personally with one Regional office person but once or twice a year (because of their inadequate travel budgets) the past four (4) years. As a matter of fact today is the first day in five (5) years our Denver RSA Regional Commissioner has been in Montana. The Montana VR relationship with Washington D.C. VR has never had to be particularly close because the chain of command has typically and effectively been through Denver, and because prior to 1981 we always "well heeled" with regular (i.e. at least monthly or every other month) issuances from D.C. of Informational Memorandums and Program Instructions on all areas of administration and service delivery in the VR program. Those issuances from Washington D.C. have decreased by at least half. The ones that have been issued by Washington D.C. the past four (4) years have typically been on the learning disabled, job placement, transitions and supported employment. The Denver Regional office has always provided technical assistance, legal opinions and interpretations of federal intent which have held us in good stead through federal or state audits and in our dealings with consumers.

While we strongly feel that our Washington D.C. federal leaders are well intentioned, they have very narrow perspectives. Also they are claracteristically very slow in advertising dollars and just generally providing the recessary tools for implementing programs, whether those tools be state plan formats, federal regulations or programs policies or directives. As an example, the new State Plan for Vocational Retabilitation was due July 1, 1985. The preprint format on which to submit the plan, arrived in the mail August 8, 1985. Another example is the Independent Living State Plan, the preprint of which arrived in May 1985 with Montana's plan not being approved until the middle of July. There are still no policy directives on Independent Living Part A dollars. Because, according to state law, spending authority on these dollars runs out September 30, 1985, special contractual arrangements must be made at state level to commit and spend those dollars.

We interpret this narrow perspective and apparent lack of knowledge of and/or experience in VR among the Washington D.C. VR leaders to be a distraction to those of us in states (who are very familiar with what the VR program should be legally) as well as a dilution of what the VR program is.

### CLOSING REMARKS

Most of our testimony has centered around the vocational rehabilitation program which is the primary mission of our program. This program, 65 years old at the federal and our state level, is one of the most, if not the most cost effective human service programs funded with tax dollars. When the program is criticized by consumers and others, typically it is because or either a lack of resources or because we can't serve people unless they are vocationally handicapped with a potential to go into renumerative work. We are very aware of the needs of the disabled who are so severely impaired that they do not presently have potential for employment. Montana VR is aware of 426 of these individuais who were closed too severe for VR in federal fiscal year 1984 and who thus require independent living services that can be purchased with Title VII part A dollars. A two year old survey by a human service organization in western Montana revealed a rising number (approximately 690) of the very severely disabled in Montana to be head injured. The intensity and con-



stancy required in delivering independent living services to meet the needs of all the very severely disabled required three things:

(1) More money than the \$96,000 appropriated for each state, and

(2) More training and technical assistance by and through our very knowledgeable regional office staff in very specialized areas so that a multi-disciplinary approach is available to this rural population of very severely disabled, and

(3) More direction and knowledgeable leadership; (a) in this area of special needs for very severely disabled individuals; and (b) in the general VR program. If this is in fact the decade of the disabled, as proclaimed by President Reagan, we in human services, such as VR, must stay abreast with medical services and technology which is allowing victims of severe injuries to survive.

Because of the flexibility inherent in the language of the Rehabilitation Act we do not recommend amending or rescinding portions of it. We feel it is model legislation and can accommodate the needs of all disabled individuals as they are surfacing today. However, unless Washington; D.C. leadership possesses the knowledge and experience of sustain VR as a national program implemented according to Congressional intent, this very effective program could become a very insulated state program with as many operational modes as there are states. However because the needs of all disabled people are national in scope, requiring a sharing of information and ideas among all states and because all necessary resources do not exist in each state; a strong federal presence is required to maintain and oversee this national service delivery system. We also strongly recommend the following:

(1) That job descriptions delineating VR knowledge and experience for Washington D.C. RSA positions be a federal requirement just as they are a regional and state office requirement; and

(2) The technical assistance responsibility of the RSA Regional offices who are very familiar with the needs of their states be restored to its former importance.

Mr. WILLIAMS: Thank you.

Steve.

Mr. BARTLETT. If you let me explore a little bit with both of you some items that you alluded to in your testimony.

Ms. Bullock, I would like to explore with you a little bit of your concept as to where we ought to go in rehabilitation in terms of employment.

That is to say, both medical technologies and technology in general in the work place has improved so vastly in the last 5 years, and will in the next 5 years. My question is what would you do to improve that 11 percent, I believe, was your testimony, 11 percent placement rate or employment rate of persons that go into a rehabilitation service? What would you do to improve the record at the conclusion of rehabilitation for independent living services of helping to place a person into a job, whether it is some sort of a subsidized employment or unsubsidized employment, or some other kind of employment? Where are the chief barriers that you see that continues this very high unemployment rate, national average of 84 percent?

Ms. BULLOCK. Mr. Bartlett, one of the real obvious barriers I think in Montana is the fact we have a high unemployment rate. We are typically a rural State.

I think it is real critical, and this is something we have tried to do, it is very critical to work with other agencies that are also doing job placement. Many agencies are doing job placement these days, not just rehab. You have a lot of private concerns that are doing it as well as Job Service and other public funded organizations.



So I think working together with all of the agencies, and this is something we have started in Montana. We have started what is called networking with other agencies that are in placement.

I think another way to improve the placement rate, if you will, is trying to keep abreast of various technological types of advances. I mean, I think we have got some people in the voc-rehab program who could return to work if we could find the right technology to help them return to work. We are aware of some of that technology in Montana, but I don't believe we have as much access to it as some of the urban areas do.

I am thinking in terms of computer technology, where you have an individual, say, an individual that is a high level quadriplegic, and the only thing that individual might be able to utilize to get back to work would be a computer—some sort of a computer system. I think we have to educate employers too that these folks are very, very good employees.

Mr. BARTLETT. So in terms of the Federal role, the first would be access to both the technology and also the knowledge of the technology that is available; and, second, would be an attitude change. Is that what you are suggesting, on behalf of employers or maybe on behalf of all of us?

Ms. BULLOCK. Weil, I think on behalf of all of us, but I think it is our responsibility to educate employers as to the availability of the population out there, the unemployed and disabled population, and the fact that they are very skilled and very knowledgeable in many areas, and we need to tap that talent.

Mr. BARTLETT. Mr. Donaldson, what can we do with the Federal law to improve an 11-percent placement rate?

Mr. DONALDSON. You understand, I think that is probably typical of other States.

Mr. BARTLETT. Yes. I was not singling out Montana. It is also typical of Texas.

Mr. DONALDSON. Some of the things, supported employment and some of those other things are in the act and have been projects. Montana has submitted a proposal on that. Those are some things.

The other is just trying to improve the national and State economies so there is more employment, and the people we are working with, the disabled, have more access to positions, and that is the crux of the basic program where you have the person who is qualified and capable and you can place him on the job and give him some kind of support.

Mr. BARTLETT. I recall a conversation I had with the Southland Corp. not too long ago. It was headquartered—operator of the 7-11 stores nationwide. They first began hiring disabled persons out of pure self-interest. It was the Target Jobs Tax Credit Act, and then they began running their computers and they discovered that statistically, and you can't generalize for any group of people for individuals, but statistically they obtained a much higher quality employee from the disabled persons that they hired in order to get their tax credit.

So they are now out seeking additional employees out of that job pool. Of course, that is in high unemployment areas and high employment areas.





Mr. DONALDSON. The key then nationally, and I think it probably will continue, there are kinds of trends in employment. There is probably going to be more jobs in the service kinds of industries; maybe more high technology kinds of jobs, some of the technical and some of the other kinds of skills, semiskilled jobs are dwindling.

But there will be more in service, such as you mentioned the 7-11. We found the same thing with a lot of the corporations in Montana, McDonald's, the 4B's chain, and whatnot. They may have started for whatever reason, but they do find these are very capable employees.

Mr. BARTLETT. One of the questions, in terms of changing thereauthorizing the Rehabilitation Act, would you-what is the match that Montana provides now? The official minimum is 20 percent State match to an 80 percent Federal, and many think that is a bit outdated. Do you think that is too high or should we change it?

Mr. DONALDSON: I do not think you should change it. We are matching in at the 20 percent that is necessary to obtain the Federal money, and I would assume if the Federal maintains and has an inflationary increase and whatnot, that the State of Montana would continue to do that.

The next panel does have two legislators who can better relate to that. In my own opinion, if you change that match or increased it to 50-50 or something like that, that it would be a direct cut in service to Montana, that the State of Montana would not replace the Federal dollars that we lost because of the matching change. That is an honest opinion.

Mr. BARTLEYT. Thank you.

Mr. WILLIAMS. Let me ask both of you a question that I will pose later to our two legislators and some of the others who are with us. It follows on Steve's last question.

Last year the total rehabilitation budget in Montan was \$4,900,000. Now, of that the Federal Government cont. ted \$3,900,000, and the State contributed \$990,000.

The State of Montana was one of only 13 States to not contribute more than the minimum that you had to contribute. Only 13 States did that, and this was one of them.

I guess my question could go down a number of avenues, but given that you are the administrator and supervisor of this effort, let me ask you about your efforts before the legislature to try to increase the amount of money that Montanans themselves contributed to support this program. The Federal Government, even with its severe deficit, which has been roundly criticized by Montanans, including the Governor, contributes significantly more to the vocational rehabilitation of Montanans than Montanans do. What have you done to try to right that situation, if indeed, you believe it needs righting? There is a question as to whether or not it isn't correct as it stands. Bob?

Mr. DONALDSON. I will answer that. I do not mind answering it. The two legislators that I know are here sitting behind me are friends of the program. Of course, there are another 148, some of whom do not see this as one of their big things.



There was a program for people process within the department of social and rehabilitation service went through, and there was a period of time there, about a year, where many consumers participated. It really was a grassroots thing.

There was a disability subsection with six people representing disabilities, and came up with priorities, which all of the human services agreed on, that this is something we need.

We need day care and we need senior centers, and we need some money in the basic rehabilitation program, some things on waiting lists for the developmentally disabled and whatno. But anyway, the basic program that you asked about, Representative Williams, was seen--we made the presentation--was seen as one of the things. That went through that process. It went through the Governor's budget process somewhat. I am sure you understand the budget process, every step there is a little taken away. But it went on through.

Basically what I can say is that we did pick up in the Appropriations Committee an additional \$50,000, which was deeply appreciated. We made, in my mind, and I say that because I am the one basically, Maggie and I, that made it, the best pitch possible. We are going to try and get more support, more consumers, because this is true, the recipients of the service who can present it the best, say that is what they did for me, and now I am here, and would have never done it without them.

Mr. WILLIAMS. Is the state contribution coming from the general fund or workman's comp fund or both?

Mr. DONALDSON. It is a combination.

Mr. WILLIAMS. Let me ask you, Maggie, if you are familiar with this, is it a good idea to begin to rely increasingly on the workman's comp fund for the match?

Ms. BULLOCK: No; it is not:

Mr. WILLIAMS. Why is that?

Ms. BULLOCK. Because the workers comp dollars are limited. They can only be spent on the industrially injured, and the majority of the population that the voc-rehab is serving are not industrially injured.

I believe the workers comp portion is about 80 percent of the population we serve. What you have happening is that people that are getting workers comp funding are served oftentimes more and better benefits than somebody who is under the general rehab program, because we have limitations under the general rehab program and you can only spread the dollars just so far.

gram and you can only spread the dollars just so far. Mr. WILLIAMS. Well, before we end with this panel, let me just note a difficulty. Many of you know I am a member of the House Budget Committee. One of the things that has come to my attention as a member of that committee is the Federal allocation to the State on vocational rehabilitation is a client per capita contribution of \$5.14.

That compares with a national average of only \$4.56. In other words, the Federal Government has done well by Montana, as it should, because the costs are higher here.

My point to you is, that at a time of increasing deficits, when the President and the Congress, and by the way, the Congress this year has voted to spend \$6 billion less than the President has asked us

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to spend, so the Congress is fully aware of the situation. That situation requires that we look for places to cut this budget, and guess which kinds of States stand out in that effort? Those States where the costs are highest per capita. Is it fair to cut those States? I think not. But I can tell you that a majority of the Members of the U.S. House of Representatives believe it is fair to cut those States where the costs are exorbitant, and we are one of those States.

Now, combined with that is the fact that Montana only contributes what they have to and not a dollar more to this effort, and that doesn't give us much ammunition with which to keep the supply coming.

Well, we very much appreciate both of you giving us your good counsel. You have been helpful, and we are glad you are here.

Mr. Bartlett.

Mr. BARTLETT. If I could indulge the chairman and ask one additional question and ask unanimous consent to leave the record open that you could answer either later or if you have some answers today.

First on the issue of the match. I would take it from the perspective of the chairman, but also from the perspective of you, if the Federal Government were to increase the minimum match from 20 to 30 percent and fund the same number of dollars, what I am interested in and what Chairman Williams is interested in is to increase the delivery of services to rehabilitate more people that need rehabilitation.

That is a 10-percent increase in your budget by the Federal Government sending the same number of dollars. Now, I suppose that's going to be the dilemma as to how you would do that.

My question then is this: You may want to think about this. Are there ways in which we could improve the Federal law, either by adding things or specifically by deleting things, are there reporting requirements that are inefficient and of no consequence, are there, and costly; are there mandates that make no sense; are there regulatory requirements that just simply that you would be better off setting the regulations yourself?

Someone mentioned the \$4,300 travel allowance. Is that a Federal mandate or Federal regulation? If there are changes in regulations or changes in mandates that we send to you that we can improve, help give you a chance to improve your efficiency that also has the opportunity of increasing your delivery of services, do you have a list now or a list later?

Mr. WILLIAMS. Bob and Maggie, because of our time constraints, we will limit your answers to about a minute apiece. Can you do that? You may want to respond more in writing. It is a good question and deserves a good answer.

Mr. DONALDSON. Hopefully we could increase our money, but by the same token, there are not too many things I think in changes to the law that would affect what you said. May be some in regulations.

Mr. BARTLETT. The regulation writers don't believe it, but we can change the regulations.

Mr. DONALDSON: I know that. But there are some people that disagree.



The only thing I am trying to say is that the paperwork, the documentation, the auditing, there is some balancing between somebody just providing service and a whole bunch of paperwork, documentation and auditing, which is a requirement too. There is some balancing there. That is all I really would like to say on that.

Ms. BULLOCK. I will say one thing. That is that the priorities in the rehab program change from, oh, like every year or so, and I think what is happening here is there are needs of various disabled individuals surfacing so we are getting new priorities in the vocrehab program of things to do that don't meet the mandate of the voc-rehab program. That is a problem.

They fall within the rehab Act, but not within the voc-rehab program. So that presents a problem in delivering services efficiently, because we are always kind of being distracted, if you will, by other things that are coming up or were supposed to concentrate on things.

Like learning disabled, just concentate on that disability group, or just concentrate on transitions or supported work, when in fact we have got a whole population of disabled people to be concerned with that don't necessary fit into those categories.

Thank you.

Mr. WILLIAMS. Thank you both very much.

Our next panel is two distinguished Montana legislators, Representative Budd Gould and Representative Dorothy Bradley.

Many or probably most of you here today either know or know of Representative Gould or Representative Bradley. Steve Bartlett does not, so for his purpose, Steve, I want you to know that these are two of Montana's premiere legislators. I don't know whether they are two of the most notorious or two of the most famous, but nonetheless, we know as much about them and their good work as we do two people who serve in the Montana House of Representatives.

Budd Gould represents Missoula, a portion thereof; and Dorothy Bradley represents a portion of the city of Bozeman.

Budd, we will begin with you. We are delighted that you traveled down here today and look forward to your testimony.

# STATEMENTS OF R. BUDD GOULD, MONTANA STATE REPRESENT-ATIVE AND MEMBER, NATIONAL COUNCIL FOR THE HANDI-CAPPED; AND DOROTHY BRADLEY, MONTANA STATE REPRE-SENTATIVE

Mr. GOULD: Mr. Chairman, it is good to see you again, and also Representative Bartlett. I am very familiar with Congressman Bartlett. He has come and spoken to me before, and I was very impressed at that time with the Congressman, with what he had to say about rehabilitation.

Mr. Chairman, and Congressman Bartlett, and staff, I am at a little bit of a disadvantage in that I sent you 25 copies of my testimony, and the only other copy is in my minicomputer, which, of course, is very much of a minicomputer.

But my name is Representative Budd Gould. I am in my fifth term of the Montana House of Representatives. For 10 years I have been a member of the Rehabilitation Services Advisory Council, 10



years the Visual Services Advisory Council, and for 5 years I have been a member of the Governor's Committee on Employment of the Handicapped, and 21/2 years ago, after confirmation by the U.S. Senate, I was made a member by President Reagan of the National Council on the Handicapped

I will be speaking today as a member of the legislature and various advisory councils, but not the National Council on the Handicapped, who will be giving you testimony on their own.

I would mention two things, however. First of all, in November, December 1983, I did a complete program review and analysis of the Rehabilitative Services Administration for the NCH, and you will be receiving a report on February 1 of this coming year from the NCH, and I think that that report to you will be very heipful.

The second thing that I would like to do is draw a little parallel, Mr. Chairman, between libraries and rehabilitation. Now, if you leave your home every day and a block or two down the street you hit a pothole in the road, you are going to call your local road department or you are going to call your local assemblyman or city councilman, or whoever it might be, and complain about that pothole in the road. But usually with libraries, it is a matter of students, and not that many adult taxpayers that use libraries.

Consequently, when the appropriations process starts for that local entity the next time, the road department does very well and of course, libraries don't do that well. Thus, they are having a great deal of problems with keeping open the hours that they should be and keeping collections updated. So it is a problem for libraries, out of sight out of mind.

You will find the same thing is true of rehabilitation. If the 36 million Americans who are part of the disabled community were united in one voice, it would be a different situation.

The next thing that I would like to mention is that in the course of your hearings, you are probably going to be hearing some horror stories and some pretty grim things concerning rehabilitation.-I would like to say that from my perspective, most of the things that I know are good. Most of the horror stories and things that are bad as far as the Reliabilitation Act and the things that are happening are coming from two major populated States; one on the west coast and one on the east coast, and the rest of the country isn't doing that badly.

One thing that is evident, I did not coordinate my testimony with the previous two people, and I had no idea Jim Balentine was going to be here from Denver.

In my written testimony, I mentioned that I think the one area that really needs to be worked on the most is the Federal regional offices. Now, back when we had HEW, before we had the Department of Education and Health and Human Services, the Federal regional offices were much stronger than they are today. Since the advent of DOE, we have seen a very large deemphasis on the authority and the power of the Federal offices.

In fact, my daughter, who is sitting behind me, wrote my testi-mony with me. At that time I noted that the travel budget is so low that if they made two trips to the outskirts of Denver, they are broke, and I decided not to put that in my testimony, but it is-Mr. WILLIAMS. I am glad you didn't mention that.



Mr. GOULD. It is almost true, Mr. Chairman. This is a very definite problem. You cannot run inservice workshops, training, these types of things from a central office in Washington, DC. I very much would like to see you people working at making sure that the Federal regional offices are strengthered.

The next area, I am, of course, very concerned with the issue of employment. I talked about it in my written testimony. When you go to Washington, DC, you can get any kind of figures that you would like, but I understand that at the very minimum, approximately \$55 billion a year is being spent in the area of rehabilitation, with only approximately \$3 billion actually goes into rehabilitation\_itself. The rest, the other \$52 billion, is spent in the area of maintenance.

With the advent of Public Law 94-142, and now we are seeing, again, using a figure of a very minimum 16,000 people per year that should be coming on to the job market and being placed in jobs, I really think this is the time when we have to strengthen the programs in spending more of the billions of dollars in the area of employment. I think that is just vitally portant, and I hope that this committee will do a great deal to bringing the programs all together.

Mr. Chairman, in conclusion, I would like to say it is going to take a great deal of creativity on the part of this committee in order to intermingle and intertwine and bring all of these things together so we can come up with programs that will work toward getting these people employed, and we are talking about things like targeted jobs tax credit, as Congressman Bartlett talked about before, projects with industry, all of these I think will test your creativity.

The last area that I would like to mention, and I am sure that Dorothy is going to be talking about this and I am sure you will have some questions, I feel that it would be just absolutely disasterous to change the match as far as the Federal-State partnership is concerned. I really think what we need to do is to maintain the 80/ 20 the way that it is, and when you do have questions to ask, I will pass on an idea as to how that can be done, and I also have—would like to be asked about overlapping conditions, Mr. Chairman.

[Prepared statement of R. Budd Gould follows:]

#### PREPARED STATEMENT OF R. BUDD GOULD, REPRESENTATIVE, MONTANA HOUSE OF REPRESENTATIVES

Mr. Chair an and Members of the Committee: For the record, I am R. Budd Gould, a five term member of the Montana House of Representatives; representing District 61, Missoula County. I have been a member of the Governors Committee on the Handicapped since its reorganization approximately five years ago, and a member of the National Council of the Handicapped which I was appointed to in 1983. In the interest of time, I will not go into the many other things that I have been involved in such as the White House Conference on the Handicapped. I think that it would be a good idea to begin by trying to draw a parallel between ababilitation and something that our parallel between

I think that it would be a good idea to begin by trying to draw a parallel between rehabilitation and something that everyone understands. I will make that example with libraries. Libraries in virtually every town in America are suffering at the present time because of a shortage of funding. If you or the average taxpayer takes the same street everyday to work and consistently hits the same pothole, you will after a few days call your local road department and complain about the pothole. Libraries on the other hand are used by a large number of students but used by relatively a small number of adult taxpayers; and when library hours are reduced or when collections are not updated as quickly as they should be, few of these adult



tax payers complain to their local government about tr e service. What this means is when it comes time for that local governments approphations, the road department does very well and the libraries do very poorly. When it comes to rehabilitation it is much the same thing. There are a few constituants groups which are usually not united together and you do not receive the great clamor that you would for something that every tax payer uses almost everyday. When you are having these hearings, in Washington, D.C., you will hear many

When you are having these hearings, in Washington, D.C., you will hear many horror stories about how poorly the rehabilitation programs are operating and how great numbers of people are not being served or are being unserved. I think, however, that if you look at the whole spectrum of rehabilitation throughout the United States you will find that there is certainly room for improvement, but by and large, that most of the programs are operating quite well. I believe that one area that really needs to be changed is the federal regional of-

I believe that one area that really needs to be changed is the federal regional offices. Since the advent of the Department of Education and the change from Health. Education and Welfare several years ago, there has been a large deemphasis on federal regional offices; and I think that these regional offices can go a long way toward making a standardized program of rehabilitation throughout the country that will head us in the right direction to where we will have more or less the same type of rehabilitation program throughout the states and territories. The effort that has been made to have everything come from one centralized office in Washington, D.C. is simply an impossible task. If there were strong regional offices with realistic travel budgets, the offices could then go back to doing the job that they were intended to do. Since 1983 there has been a considerable amount of talk about combining some of these regional offices which I think would be a very drastic mistake. In Service Training Workshops for the various states in a region are the type of things that will go a long way toward making a stronger rehabilitation program in each and every state.

I believe that it is imperative that the one-ten grant program be maintained at the level that it is with a 20% state match. There have been many rumors about changing the match to 60-40 or 50-50. I think that if this is done, we would have to look at the parallel that I drew with libraries and roads. I believe that it would be a total disaster to change the match or to go to a block grant program. Virtually every state is in a difficult financial situation and I believe that if the match were changed it would be disasrous for rehabilitation in the United States. I believe that if we were to have a block grant there would be money syphoned from the grant to go to administration of all state government and the rehabilitation programs would suffer greatly.

My major field of endeavor and interest is the finished product. What are we getting and what have we done for the billions of dollars we have spent. The lowest estimate I have heard is 55 billion dollars a year being spent on disabled Americans. Of this \$55 billion minimum, we are spending approximately three billion dollars on rehabilitation. We definitely could improve on the money we spend if we spent more of it in the area of rehabilitation rather than in just maintenance of the d sabled or nandicapped people. I feel that we must make the disabled person into the disabled worker and that many things can be done. Not the least of these is a demonstration program where data can be compiled pertaining to the use of attendant services for those people who need them in order to become skilled workers. In many instances this would tend to take people such as brain stem injured people and make them into attendants for handicapped individuals.

<u>I will conclude by saying that we need to put a much greater emphasis on employment.</u> The reason I say this so strongly and believe in this so deeply is because we not only have the disabled worker who may have been injured in some accident, but due to Public Law 94-142 we now have at the very minimum 16,000 people per year that will be coming into the job market.

It is very important to note if you look at statistics, that if these people are not put into some type of employment program within a relatively short time after graduation you will lose them permanently. When you have lost this person from becoming a self-sufficient individual, you have lost a tremendous amount of tax dollars that have gone into educating this person and trying to make them a productive independent individual.

The creativity of this committee and its excellent staff will be severely tested in its efforts to come up with a good rehabilitation program for our country that is intermingled with other programs, such as Targeted Jobs Tax C.edit Program. Job Training Partnership Act and Projects with Industry—so that the total program of rehabilitation can come to fruition, and we will have spent our 'ax dollars wisely. Thank you



Mr. WILLIAMS. Thank you, Budd. Dorothy.

Ms. BRADLEY. Chairman Williams and Congressman Bartlett, I want to thank you first of all for bringing this topic to Montana in your proceedings on reauthorization. I think the main reason I appear is that, Congressman Bartlett, I was serving on the appropriation subcommittee that dealt with human services. That is three senators and three representatives, and while those budgets changed all during the process, we were the ones that got the original ball rolling. This happens to be an issue that is very important to me, and I am really pleased to be able to present some points.

What I thought I would discuss is a little bit about what the legislature did specifically in appropriating money for these programs, programs that are closely related, and finally raise several points where I think there might be some room for improvement. I think I am talking both from the Federal angle and the State angle.

In discussing the budgets, I thought the clearest way for me to do this would be in the context of priorities for people. Mr. Donaldson already raised that program that had taken place, or that approach that had taken place. I was so impressed by this as a legislator, that I thought it would help discuss the budget. I don't like to discuss budgets or how the legislature handles appropriations just in a vacuum, because then I think it can either look good or bad, but there is nothing to compare it to.

This program was important to our assessment of the needs. What the State did was to bring many consumers and providers together who worked over a period of time on a consensus approach to try to decide what their priorities were, with the realization that the legislature just simply cannot fund everything. We all came with our special interests about daycare, senior citizens, subsidized adoption or whatever it was, wanting to be an advocate. Yet through this consensus approach, we finally established five tiers, and we concentrated on the top one, and that is just about it, but in each of those tiers they had approximately 10 priorities.

What was important to me in discussing the budget in that context is that in that very top tier, three of these priorities dealt with vocational rehabilitation. I think really says something about how the people out there in the field are preceiving these issues, and the importance relative to everything else that they are giving it. Those three areas being rehabilitation and visual services, extended employment, and special disabilities. So let me just outline each of those very briefly.

On rehabilitation and visual services, that is where we get the 80 percent Federal match-7,000 to 8,000 people are served in some capacity, according to Priorities for People. I will just refer to that as PFP. They requested a general fund appropriation of approximately \$300,000, and that would have served 800 more people than the 7,000 or 8,000 that we presently serve.

The appropriation that the legislature gave was about of 230,000 for the biennium. That is less; but not too much less. The problem that I see here, and I really think, Congressman Williams, you raised this, but I think this is a State problem, but about two-thirds of that money is workers comp money.



My sentiments as far as what we did is, first of all, I do think that the legislature made a fairly good appropriation. I cannot tell you the pressure we were under to cut budgets; and the competing programs were very hard to prioritize. My second sentiment is that I think this payment or inclusion of workers comp money, some of that is appropriate. But I think that large sum; two-thirds of the State money from workers comp, I think that may come back to haunt us down the line: Because only approximately 10 percent of the recipients are into that category, and so, therefore, the problem is twofold.

It gives sort of a preferential treatment to a particular group, but second of all, we have to get through all of the State funds before we can get to the Federal funds. So we are sort of juggling around there where we are trying to spend money that is slightly limited in order to get to the Federal funds. But as I say, I think that is a State problem that we will have to assess over this 2-year period. I am a little uncomfortable with it, but we will see what the information produces.

The second program that was also in its first tier of priorities is extended employment. Individuals involved in this program are producing goods, such as highway stakes, outdoor equipment, and this kind of thing on a contract basis. But these individuals involved in this program do not come under the Federal rule of being capable of competitive employment.

Approximately 60-people are presently served in extended employment, and to the best of my knowledge the bulk of these, the largest bulk of these were suffering from afflictions of mental illness. The PFP request in the first tier was for an additional \$200,000 to serve 20 more people, and the second tier was for an additional \$300,000 for 30 more people. What the legislature appropriated in that context was \$100,000 extra for 10 people.

Let me make a number of points here, because this is, to me, getting to the heart of my recommendations. Now, \$100,000 is a lot of money for the legislature to appropriate in Montana. But when you look in detail at what this means per month of a subsidy for these individuals, it is only about \$350 to \$400 per month, and that is simply not an extravagant fund. I want to emphasize that.

The second point for this program there was no Federal match at all. And that is surprising since this is such a close relative to vocational rehabilitation. The State was simply out on its own in this particular fund, and again we are talking about \$100,000 of general fund money which is more general fund money than we actually put into rehabilitation.

Third, there is a need for this program, and that is why the State had to do it. There are individuals out there who do not fit into developmental disabilities programs, and the reason is because there are Federal and State rules requiring that that disability be contracted before the individual reaches 18. They don't fit into the regular voc-rehab program because they are not capable of competitive employment. They are only capable of some reenforced employment.

This kind of narrow categorization, to me, has its real flaws. You can, for example, have an individual who is 17 years old who is disabled in an automobile accident. Because he is 17 and not an adult

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yet, he would fit into DD. But if he is 19 and he is severely disabled, he would not come under DD or voc rehab. That is why we had to consider some alternatives such as this, because otherwise these people will totally fall through the cracks.

Now, if that person is recently disabled, chances are that he is on a waiting list and he is sitting out there with no help at all either from the State of Federal Government.

The fourth point, and Congressman Williams, I think you were asking about this, and that is Montana being ungenerous in its support for these programs. Yes, we are only staying with the 20percent match, but one of the reasons is because we have had to extend out into other fields to help people that don't get help from the Federal match. We are out totally on our own without a dime of Federal money. I don't feel ungenerous in that respect because we are striking out on our own in this area to try to take up the gaps that have been previously created.

My final point is that we cannot lose sight of the fact that while some of these people are severely disabled, that they are capable more and more of productive employment; of creating sellable goods and working in employment positions. That is a really exciting area about this whole program. We are doing things in this area now that we never even dreamed were possible 10 years ago.

The third area that was also in this very top tier is the special disabled, and the individuals who come in this area are spinal and head injured, multiple sclerosis, blood problems, and those kinds of individuals. The legislative history or the history in Montana for services that have been provided are, unfortunately, pretty much limited to what families could provide until they literally burned out, and then institutional care, such as nursing homes.

I think that in some cases this is absolutely not necessary to relegate these individuals to that kind of a life. There could be certain kinds of capacities that they could reach if the help and training was there.

PFP proposed 500,000 for 100 people. That was kind of a shot in the dark, because we don't know how many people all out there needing our help. That is another weakness of this whole thing. What the legislature appropriated was only \$40,000. I might say that was only at the very end of the session. The House side did not put that money-in. It came in at the very end of the session when the Senate was meeting, and we felt lucky about that, because I think it was becoming evident that there was a one-shot Federal sum of \$96,000. We did put in a fairly minimal amount compared to what people thought was legitimately needed.

My points on this program are twofold. First of all, Montana did go out on a limb to support this program in spite of the fact there was no definite Federal guarantee for future matching funds; and, second, that, I think, we can clearly say there is an increasing need for this kind of a program. If you just assess automobile accidents in the State alone, we know that fewer people are dieing in automobile accidents; but more are living. I think this means that medical technology has in some cases, kept them alive. There is an increasing need, and we are probably not meeting it.

So my suggestions are these: First of all, I think Montana and other States need more flexibility from the Federal approach. If



you take the categorization that we are structured with right now, either you have to be in VR, you have to be in DD, and if you carry that to an extreme, we will have a category for MS, category for head injured and spinal injured, and I think that that approach is not efficient and will really get out of hand, and worst of all, people will be left out.

I think it would be much preferable of an overall umbrella type of approach where you are giving more trust to the State to try to deal out the money as they see fit. I am concerned that we will keep leaving people out unless we have an umbrella-type of approach that covers services for the disabled, not for this kind of disabled, that kind of disabled. Specifically, that means we would be getting away from this strict categorical approach and we would be getting into broader categories somehow of people that would be served.

I also think that this would create a little less pressure on vocational rehabilitation for successful closures of their cases. Now, this has always been one of the strengths of this program. You can always throw out figures and say look how many successes there have been. But if we want to reach more people out there that clearly need the help, then we have to be able in our State to take more risks and to perhaps face more failures, and failures will be there, but in the procedure we will reach people that have never been reached before. I cannot stress how important I think that that is.

I also think that this will be a positive financial outcome in that there will be less duplication. A lot of times there is duplication in our State now in, say, evaluations of shelter care between DD and VR. I think if there was this broader approach, we might be able to avoid some of that. I think a further beneficial outcome would be that you allow rural States more flexibility to handle their particular programs and urban States to handle theirs, whatever they may be.

A second suggestion, I really believe we need more help in higher education. Montana State University is in my district, so I happen to be particularly interested in the program there. But I think education is so often the road to productive employment for disabled people. Montana State University has gone from 75 disabled people, students, to 350 in just 7 years. It is really a burgeoning population. And I think part of the reason is because Bob Frasier and others here have done such an incredibly good job to meet the demands.

My initial assessment is that the Federal approach of competitive grants is not very helpful to our university. We don't have the staff, we are so limited in staff and so limited in finances, that we don't have the individuals to write the grants, monitor them and do all the necessary things. I think a preferable approach is the broader, more flexible sum of money going to the States and the States figure out what their priorities are:

States figure out what their priorities are. I guess my final point is that we need a better system in Montana of identifying people. We are able to identify developmentally disabled fairly well through the educational system. But it is very difficult in this rural State to identify people who are in the vocrehab area. I feel badly because I don't think we are doing it. Of



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course, there is a strong incentive not to do it because we have to spend more money for outreach and we have to pay more once they are reached, but I think that that is a need, and so I thought I would address that:

Thank you.

# [Prepared statement of Dorothy Bradley follows:]

# PREPARED STATEMENT OF DOROTHY BRADLEY, REPRESENTATIVE, MONTANA HOUSE OF REPRESENTATIVES

I wish to thank you for bringing the topic of vocational rehabilitation to Montana during your re-authorization proceedings.

My intention this morning is to discuss in some detail the actions of the 1985 Montana legislature regarding funding of vocational rehabilitation, and then raise several points where there might be room for improvement in the state and federal approaches.

Perhaps the best way to discuss legislative action is in the context of what was recommended to legislators by the Priorities for People project. PFP was a unique and helpful procedure in which the state brought together numerous grass roots and height processing a consumers of human services. Through a consensus process these in-dividuals set five tiers of priorities with a select number of priorities in each tier. It is notable that three of the ten priorities in the highest tier dealt with vocational rehapilitation. It is significant because the consumers and providers all advocated their own particular interests, but all agreed about the importance of vocational rehabilitation. I will summarize these three priorities.

# REHABILITATION AND VISUAL SERVICES

These revenues, which bring a 20/80 federal match, serve approximately 7.000 ininese revenues, which oring a 20'00 ferefait match, serve approximately robot in dividuals. PFP recommended an expansion to serve an additional 800; for a biennial general fund appropriation of \$300,000. The legislature appropriated about \$230,000; but over two-thirds of this is from workers' compensation funds. My sentiments on this budget are two-fold. First, I think the legislature did quite well in its level of funding. Second, the problem of workers' compensation money may gone head to have use for injurate workers only comprise about 10 percent of

may come back to haunt us, for injured workers only comprise about 10 percent of the recipients. Workers' compensation funds are not as flexible as general funds, but all the state money must be used up before we can reach the federal dollars.

### EXTENDED EMPLOYMENT PROGRAM

Individuals in this program are involved in productive employment, but cannot be categorized within the federal mandate of being "capable of competitive employment. The number served is approximately 60, the largest number of which suffer from mental illness. PFP recommended in their first tier that an additional \$200,000 be appropriated to serve 20 more people, and recommended in their second tier that an additional \$300,000 be appropriated to serve another 30. While this is a lot of money for <u>Montana legislature</u>, it amounts to approximately \$400 a month per person. That is . st an extravagant sum. The legislature appropriated an addi-tional \$100,000.

Unfortunately there are no federal matching funds for this program in spite of its close relationship to vocational rehabilitation. Individuals in this program mether qualify for VR, nor do they qualify as developmentally disabled because of state and federal requirements that the disability must be contracted prior to reaching the age of 18. This is a great concern to me. Our narrow categorizations are allowing people to fall between the cracks because they do not quite fit the definitions. I am eager to bring this to your attention, because some might argue that Montana is not funding vocational rehabilitation with as generous a match as other states. However. I would argue that we have had to broaden our approach in areas where there is not a dime of federal match. We do need federal help. We are finding that many individuals are becoming productive members of the work force in ways we would not have thought was possible 10 years ago.

## SPECIAL DISABLED

The special disabled includes indivduels with MS, head and spinal injuries, and similar afflictions. The history of services for these people is unfortunately limited to whatever their families can muster, and institutional and nursing home car:



Such a bleak future is not always necessary. PFP requested about \$500,000 for the biennium to serve 100. The legislature appropriated \$40,000. There is a one-shot federal match of the first years, and an unknown future thereafter.

Again, I want to stress Montana's support, even in the face of no guaranteed federal match. And again, I want to express the experimental nature of this program. We don't have great insight regarding the need. We know that car accident deaths may be dropping, but more victims are surviving severe accidents because of medical technology. It is safe to guess there is an increasing need

## SUGGESTIONS

A more flexible approach from the federal level is advisable. If we carry the present "VR" and "DD" categorical approach any further, we will have categories for MS, head injured, and on and on. We need an umbrella system of "Services for the Disabled." More flexibility would mean less pressure on VR for high percentages of successful closures. If we reach into new areas where there is an obvious need, we need to be able to take more risks, and accommodate more failures. But the outcome will be fewer people falling beween the cracks, less duplication, and allowing rural states to better respond to their own particular needs.

We need more help in our institutions of higher education. MSU, which lies in my district, has done such an excellent job under the guidance of Bob Frazier, that the disabled student population has increased to 350, while it was only about 75, 7 years ago.

The federal competitive grant approach is not particularly helpful because there is not a large enough staff to seek and monitor grants. A preferable approach is more flexibility in the federal funds, and letting the state decide the priorities.

We need a better system of identification of those in need of services. Our best information is the census, and it indicates the need for outreach. While children with developmental disabilities are more readily located, beneficiaries of voc rehab are more difficult to find. Perhaps traveling workshops are a possibility.

It goes without saying that a five year re-authorization would be helpful. And while the possibility of Congress returning to a July instead of October fiscal year is remote. I would add that such a change would help providers in troublesome bookkeeping procedures.

Mr. BARTLETT. Thank you, Mr. Chairman.

I detect a difference, and I want to make sure I am correct, I detect a difference of approach and strategy between the two representatives. Ms. Bradley, you testified, we usually call what you refer to as an umbrella grant. We usually call that a block grant. I want to make sure that that is really what you are saying. You would take more of what you called umbrella or more of a block grant approach and eliminate the barriers between the various categorical grants, send the money to the States and let the States serve the needs. While Mr. Gould, you testified pretty strongly against a block grant. Am I accurate in detecting that you have a difference?

Ms. BRADLEY. Well, I think there probably is some difference. I am more newly working in this field than Representative Gould. I hesitate to use the word "block grant." I didn't think umbrella would catch your attention so quickly.

Mr. BARTLETT. It is a nice word. I might use it myself.

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Ms. BRADLEY: That is my approach, and I am throwing it out as a matter of discussion. To me that fits the problem that I see. We are having to fund these small programs to reach other categories that have been left out, and that is what is disturbing me. If you could count the State money that Montana is putting up for these other programs, you would find what we are putting up to get a Federal match is substantially more than what we are given credit for.



I guess I would also say I think some people worry once you have a large block grant type of program coming in, people will slip through the cracks, because they will be left out of the debate.

You have to trust some group to make those decisions, and I feel that while we have a good legislature and a very active citizenry, particularly through this PFP approach, that the greatest needs are going to surface when we are debating all of this and those greatest needs will be responded to.

Mr. JARTLETT. You are suggesting the reverse is true, using the narrow Federal categories with very narrow definitions, then people fall through the cracks.

Ms. BRADLEY. I felt that was the case while I worked on the Appropriations Committee this last year.

Mr. BARTLETT. Representative Gould, at the conclusion you asked me to ask you two additional questions. I am now going to ask them. The first one was and I paraphrase your question that you asked me to ask—what ways can we improve the Federal law, the Rehabilitation Act, to provide for better delivery of services? Are there requirements and mandates and reporting requirements that we can delete? Are there additional kinds of Federal services that we can provide, or both?

Mr. GOULD. Congressman Bartlett, first of all, I will answer just a little bit on this categorical thing. What scares me the worst about block grants are what we see with low-income energy assistance and pretty substantial sums of money coming off the top of those programs for running basic State government, and that does scare me.

Getting back to this other situation you are talking about, one area that I am very concerned about, and that is the area of research. We have the National Institute of Handicapped Research, which basically should be the main thing that we have as far as research is concerned. In doing some investigation and so forth on my own with Dr. Do g Fenderson, who was an excellent person, and head of NILR. Dr. Fenderson has left several months ago, and as of this date, I do not think he has been replaced. There are 32 other divisions, or branches, of Federal Government with research as part of their budget. Dr. Fenderson set up an interagency committee with all of these agencies that were getting money for research. I am airaid that with Dr. Fenderson gone, if we don't get a good person in there, then I think that you people should statutorily set up the interagency committee. With 33 Government agencies, you both have been in Government long enough to know how much talk and cooperation there is between Government agencies. This is something that is going to need to be watched very closely in order to make better and more appropriate use of our funds.

Mr. BARTLETT. Meaning there is a lot of talk and very little cooperation?

Mr. GOULD. That is true. The other area that you were talking about and had some questions about, I think one of the things that is going to have to be done is that the groups of recipients; the handicapped individuals themselves are going to have to get together such as the heart association, the lung association, cancer, et cetera. They are going to have to start making the public aware of the benefits of the rehabilitation dollars that are being spent by



the Government. Taxpayer dollars that are being spent, in order to get more help for you people who are on the firing line, for us over in the legislature who are on the firing line with the State dollars, and I think it is something that can be done.

It is going to be an educational process, but I think it is the only thing that is going to free up the dollars that are going to be needed for rehabilitation services.

Mr. BARTLETT. One final question. Do the two of you see the population changing, the population of disabled persons, and specifically I am asking what we can do to improve our transitional services, transitional out of the education system. We have a generation now—I believe one of you testified 16,000 students a year graduating with a good education and graduating into the world of unemployment. That is extraordinarily sad for those persons, but equally important, it is extraordinarily sad for the taxpayers in this Nation that are deprived of their productivity, if you will:

What can we do with the Federal law to improve that?

Mr. GOULD. Congressman Bartlett, as I said at the end of my testimony, it is going to take a very concentrated effort. You mentioned Southland Corp. A representative is here today of MARS of Missoula, which employs 110 people, and they do targeted jobs tax credit work. One of their clients is Southland Corp.

Anyway, it is going to take a basic intermingling or intertwining of all of these programs in order to try and get this person at the very outset. I can't stress that enough. In the papers that you are going to be getting from the NCH, it is basically stressed that one of the things we have to do away with, and it would take all day to go into these, but this is going to be very helpful, are the disincentives that are built into people becoming employed. We have to get these people into the world of work right away.

We can't wait 3 and 4 and 5 and 6 months for these people to get into, we will say, SSI syndrome. Living in the hands of the Government in some type of more than likely Federal program, like SSI, and getting into that syndrome. We have to get these people immediately, right from the time they are getting out of school, and place those people in some type of hopefully competitive employment.

Ms. BRADLEY. May I answer that?

Mr. WILLIAMS. Please.

Ms. BRADLEY. I agree with what Representative Gculd has said and also the previous panel. I want to once again emphasize the point that I am trying to make. That is broader help from the Federal level, not just so narrow in voc rehab that you absolutely have to be perceived as able to get back into competitive employment in order to get help. If there was more help for the disabled at the university level, I think you would find more people able to go from there into the employment picture. There isn't enough help there right now, and we need Federal help. I think we need more State help, too.

Again, we are only funding the extended employment program with State money. Yet, if you could take more risks and agree that you were going to have more failures, it might be feasible in this day and age to have a 20-percent success rate. Whereas they are definitely back to competitive employment when they weren't pre-



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viously thought so. I think more flexibility in your program will help us get more people into employment.

Mr. WILLIAMS. Budd, let me make note of one thing that you said, and it is also in your testimony, quoting now, "The lowest estimate I have heard is \$55 billion a year being spent on disabled Americans. Of this \$55 billion, we are spending approximately \$3 billion on rehabilitation."

I know this is not your intention, but just for clarification, I wouldn't want folks to think the other \$52 billion was being spent on administration. In fact, the vast majority of that money goes directly to individuals in a paycheck, in a check, and, Budd, your point is different than that, isn't it?

Mr. Gould. Yes. SSI, et cetera.

Mr. BARTLETT. His point still is, and it makes the point even stronger, and that is the enormous problems that the taxpayers could save from those paychecks or transfer payments of the other \$52 billion of cash payments, plus another \$120 billion of medical payments, by using that \$3 billion, or increasing the \$3 billion, to have more paychecks from full employment. There is a vast savings there.

Mr. GOULD. Correct. Also, if I might adjust one thing to that. That is the lowest figure that I have heard, and I believe that the figure that comes out of like Rutgers University is it exceeds \$100 billion. I took the very lowest figure that we have heard as members of the National Council on the Handicapped working in this area.

Mr. WILLIAMS. The Federal debate in the past, at least during the past decade, has centered around the question how best to serve disabled people. In the past few years the debate has taken a different focus, which was at the heart of my first question to the first panel. Because of difficult economic times in a staggeringly increasing deficit, the debate now becomes, who pays?

Unfortunately, and probably tragically in the long pull, the acbate has moved away from how do we best serve folks to what is the cost and who is going to pay it? Now, that is a path down which I prefer not to go, but we have the reality of the deficits before us.

So let me pursue that some more and note in doing so, Dorothy, you answered several of the questions which I was going to ask in your testimony, and I appreciate that. Let me give you some figures that I have, and they are estimates. I received them from folks here in Montana. There are approximately 38,000 people in the State in need of help of rehabilitation services, and that excludes the visually impaired. So, 38,000. In Montana, we serve 6,500, only 6,500. There is a further estimate that there are 8,000 visually impaired people, and we serve only 500 of them. So of perhaps 46,000 people in need of assistance, we are serving 7,000 of them.

Ten years ago, there were fewer of them, and we served nore. We served not 7,000, but 10,000 of them in 1975. Now what has happened? Well, inflation set in the cost of serving. That is one thing that happened. That is relatively important, but not absolutely critical to this diminution in the number of folks that are needing help that are being served.





The second thing that happened, of course, there were freezes and cutbacks at the Federal level. This was with the stated hope and some expectations in some quarters in Washington, including people in very high places, that the States would pick up what the Federal Government wasn't going to do.

That brings us to the third part of the dilemma, the States cut their budgets. The State of Montana now contributes less of its share than it has in the past.

So we can debate about whose job it is or how the money comes out, but the real debate should center on, are the people being served? The fact is, that fewer are being served today than 10 years ago. The question is, who is responsible for serving them, who is going to pay the way?

That is a philosophical question, but very important if these people are to get service. So let me ask Dorothy first just in that general kind of a question, can you give me a general kind of an answer?

Ms. BRADLEY. What is the question?

Mr. WILLIAMS. The question is, should they be served; and if so, who is going to pay for it?

Ms. BRADLEY. State or Federal?

Mr. WILLIAMS. Sure. Or what combination, or both? Should the Federal Covernment really be sending 80 percent of the share in here when we have a deficit and you don't?

Ms. BRADLEY. We don't because we are not allowed to by our constitution.

Mr. WILLIAMS. We hear a lot about "our constitution." We do it the way we Montanans do it. Here is how we do it in the Federal Government. We do it the way you do it. We simply would say we are not going to count as State spending any capital expenditures: You know, folks, when your State government spends money, they don't count that money that they spend for capital expenditures. Any cement they pour, they feel that is not State spending.

So they balance your budget not in actuality, but with an accounting trick. Montanans have always done that. And most States do it. The Federal Government doesn't. Every dime we spend we count. We can have a balanced budget amendment to the Constitution, Dorothy, and we can mect it if we use the same accounting trick that Montanans use.

Ms. BRADLEY. I remember the Grace report, Congressman Williams. I hesitate to raise that name, but there were some very interesting ways that the Federal Government could save money.

Mr. WILLIAMS. Should we save it on people in need?

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Ms. BRADLEY. I am in agreement with your position on that one. I wanted to just rephrase the need. if you were expecting it. One set of statistics that I saw, according to our census report, approximately one in seven Montanans has some kind of disabling condition. Not all of them need help, but a great many of them do. It concerns me a lot, because as I said in my testimony, I don't think we have properly reached these people. We don't know exactly what the need is, and when we are appropriating money in the legislature, we are just kind of grabbing onto whatever we can in the way of statistics that show some kind of need, and we are not completely knowing. It is a really difficult situation.



As far as serving fewer people now, there is some thought that when we switched the general fund to the workers comp fund; there were people who were actually dropped off then. I am trying to get to the bottom of that.

I don't know if that is the case. That is what we were told in the legislature when we were urged to put in general funds instead of workers comp funds. But at this particular point, people are saying, "Well, it looks like those funds are reaching the people that need it." So I am not certain what is happening.

I just have to reiterate, I think my point is, one, we have to do a better job in identification. There is some feeling that there may be a lot of people suffering from disabilities up on the highline from oil rig accidents. They don't know what the State has to offer, and we don't know that they even exist. Maybe a series of traveling workshops could help identify those people and let them know what services are available and that they are there.

Finally---

Mr. WILLIAMS. That is going to cost more money, Dorothy.

Ms. BRADLEY. That is right. That is why it is not a popular thing. Mr. WILLIAMS. Who is to pay for that, the State legislature or the

U.S. Congress?

Ms. BRADLEY. We have to do it in combination. I don't know what the proper match is. As I said earlier, we are under incredible pressure, just as you are, to cut spending. I really tried to think when I came today of places where I felt there was improper expenditure of funds in this program. I really don't think there were any. You didn't hear an incredible outcry at the end of the session about lack of funding because we cut that program down so fast and so early, that when the Senate put in a few extra dollars at the end of the session, people were so glad to get anything, even though the legislative appropriation was far below what PFP recommended, everyone was glad to get something.

That is how I felt at that stage. I mean, we were so desperate in this session, as you are well aware, we took able-bodied young people off of welfare. The reason, at least in my mind, being that we are trying to direct those dollars to those that don't have able bodies and who are thus more dependent on what the State decides to do with the dollars.

So I don't have a good answer, but I would say if you are considering changing that match, and I know that a 20/80 match is very generous on the Federal part. I think it is really fine, and we have been lucky to have that kind of a match. But if you change that match, at least give Montana credit in some of these other areas that are just a little bit out of the ballpark of the traditional vocational rehabilitation funding.

Mr. WILLIAMS. I am not for that. Well, in the interest of time, let's turn to Budd.

Mr. GOULD. Mr. Chairman, I will be very brief, because I can only echo really a lot of what Dorothy has just said, but going back to what I said before, I think it is going to have to be an educational process of the general public so that we can get the support to appropriate more money both on a Federal level and on a State level for the programs that we are talking about.



Now, I also think we can look at many things that will work hand in glove together. I would like to see some sort of a pilot project, and I think with attendant services, you can say—when Maggie gave her testimony, I believe, she talked about the fairly high level functioning quadriplegic. Well, that quadriplegic probably is going to need an attendant. Well, that attendant could very well be a brain-stem-injured person who has a very short attention span, but with the help of somebody who is the quad that needs the attendant, then you are employing two people.

I think there are many, many instances where innovative types of things are beginning to surface. We are approaching what is, I think, one of the greatest buzz words that I have heard in Washington. Of course, you folks in the Washington area great for those buzz words. Independent living was the buzz word 10 years ago, and it has lasted for quite a few years. I think "transition" now is the current one that you hear of the most.

And, Mr. Chairman, that is a word that I really believe in, because I think that we are a country in a period of transition, we are in a period of transition. We have to make that transition you were just talking about from the runaway deficits on the Federal level and our innovative creative bookwork on the State level. We are going to have to put the two together, and we are going to have to come up with things that work. We are going to have to come up with making sure that the public knows that those are the things that work. We are not going with the same as we are doing now with, we will say, 6 percent going actually for rehabilitation and 94 percent, or whatever the figure actually is, that is going for just maintenance, keeping people alive in some sort of comfort.

Mr. WILLIAMS. I am well over my own stated time limit but with Mr. Bartlett's indulgence, I want to say one additional thing here, take a little extra time with this legislative panel. Steve, if you have any other questions, we can certainly take those.

Because of the current economic and budget difficulties, the situation that has forced upon the Federal Government the necessity call it whatever we can—for a more moderate, more prudent, or more conservative spending pattern. Now, in some services, such as those about which we are speaking today, the Federal Government, by significant majority vote, does not want to abandon the payment of those services or delivery of those services if the States will not assume them. This is because we are convinced at the Federal level that appropriate vocational rehabilitation, appropriate help for the disabled, is an investment which returns money to the Treasury and reduces the deficit in the out years.

Looking at it only from the standpoint of an accountant or an economist, it is good business. Setting aside the generosity involved in it and all the rest, it is good business, so the Federal Government doesn't want to abandon it:

We look to the States to find out whether they are increasing or decreasing their generosity during these past 5 years as the Federal Government begins to pull itself away. Some States are holding even, some States are decreasing, some are increasing. I think it is clear now that the ability of the States to assume an ever-increasing appropriation for these services is very limited. The States'

ability is very limited. The States are not picking up a significantly increased amount.

The greatest example of good cost benefits is early childhood intervention for children that are disabled. Yet, Montana, by two votes in the last legislature, turned down special education for preschool children. Now, that sends a signal to the Congress, and the signal is the deficit be damned, you have got to spend this money because Montana and other States won't do it.

Do you see the dilemma that faces us? It isn't as if what you do out here you do in a vacuum and we don't know about it back in Washington. We have our stethoscope placed on the treasury of Montana. We listen to the heartbeat. When we find that you are less generous than we assumed you would be, it creates this enormous problem for those of us who do not want to abandon the national commitment to help those who need the help.

So I say to you two legislators who understand this need and have the commitment, I commend you and tell you the Congress does watch Montana and States like Montana and Texas to determine whether or not we are going to be able to pull away from our historic financial commitment to these efforts.

Mr. BARTLETT. Let me try the \$64,000 question that I would like your opinion on. First I very much appreciate the testimony that the two legislators, and particularly I appreciate the service Budd Gould gives us at the National Council of the Handicapped. My question is, In your opinion, knowing what you know of the State of Montana's budget and the legislative process and of any State's, including Montana's, tendency to want to obtain Federal funds if they are not too costly, given of what you know of vocational rehab, if Congress, beginning 18 months from now, after the end of your next legislative session, were to say phase in a higher match, say phase it in at 5 percent a year, just for argument sake, would Montana continue to meet the minimum match?

Mr. GOULD. I would say it would be very difficult. I—we might do it. Montana—I am very proud of the things we have done. The executive director of the National Council on the Handicapped will be coming to Montana in a little over a month to look at Boulder, our institution for the mentally retarded, which Dorothy and I both saw 10 years ago when it was an absolute disgrace, Boulder is something that has undergone one of the most magnificent changes that words can describe, and we have been a progressive State.

Congress has just passed a law that deals with what we call the board of visitors of Montana that started in 1975 or 1977. It was one of those 2 years. We are doing a great deal of things that the major progressive States, like New York and California, that are thought of to be really far-out, great liberal, wonderful States, and yet Montana has done these things already. We might be able to do it, Congressman, but, boy, it would just be nail biting.

I mean, if you could have seen some of the ways that I bled all over the table when we were trying to get the money on brain stem injuries, which would have raised license fees. There was blood from one end of the committee table to the other, and it was all mine. I went into Hutchinson's disease and several things that I wasn't even aware of until a meeting down in Austin, TX, that we



held, and all of these things, trying to get things done, and we got \$40,000 over in the Senate, as Dorothy mentioned.

Like I say, we can certainly—Dorothy and I, if we are reelected will be in there fighting and scratching and so forth if the match were greater. But, like I say, certainly I have a hard time thinking of the words to come up with how difficult it would be.

Mr. BARTLETT. Ms. Bradley.

Ms. BRADLEY. Congressman Bartlett, I agree with Representative Gould there are plenty of us who would sure try to come up with more money for a higher State match, and I think there is a constituency out there that would be helping us, too. If you ask me right now where that additional State money was going to come from, I absolutely couldn't tell you, because we have been scraping the barrel and going through heated debates about new taxes and so forth.

I want to emphasize in this past session Montana did come in above the current level in the appropriation. So I think that shows that the legislature has an open mind about these programs. They are well aware of the need, and doing the best that we all can.

I am very sympathetic to your desire to change that match, and if I were in your shoes, I think I would be doing the same thing. But you have to understand legislative perspectives, too, and that is so often we feel we are held out a carrot from the Federal level for a program, and we jump at it because it is a great match and the bulk of it is coming from the Federal money. But we are getting very wary of that now because so many people feel if we take that match now, we will get locked in on that program, and 5 years down the road the Federal money will be all pulled out and we are going to be stuck with the whole thing at the State level. We can't afford it. That is the stethoscope that the legislature has on Washington, DC.

Mr. BARTLETT. I think that is a legitimate concern and a legitimate criticism of the Federal Government in terms of the matches. Sometimes Federal grants cost far more than they deliver. Thank you. Thank you, Mr. Chairman.

Mr. WILLIAMS. Well, my sincere thanks to both of you for your help here today and putting up with our questions. We appreciate your being here. We appreciate your good work.

Mr. GOULD. Thank you for giving us the opportunity.

Mr. WILLIAMS. Our final panel for this morning's portion of the hearing is Boyd Peterson, Susan Bertrand, and Zana Smith. Boyd Peterson is representing Wheelchairs, Crutches, and People, Montana State University; Dr. Bertrand is director of Missoula Community Hospital Rehabilitation Program; and Zana Smith is executive director, Montana Independent Living Project.

## STATEMENTS OF BOYD PETERSON, WHEELCHAIRS, CRUTCHES AND PEOPLE, MONTANA STATE UNIVERSITY; SUSAN BER-TRAND, M.D., DIRECTOR, MISSOULA COMMUNITY HOSPITAL RE-HABILITATION PROGRAM; AND ZANA SMITH, EXECUTIVE DI-RECTOR, MONTANA INDEPENDENT LIVING PROJECT

Mr. PETERSON. Thank you, Mr. Chairman. I guess I would just like to start by saying that I didn't know a lot of these things that



have been brought out already this morning, so when I go through my testimony, it might sound a little weird, but that is just because we don't find out many of these things.

Mr. Chairman and committee members, thank you for the opportunity to be able to testify on the reauthorization of the Rehabilitation Act. I became disabled in 1975 due to a motorcycle accident. From approximately 1 year later to the present, I have been a consumer of these services and an elected representative of the Disabled Students of Montana State University. I would like to share some of my views regarding rehabilitative services.

In all fairness, I would have to say that rehabilitative services have been significant in getting me where I am today. Rehabilitative services have allowed me to attend Montana State University, where I am working on a degree which will allow me to enter the rehabilitation field. By allowing myself and others to attend post-secondary institutions, we will be able to lead as close to normal lives as possible. We will not need to rely on someone else financially and in many cases for personal care.

Independence is a virtue I feel everyone should have the right to enjoy. In some cases, there is a need for personal care attendants. Without the Rehabilitation Act, this would not be possible for a lot of individuals.

Now, to give some views of the other side of the issue. As with any organization, rehabilitative services has its problems. Those problems which have been encountered by my peers or myself include the following: Counseling techniques and counselors in general, personal contact between counselor and consumer, educational opportunities for the consumers, lack of understanding toward the everyday needs of the disabled consumer.

First, I would like to address the counseling techniques used by some of the rehabilitation counselors. In most consumers' opinions, there are no counseling techniques used. We are simply names and Social Security numbers. They seem to be more worried about how they are going to look to their supervisors than they are about getting the consumers rehabilitated.

In Montana, there are such great distances to travel to see your counselor that contacts in person are minimal. As a case in point, I have not seen my counselor for almost 3 years. All of our contact is by phone or correspondence, and then it is only when one of us needs something.

I think I should add, when he finds out what I have said today, I think he is going to give me a call.

Mr. WILLIAMS. You are obviously in need of more counseling.

Mr. PETERSON. The counselor seems to have no idea of what the daily needs are of a disabled person. My point is, that something needs to be done to educate the counselors on their interpersonal approaches to consumers. This is not true of all counselors, but a majority of those I hear about, it is definitely true.

On the subject of education, I would like to give some positive views and possibly some ideas that may be added to existing programs. It should be duly noted that a majority of rehabilitation consumers are able to put back many times more dollars to the system than was used to rehabilitate them. I didn't know, it was almost 11 times before this morning. If for some unforeseen reason

they are unable to put money back, someone else will make up for their inability to do so. This makes the rehabilitation program extremely unique in that it is actually paying for itself many times

College campuses offer excellent opportunities for people with disabilities to meet and interact with able-bodied persons. The disabled have a chance to learn to be independent and make a lot of friends who do not look at them as being disabled.

I feel this is extremely important in a rural State like Montana. It is all too easy to stay in a rural community and allow everyone to take care of you and feel sorry for yourself. Rehabilitative services allows eligible consumers the option of getting out of a situation such as this. It is just too bad that everyone who has potential cannot be reached in rural Montana. More could be reached, I feel, with a little more money allocated to rehabilitation and a few changes to the system.

As some easy ways to increase the amount of return, I would like to offer a couple of simple suggestions. If the persons attending postsecondary institutions had the opportunities for internships, they would be better able to enter the work force confidently. What I am saying is that there needs to be some sort of financial incentives to employers to hire disabled persons for intern programs. This would also help to break down the attitudinal barriers faced by disabled persons from potential employers.

Along with the internship idea, there needs to be money allocated to postsecondary institutions for areas of research. The research would be in areas of interest to students who feel certain aspects could be made better, using the research moneys to have researchers or ultimately students in the field find better ways to run existing programs or create working models of new programs needed at

There needs to be many changes made within the rehabilitation system. I would like to offer a few specific suggestions, which I feel need to be made more aware of the consumers' daily needs. They also need to be made more aware of the many new technological As stated confirmed to be made to be made more aware of the many new technological

As stated earlier, I also feel counselors need to know how to relate on a more interpersonal level. All of these changes could be done very easily by offering mandatory workshops for counselors

I sit on the advisory council for rehabilitative services. It is called an advisory council, but we really do not give any advice for making the system work more efficiently. I thought that was why it was formed. Maybe the fact that persons are allowed to sit on it as long as they want is the problem. There are too many traditional people on it. My suggestion for this is that some of the members should be replaced and new and existing members toid exactly how much power the council has. If it does not have the power to make changes and have its voice heard, then it may as well be disbanned.

At the legislative level, there need to be a lot of eyes opened also. I really feel by making our State and Federal legislators see what the rehabilitation program can be, we would be allocated the money which is so desperately needed.



We, the disabled, need the Rehabilitation Act to be able to make our stand in/against society's norms. By not reauthorizing it, you will take away our chance for becoming independent persons who will pay their own way and not have to live off the system.

Mr. WILLIAMS. Thank you very much.

## [Prepared statement of Boyd Peterson follows:]

## PREPARED STATEMENT OF BOYD PETERSON, WHEELCHAIRS, CRUTCHES AND PEOPLE, MONTANA STATE UNIVERSITY

Mr. Chairman and Committee members, thank you for the opportunity to be able to testify on the reenactment of the Rehabilitation Act.

I became disabled in 1975 due to a motorcycle accident. From approximately one year later to the present, I have been a consumer of these services and an elected representative of the disabled students of Montana State University. I would like to share some of my views regarding Rehabilitative Services.

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Now, to give some views of the other side of the issue. As with any organization, Rehabilitative Services has its problems. Those problems which have been encountered by my peers or myself include the following: Counselor techniques and counselors in general, personal contact between counselor and consumer, educational opportunities for the consumers, traditional attitudes, lack of understanding toward the everyday needs of the disabled consumer.

First, I would like to address the counseling techniques used by some of the Rehabilitation Counselors. In most consumers opinions there are no counseling techniques used. We are simply names and social security numbers. They seem to be more worried about how they are going to look to their supervisors than they are about getting the consumers rehabilitated. In Montans there are such great distances to travel to see your counselor that contacts in person are minimal. As a case in point, I have not seen my counselor for almost three years. All of our contact is by phone or correspondence and then it is only when one of us needs something. The counselor seems to have no idea of what the daily needs are of a disabled person. My point here is that something needs to be done to educate the counselors better on their interpersonal approaches to the consumers. This is not true of all counselors, but a majority of the ones I hear about, it is definitely true.

On the subject of education, I would like to give some positive views and possibly some ideas that may be added to existing programs. It should be duely noted that a majority of rehabilitation consumers are able to put back many times more dollars into the system then was used to rehabilitate them. If for some unforseen reason they are unable to put money back, someone else will make up for their inability to do so. This makes the rehabilitation program extremely unique in that it is actually paying for itself many times over.

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ployers. To go along with the internship idea, there needs to be monies allocated to post secondary institutions for areas of research. The research would be in areas of interest to students who feel certain aspects could be made better. Using the research incnies to have researchers or ultimately students in the field, find better ways to run existing programs, or create working models of new programs needed at the institutions.

There need to be a lot of changes done within the rehabilitation system. I would like to offer a few specific suggestions, which I feel could be easily accomplished. Counselors and administrators alike need to be made more aware of the consumers daily needs. They also need to be made more aware of the n ary new technological advances. As stated earlier I also feel counselors need to know how to relate on a more interpersonal level. All of these changes could be done very easily by offering mandatory workshops for counselors and administrators.

I sit on the Advisory Council for Rehabilitative Services. It is called an advisory council, but we really do not give any advice for making the system work more efficiently. I thought that was why it was formed. Maybe the fact that persons are allowed to sit on it as long as they want is the problem. There are too many traditional people on it. My suggestion for this is that some of the people should be replaced and new and existing members told exactly how much power the council has. If it does not have the power to make changes and have its voice heard, then it may as well be disbanned.

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We (the disabled) need the Rehabilitation Act to be able to make our stand in/ against societies norms. By not reenacting it you will take away our chance for becoming independent persons who will pay their own way and not have to live off the system.

Mr. WILLIAMS. Dr. Bertrand.

Dr. BERTRAND. Well, I am very pleased to be here today and to be asked to provide testimony. I feel I have gathered some information and perspectives from two different vantage points. One, as a psychiatrist or specialist in rehabilitation of the disabled, and the other as the district medical consultant for the Missoula Vocational Rehabilitation Office, where I have been for the last 6 months providing their medical consultant services about once a week.

As many people have stated today, the vocational rehabilitation program is very necessary, and very effective. We train persons with disabilities to employment, and it is very practical and cost effective, and that has been gone into, and I will not go into that.

We are seeing an increasing number of severely disabled persons who are requiring vocational rehabilitation services. This is as a result of increased emergency care, increased intensive care from the medical system so that persons who previously would have perished in their accidents are now surviving with increasingly more severe disabilities.

There are two groups that stand out that I would like to speak about today. One is the severely physically disabled, essentially the quadriplegic person who may even be respirator dependent. These persons were not surviving accidents even 10 years ago. The increasing numbers that we are seeing within the population require vocational rehabilitation services. Technology now exists so that these people can i center a productive employment situation if the appropriate technology is available, including computers, and advance switching techniques.

This is all very expensive. The cost of rehabilitating even one person at this level may exceed a counselor's budget for the entire year. So a counselor is faced with the problem of trying to rehabili-



tate one severely disabled quadripletic, or many people within a budget.

The other group who have similar needs, although who appear very differently, are the brain-injured population. This population is increasing faster than any other single population of disabled persons within the population. They require a continuity of care and an intensity of service that, again, exceeds a counselor's budget for the year to provide service for even one person. This is because the organ which we use to retrain, that is the brain, is that very organ that is injured. So that highly specialized, highly skilled professionals always are required on a practically 1-to-1 basis for up to 6 months to even prepare the person to begin a retraining process. Then as one enters the retraiting process, there is a lack of ability to integrate or to carry over from one environment to the next, so even that needs to be monitored and assisted along the way.

Selective competitive employment is available, or possible at the end of the training process. If one never pursues the training process because of the expense, then these people fall into the toosevere classification because of the level and intensity of service they need to reach their productive potential.

The unfortunate problem for these individuals is that both the quadriplegic or the spinal-injured population and head-injured population tend to be very young at the onset of their injury. For spinal cord injuries, it tends to be between the ages of 15 and 25. For head injuries the predominence is between the ages of 25 and 35. So that you have young people with essentially a normal life expectency who, without these very expensive services, are going to be very expensive to the system for the rest of their life. So the cost may well be cost effective if the appropriate services are provided.

Vocational rehabilitation and the Rehabilitation Act recognized this type of problem with the visually impaired and have set aside special funds to serve the visually impaired because of their specific needs, which are different from that of the vocational rehab population in general. This perhaps may be a way to address this problem with the severely physically disabled as well as the brain-injured population.

Thoug 1 it is not part of my testimony, I would like to offer a suggestion or recommendation in response to your question, who pays? It is probably not a very political thing to say, but the Federal Government has gotten into a position of acting as an insurer, and other insurance carriers in the field look at the actuarial data as to who is at risk, so that those of us who are at risk pay more. There are some easily identifiable risk factors for persons sustaining disabilities.

This also will make me terribly unpopular, but there is not any reason why we should not approach persons who choose risk factors, choose to engage in risks, and look at the possibility of having them pay for the results that documentation shows are very likely to occur.

Some of these easily identifiable risk factors include alcohol. About 80 percent of automobile accidents where disabilities occur occur as a result of alcohol-related automobile accident. Motor vehicles themselves tend to make up a large proportion of the severely disabled through accidents.



Motorcycles stand out even further in the area of these factors. Montana doesn't have a helmet law. Those are areas it seems reasonable to look for resources to pay for the cost of the rehabilitation of the accidents that occur as a result of the risk factors.

We approached the legislature here in Montana looking at just motor vehicle registration as a possible source of revenue for fund-ing some of the rehabilitation programs. That didn't happen this time, but I don't think that is an unreasonable approach in looking at the budget and also looking at the Government as acting as an insurer. Thank you.

Mr. WILLIAMS. Thank you very much.

## [Prepared statement of Susan Bertrand follows:]

## PREPARED STATEMENT OF SUSAN T. BERTRAND, M.D., P.C., MISSOULA COMMUNITY HOSPITAL REHABILITATION PROGRAM, MISSOULA, MT

In response to your request for testimony about the special demands of Vocational Rehabilitation in a rural setting, I would like to address three specific areas: (1) Current trends in rehabilitation, populations served, services, treatment and equipment; (2) rural perspectives; (3) comprehensive independent living services.

I currently have an active rehabilitation medicine practice where I treat both re-cently disabled and the long-term disabled. I have also served as the District Medical Consultant for the Vocational Rehabilitation Office in Missoula, Montana, for the past six years. From these two vantage points, I have gained both an overview perspective on the functioning of the Rehabilitation Act as well as a close-up perspective on how it serves my patients.

## 1. CURRENT TRENDS-POPULATIONS SERVED

Multiple factors contribute to the shift in the types of clients presenting for services. As emergency medical care improves, more severely injured persons are surviving accidents and injuries, but they are surviving with severe disabilities. At the same time we, as a nation, are moving toward de-institutionalization and communi-'y re-integration of severely disabled. These factors present a larger number of severely disabled adults who require comprehensive services over a longer period of

time to a community with shrinking social service resources. Of the group: of severely disabled, two stand out requiring special mention: Survivors of moderate to severe brain injury (including vascular accidents, head trauma and encephalopathy) are rapidly becoming the largest single diagnostic grouping of disabled within the nation; exceeding, both in incidence and prevalence, spinal cord injury. Cerebral Palsy, Multiple Sclerosis, and Muscular Dystrophy combined (see attached chart).

According to Dr. Sisidon Berrol, Chief of Head Trauma Rehabilitation, Santa Clara Valley Medical Center, services to this population must be provided in a con-sistent, coordinated fashion over a number of years for successful rehabilitation and sistent, coordinated iashion over a number of years for successful renar interior and vocational placement. Currently, however, the type and intensity of services re-quired to return one brain injured individual to gainful employment may cost more than a vocational rehabilitation counselor's yearly budget for services to all clients. As a result, services are either provided in an isolated, episodic fashion (which is doomed to failure by virtue of being inadequate) or not provided at all because the client is deemed "too severe" or "unlikely to become gainfully employed as a result of vocational rehabilitation services". This is not an unreasonable stance given the

long history of employment failures with brain injured persons given episodic help. Brain injured persons typically are in the 25-35 year old age group at onset and have a normal life expectancy. To relegate them to a fate of being permanently un-employed leaves society with the burden of support for a lifetime and the individual

with a lifetime of dependency, lack of purpose and lack of productivity. Programs with demonstrated success at return to gainful employment for brain injured persons do exist.<sup>1</sup> They are long (6 months-3 years), intensive and expen-



Silver S., Ben-Yishay, Rattock, J., Ross, B., Lakin, P., Pinsetsky, E., Ezarch, D. and Diller, L., 'Occupational Outcomes in Severe Traumatic Brain Dama, ed Persons Following Intensive Cog-nitive Remediation: An Interim Report"; Rehabilitation Monograph No. 66 New York Universi-ty Medical Center Institute of Rehabilitation Medicine. pp. 79-91.

sive. Compared to a lifetime of unemployment and dependency, however, they are definitely cost effective. Because of the expense and the limited general budgets within vocational rehabilitation, it seems reasonable to create a category of separate funding such as currently exists for the blind; thus, allowing counselors to serve the brain injured adequately without depriving their other clients of needed services.

Severely physically disabled persons with intact brain functioning present a different problem. The barrier to effective return to independent living and gainful employment is usually two-fold. First, is the barrier of equipment. Electronic devices now exist which can enable even the ventilator dependent quadriplegic to type, answer phones, and do data entry on computers. The initial cost is outside the range of current vocational rehabilitation resources; but, again, this is a young (15-25 years at onset) population with a normal life expectancy. Exceptional funding may again be c cost effective answer.

The second barrier that this group faces is that they will never be totally free of the need for assistance with daily activities such as feeding, grooming and dressing, no matter how much equipment is put hased. Recent changes within Social Security seem to allow for such persons to retain that necessary personal care assistance while returning to gainful employment. To this point, that does not always happen smoothly. Coordination of Social Security services through the vocational rehabilitation office for these persons will make their lives less confusing and frustrating and the maintenance of employment once achieved a possibility.

#### 2. RURAL PERSPECTIVE

Aspects of vocational rehabilitation in a rural environment which impact on care can be divided into 3 categories: Distance, population and types of employment available.

Types of employment available in a rural setting tend to be more physically demanding, especially for entry level positions. We lack the factory or "assembly line" type light duty entry level positions. This limits the ability to transfer clients into lighter duty entry level positions after a relatively minor back injury without retraining to a more skilled position. The absence of repetitive type light duty entry leve' jobs within the labor market creates a necessity within vocational rehabilitation and rehabilitation facilities for creation of jobs and opportunities. This is more than selective placement. It encompasses such things as making contracts with compassionate employers, job modification or restructuring, task analysis, careful selection and placement of clients and the coordination of other community resources. This job creation or modification takes time and increases the relative weight of otherwise simple cases within the counselors caseload.

erwise simple cases within the counselors caseload. The relatively small population spread over a relatively large area effects the availability of supportive and treatment services as well as limiting the number and range of available jobs. While excellent rehabilitation services exist within Montana, North Dakota, Scuth Dakota and Colorado, they are located within the major population centers. They may be relatively inaccessible to those who live one hours drive away, but who are unemployed and on a limited income. Receiving services may mean relocating temporarily or a long expensive commute. Neither of these are likely to be within the client's or the counselor's budget.

- The answer to this problem is not to replicate the services in more remote areas as adequate utilization for cost effective operation necessitates a large population. Coordination of z, valiety of services for a given client is frequently necessary and this, too, is difficult to arrange in more remote areas. Rather a means of providing for extraordinary transportation or temporary housing may mean the success or failure for a rehabilitation plan in a rural setting.

#### 3. COMPREHENSIVE INDEPENDENT LIVING

The most significant change toward effective vocational rehabilitation of the severely disabled to have occurred in the last 6 years has been the move toward independent living center utilization and this year the comprehensive independent living program. The effect of this legislation has been to eliminate one of the significant barriers to successful vocational rehabilitation and employment—being inadequately prepared for efficient living within the community. It is impossible to imagine being a successful student or being successfully employed if one's living situation is in upheaval. If one's bathroom is inaccessible or one has no way to do grocery shopping or laundry, if all these are possible but take four times as long as your non-disabled neighbor, it is illogical to assume that one can successfully complete in the work world. The independent living program has addressed these barriers as well as many others.



For many who are more severely disabled still the comprehensive independent living program has offered services for which they have previously been ineligible. Many who will not be able to achieve gainful employment in the near future are being enabled to achieve more independence within their home and community.

Incidence of persons surviving traumatic head injury in the united states 1

| Sevenity of brain damage | Incidence per<br>100.000 per yr | Nationally | Montana <sup>2</sup> |
|--------------------------|---------------------------------|------------|----------------------|
|                          | -                               |            |                      |
| Mind                     | 131                             | 294:750    | 900-+                |
| d - transfer             | 14                              | 30:500     | 100-                 |
| NGLIET ATE               | 14                              |            |                      |
| evere                    | 6                               | 13,500     | 5                    |

Kraus et al., American J. Epidemiol., 1984.
 \* Extrapolated based on 700,000 + Population of Montana.

PREVALENCE OF BRAIN DAMAGE FROM TRAUMA VERSUS OTHER NEUROLOGIC DISABILITIES 1

| Disorder                                   | Prevalence per<br>100.000 | Extrapolated for<br>Montana |
|--------------------------------------------|---------------------------|-----------------------------|
|                                            |                           |                             |
| Traumatic brain injury, moderate to severe | 800                       | 5,600                       |
| Soinal cord injury                         | 50                        | 350                         |
| Multiple scierosis                         | 60                        | 420                         |
| Cerebral palsy                             | 250                       | 1.750                       |
| Muscular dystrophies                       | 20                        | 140                         |

<sup>1</sup> Kurtzke, J.E. Neuolog: 32:1207. 1982

Mr. WILLIAMS. Ms. Smith.

Ms. SMITH. Thank you for inviting me for speaking on behalf of the Montana independent living project. I want to thank you also for holding this hearing in Montana, and I hope it is a reflection of your concern and your committee's members' concern of rural issues in rehabilitation.

One of the things we have heard a lot today is that our ruralness has significant impact on our service delivery to persons who live in the remote areas of our State. We have also heard a little bit about the strength of our rural lifestyle and our rural heritage, and I hope having the committee meeting here, that you see both the impacts of ruralness and also the strength that our rural State gives us and our citizenry.

We heard a little bit earlier that persons in remote rural areas get by and make do. I hope that we encourage an expanded design in our RSA policies which provides outreach to those persons in the rural areas.

Just for a little clarification, the Montana Independent Living Program is funded under the projects for independent living centers under title VII.

We have found while the independent living center concept is vital and needs to be strengthened in Montana, that the distances between our consumers and our Montana community necessitate modification in the service design and the service provision that is quite different from that which is emphasized in the current living independent structure in RSA policies.

Services to reach the most severely Montana disabled need to be in an outreach model, and that requires travel, and it results in additional costs both in terms of staff time and in terms of transportation.



The current Federal grant emphasis on justification of low services and large population impact objectives directly discriminate against the very nature of our rural project, and I think it influences both the effectiveness of designs that are encouraged and in the cost of our projects.

- Increased awareness of these rural realities and the problems cncountered in rural States, both in terms of program design and emphasis and in dollars, needs to occur within the Fede 1 administration.

The independent living movement, which Montana independent living project is involved with, has sought to broaden the perspective of rehabilitation to encompass and support the holistic attitudes of the person. We support the whole activity of daily life, participation in society, participation in family life, and community leadership. I suggest that independent living services and the goals of the general vocational rehabilitation program from vocational preparation and long-term work placement should work in tandem rather than in separation from one another. The daily lives and the daily issues of severely disabled persons, when services are provided to support and bring competency to those issues, will positively influence the employability of those persons.

Funding support of the latent of title VII, as it is now, is essential to the long-term investment in severely physically disabled persons. The current language in title VII gives recognition to the quality of life issues faced by severely disabled persons in their efforts to achieve as much independence as their disability allows. Independent living services have proven to be an integral part of the rehabilitative process. Yet, at the State and Federal level, we feel there is a hostility toward these independent living services.

Independent living services usually foster a continuum of complementary services and seek to create and support the network that is individualized for consumers who are often forgotten by traditional rehab systems. It has been our experience that the populations that are most unserved or uncerserved in Montana are persons afflicted with progressive diseases such as MF, MS, and MD; older disabled persons, typically those whose disability onset occurred after the age of 45; and these with acute mobility impairment—and head injury.

The commonality of these groups is they do not easily fit into the employment basis criteria operant in general rehab services at this time. I feel these groups will continue to be at risk because there is a lack of cross-disability planning and service continuum continuity planning at both the Federal and State administrative levels. The Federal-State partiership planning seems to avoid assuming the long-term planning responsibilities necessary to develop service continuums for the severely disabled. This type of planning is essential, and it would reduce the tragic gaps which we have heard about earlier today.

There are persons who, at this time, because of categorical eligibility implied by the development disability system, the Medicaid waiver system, and the vocational rehabilitative systems, either go unserved or are overserved in an institutional program, which is usually more costly and does not provide enabling kinds of services that will support long-term independent living attitudes and skills.



One of the problems that we have continued to identify is that current State and administrative policy tends to pit one population group against another in competing for limited State funding. What I suggest is that the independent living movement and the Montana Independent Living Program seek to forge coalitions across disability interests. These coalitions are the strength and means to long-range planning. By working through a cross-disability planning model, more appropriate and effective rehabilitative services would be developed for all disabled citizens. The tandem, which is the goal of all Rehab Act legislation, of bringing independent living to the daily lives of severely disabled persons, those skills that are needed, for a long-term employment objective.

Finally, in looking at the title VII funding, I would like to encourage that independent living funding under title VII continue to support public and community awareness activities which seek to create an accessible society for all people regardless of their disability.

I suggest that the success here in Bozeman of creating a business district that is accessible, a community that is accessible, brings an integration to disabled persons and that in the long run will break down attitudes for employment of those same people.

Finally, we have, I think, some exciting language in the title VII part of the Rehabilitation Act, and I would encourage continuation and expanded funding for the commitment we do have. I think basic funding commitment to title VII is a c titcal move in recognizing the civil rights of disabled persons.

Thank you.

[Prepared statement of Zana Smith follows:]

#### PREPARED STATEMENT OF ZANA SMITH, EXECUTIVE DIRECTOR, MONTANA INDEPENDENT LIVING PROJECT

Chairman Williams, Members of the Subcommittee on Select Education, my nume is Zana Smith, I am Project Director for the Montana Independent Living Project, I thank you for coming to Montana to hold this Hearing. It is my hope through your visit to this vast and beautiful Big Sky Country that you will better understand the service delivery chailenges created by our State's rurainess, and also glean a greater appreciation for our rural heritage and valued lifestyle juxtapose to the limited availability of needed services, isolation and lack of options caused by our ruralness, is a heritage, rich in extended family and community supported value of the individual. This rural heritage underwrites the reasons disabled Montanans are resistent to the current RSA policies which seem to insist on relocation (or from a rural perspective, displacement).

Increased awareness of an commitment to the service delivery realities in rural states needs to occur within the federal administration. The distance between Montana communities necessitates modification in service design and service provision quite different from the urban models emphasized in the current RSA Grants. Rural services require travel and result in increased costs of staff time and transportation means. Current Federal grant emphasis is on justification of low service costs and large population impact objectives discriminates against the very nature of rural projects in their application and competition for the (inadequate) funds that are available.

The Independent Living Movement has sought to broaden the perspective of "rehabilitation" to encompass and support the hole person and their activities as they conduct their daily lives and actively participate in society . . . Be that in their personal life management, in their family, in their work and in the contributions to the community.

Funding support to the intent of Title VII of the Rehabilitation Act is essential and gives recognition to the quality of life issues faced by the severely disabled in their efforts to achieve as much independence as their disability allows. Independ-



ent Living Services have proven to be an integral part of the rehabilitative process as Independent Living Services foster a continuum of complementary services and creation of individual support networks for disabled consumers ofter. orgotten by the traditional rehab system.

It is our agencies experience that populations most often identified as non-served, especially by RSA general rehab, in our state are (1) persons afflicted with progressive diseases (such as MS & MD); (2) older-disabled persons, typically those whose disability on set occurred after the age fo 45; (3) those with acute mobility impairments; and (4) head injury survivors

The commonality of these disability groups is they do not easily fit into the employment basis criteria operant in current RSA program funding. These groups continue to be at risk because of the lack of cross-disability and service continuum planning occuring with the federal and state administration systems. The federal-state partnership planning seems to avoid assuming the long term planning responsibilities necessary to develop service continuum structures which are needed and would reduce the tragic service gaps which exist in the hit or miss planning that is prac-ticed. Current practice by federal and state administrations serve to pit disability populations against one another in competition for the limited and inadequate fund-ing that is available. I challenge that it is the state and federal administrative responsibility to support the efforts of the Independent Living Movement, in forging coalitions of across disability interests. These coalitions are the length and means to long range planning, for appropriate and effective rehabilitative services for all disabled citizens.

I would encourage future Independent Living Funding to continue to support Community/Planning awareness activities which seek to create an accessible society for all people regardless of their disability.

In closing, I encourage the continuation and funding of the program intent of Title VII of Rehabilitation Act. Funding commitment is critical to recognizing and supporting the Civil Rights of our disabled citizens.

Thank you.

Mr. WILLIAMS. Thanks very much.

Steve.

Mr. BARTLETT. Thank you, Mr. Chairman.

Mr. Chairman, this is an excellent panel.

I have about 6 days of questions to ask you that I will try to get to in the time that we have before lunch. The panel brings an excellent real world perspective. Let me begin with Ms. Smith.

Tell us just briefly how large is the Montana independent living project, how long you have been in existence, how are you funded, total number of clients you serve.

Ms. SMITH. The Montana independent living project is in its fourth year of operation under section B of title VII. We are on our second year of direct service operation. Our first 2 years were primarily advocacy and what they now call community development activities, breaking down the barriers for an accessible society for Montanans disabled. Our last 2 years have been in direct services.

Structurally, we are not a center. We are a satellite system. We have offices in Great Falls, Billings, and Helena. That gives us greater access to Montana's severely disabled population. It also creates incredible demands on our staff of six.

Mr. BARTLETT. How many clients do you serve?

Ms. SMITH. We have 72 active cases of severely disabled persons. That includes quadriplegics that are respirator dependent, MS persons, and head injury persons. We tend to serve those people who are underserved or not served by the traditional or generic service system in Montana. So, we would tend not to serve the developmentally disabled unless their function level was high enough usually that they wouldn't be appropriate for the system.



Mr. BARTLETT. How do you measure your success with your direct services? That is to say, do you measure it in terms of the percentage that are placed into employment, or how do you measure the success?

Ms. SMITH. Actually, there is no criteria at this time for that under the independent living center process. We measure success in the people that are maintained in their homes, and that is a population that is usually with people with atrophying conditions.

One way we measure it is the placing of a person into vocational rehab. One of our objectives for our population would probably be to make that person ready in terms of their personal skills management, so they would be attractive applicants for general rehab.

Mr. BARTLETT. As you may or may not know, Chairman Williams and I are both fans of the independent living concept in title VII, and in fact we had something to do in the last session with getting part A funded for the \$5 million.

Now comes the dilemma. Independent living centers around this country have reached a certain maturity in terms of having proven their worth, as yours has done. The difficulty is the funding is all going in at this point—or the bulk of it, \$17 million, is going into the temporary funding, the part B funding to get you started, and no funding presently. We hope by the end of this month \$5 million will be funded for part A, which is the permanent kind of funding.

So, my question of you is, if you were in our shoes, would you make that hard choice to take money from part B, or startup kinds of funding, and convert that over to part A, which is the ongoing permanent independent living projects funding?

Ms. SMITH. I think it is premature to move that money from part B to part A. Part of that is that maybe we haven't done our job well enough working on general rehab. But last weekend I was at a conference where the administration of general rehab said that they had some independent living dollars, but they had nothing to do with rehabilitation in general.

So, I think that there are still those attitudes and those networks that need to be forged. I think we are well on our way to forging those.

--I-think Boyd's testimony gives light to the fact that general rehab, who would control part A, does not yet totally understand life preparation skills, for example.

Mr. BARTLETT. OK.

Dr. Bertrand, suppose when you answer the question, who pays, and the Federal Government is an insurer—and you are correct; some 37 percent of the total medical dollars paid in this country are paid through the Federal Government, through Medicare and Medicaid.

My question, then: Other third-party pay insurance companies, how successful are they, do you think, at paying the up-front costs to avoid the long-term maintenance costs? More successful or less successful than the Federal Government? What can we learn from them?

Dr. BERTRAND. I think if you look at auto insurers, who are one group of insurers who look at the risks you take by purchasing a special type of vehicle, more power in the engine, more sporty, more insurance—if you are a nondrinker, you get special rates—



they seem to be using that data to offset their costs. Health insurers have used data for predicting illness. They don't seem to be as aggressive about predicting accidents.

Mr. BARTLETT. OK, in terms of predicting the risks.

Now, in terms of spending their insurance dollars that they had collected as premiums for up-front rehabilitation and reentry into employment as opposed to using those dollars for continued maintenance and disability payments, are insurance companies doing a better job than the Federal Government? I think the Federal Government is doing a rather poor job of it, but are insurance companies doing any better?

Dr. BERTRAND. It depends. In Montana, Blue Cross and Blue Shield have not covered themselves with glory. Some of the other carriers have done a much better job. Bankers' Life, I think, rings a bell as being one of the ones who have done a good job of seeing how much they save by doing rehabilitation up front rather than paying and repaying and repaying for the same types of unnecessary illnesses caused by lack of care initially.

No one but the Federal Government is doing a very good job of doing vocational rehabilitation or putting people back into employment over the last several years. During the last 2 years, some of the disability insurers, private disability carriers, are beginning to see the cost benefits of including mandatory rehabilitation, vocational rehabilitation, in their disability policies. That is a new thing for them. But they are beginning to get into that.

Vocational rehab has done a better job, has been the only one doing this job, and——

- Mr. BARTLETT. You raise a very intriguing area that I think that Congress needs to look at the totality of resources. The resources for rehabilitation should come from the dollars that are saved from not rehabilitating someone. Those are both dollars that are saved by third-party pay insurance companies and by the Federal Government, Social Security, and SSI.

I don't think either the Federal Government or insurance companies are doing a particularly good job at making that connection, and perhaps some time in the next several years Congress can help make that connection in both ways.

Now, Mr. Peterson, you offered excellent testimony. My question: There are about 350—is that right—students in your organization, or at least disabled students?

\_\_Mr. PETERSON. That is how many disabled students there are at MSU.

Mr. BARTLETT. Of the students you work with, I have two questions. Can you generally tell us how many of them upon graduation go into a career, and what kind of careers they are going into, how they obtain that employment?

Second, can you tell us, both as students and then when they graduate, how did they obtain medical insurance—and I am speaking of medical insurance just to be able to have just regular medical insurance from illness, as they are students and when they graduate?

Mr. PETERSON. As students, I would say most of the people that are disabled are usually on Medicaid or one or the other. Upon graduation, from what I know—I mean, I don't work here; I am a



student—but from what I know, we have 100-percent placement of students into the work world. A lot of the students are going into high tech jobs where, you know, it is not sitting behind a desk and pumping out papers like——

Mr. BARTLETT. Like Congressmen.

Mr. PETERSON. Jobs where you really use your mind.

As far as medical insurance goes, after you get out of school, they can't discriminate against us because we are disabled. It is just like any other person. When we get out there, you have to find a job that you are going to get the benefits from the company to get your insurance. Once you start working, then Medicaid and Medicare will cut you off.

That is why we have to—it might take us 6 years to get through school, but it takes us that extra time because we need to get a high enough paying job so we can get into the jobs that offer the benefits. I think that is what a lot of the students at MSU or any other institution are going for—the higher paying jobs, anyway.

I am not. I am going to be a counselor. But that is neither here nor there.

Mr. BARTLETT. If we do our jobs right, maybe they will become a higher paying job.

Thank you.

Mr. WILLIAMS. Mr. Peterson, you mentioned internship as a good transitional service. Do you have any other recommendations?

Mr. PETERSON. You mean as other ideas? Not right off the top of my head.

Mr. WILLIAMS. You seem to indicate that the counseling available was not of either a quality or an intensity that was really helpful to you. Did that have to do with the unavailability of enough counselors or professional nature of your counselor?

- Mr. PETERSON. It is not only my counselor. I mean, I am not singling out my counselor. I am going from what I find out from other students and what they tell me about all their counselors. What I hear from students is the only thing their counselors are worried about is getting them through school. If they can't finish in 4 years, well, then that is too bad.

I don't think that is right, you know. It may take longer to get through school.

They don't look at us as having extra problems, or anything like that. I think there are a lot of people that are being shafted because, if they can't finish school in 4 years, hey, that is too bad. When rehab cuts them off, they have no way of finishing school.

I think also—I don't know, I don't—I look at the word "counselor" as being a person you can talk to about problems. You just don't talk to a rehab counselor about problems unless it has to do with money, in my opinion.

Mr. WILLIAMS. Ms. Smith, in your testimony you mentioned the problems with the RSA grant specifications for rural States. Besides the issue that you raised, what type of new initiatives in R&D might be more helpful to rural areas?

Ms. SMITH. Research for rural design service systems that aren't piloted in what we consider metropolitan areas would be helpful. Most of the rural designs and research models still, for those of us in the West, look like metropolitan areas.

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Mr. WILLIAMS. Give me an example of one that works in New York and doesn't work here.

Mr. BARTLETT. Nothing works in New York.

Mr. WILLIAMS. Give me an example of one that doesn't work in New York and doesn't work here, either.

Ms. SMITH. One of the examples, like the peer counseling, most of the models that are emphasized in peer counseling are urban based, large groups: where here in Montana, to get at real rural issues—which I think peer counseling is a major program that can be geared for our rural outreach program—we need to accommodate a different model in terms of training and interaction. And yet, none of the real models that come out specifically identify or assist us in taking in those realities of separation.

The other type of model would be spinal cord injury rehab that happens in hospitals. They assume peer contacting communities, where we find in our independent living center we have to bridge from rural community to rural community to ensure there is that peer contact. That is essential in long-term goal planning in life skills options that we can't look at only the urban setting for models in terms of role models.

We have to look at—one may be agriculture, a farmer who has made some technological adjustments to his truck, and his whole ranch operation is a model for other disabled rural people. There are a lot of other examples. We have to bridge those gaps constantly. Designs that come out of our research centers don't help us with that. We are so small, we are not qualified to really do the research.

Mr. WILLIAMS. The advantage of federalism in the 80/20 match, is obvious. There are significant amounts of national money available for States that are unable to come up with those models, States such as Montana. That is the benefit.

The liability in this time of federalism is that the Federal Government has to be accountable for the money which it sends to every State, and that money has to meet a national need. So the regulations are written on a national basis, and they don't always meet the local need.

I don't know that that dilemma is resolvable except to turn around the matching grant and let the States write the regulations and pay 80 percent and the Federal Government pay the 20. That is not in the cards, is it? There is our difficulty.

We have struggled, Steve and I and all the others, and the people in the regional office struggle all the time with trying to write regulations in such a way that allows appropriate flexibility for Bozeman as well as it does for New York City. But that is very difficult to achieve.

Ms: SMITH: Right: I understand that.

\_ One point, Montana is just starting to look at is innovative programs for the populations we are talking about.

Mr. WILLIAMS. Dr. Bertrand, there is a national network for rural rehabilitation technology that has been established in North Dakota. You are familiar with that network?

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Dr. BERTRAND. No.

Mr. WILLIAMS. No?



Tell me about the needs that you have for technology based on what we were just speaking of here, and how those needs can best be adapted from the Federal level to service the Montana clients, rural clients.

Dr. BERTRAND. Well, I think----

Mr. WILLIAMS. Would it be through networking, State by State, rural State by State?

Dr. BERTRAND. That would have been my first suggestion.

I think there are a variety of things happening within Montana. We are far enough spread out that it is hard to keep tabs on what is happening everywhere. Our center has people coming in from Miles City, Missoula, from Great Falls area, and for me to know what is happening in those communities that they are going back to, it is just impossible without some formal networking.

We do a lot of phoning around and trying to make contacts with appropriate resources in their house communities. But that is not always real accurate. It is not ever very efficient. So, a networking approach would be very helpful.

We have on the drawingboard in our office a networking plan, and we are trying to find a way that we can, with private funds or with available services, fund such a networking approach. But so far it is still on the drawing board. There is not that kind of money.

The other thing that we are working with is bringing groups together off and on to provide the higher tech services. There are remote control, environmental control systems available in the Seattle area, and we have a vendor who will come once a quarter. We bring groups of people with similar disabilities together, and we can, on a regional basis, on a scheduled basis, provide for needs.

can, on a regional basis, on a scheduled basis, provide for needs. That still requires travel on the part of the disabled person to come and observe that. It requires bringing that kind of technology back into their 1 me community, which means there has to be somebody in their nome community that knows how to manage it. So we are looking at lots of travel money for the disabled or their attendant or their family or their counselor. We are also looking for travel for the vendors and for the professionals who are working with the vendor, the family and the client.

So there are some options available. Again, it is a matter of funding to provide this thing that is not really a medical service, and it is not really a rehabilitation service; it is travel. And yet, travel is often a barrier to getting the kind of services that are actually available.

Mr. WILLIAMS. Well, our thanks to this panel and the other two panels who appeared.

Before we close this morning's hearing, I want to make the point to this panel and the others, and the folks that were good enough to join us today. My questions surrounding the fiscal questions of who pays, as I think most of you know, do not have to do at all with my sense that the Federal role is inappropriate or the Federal Government should not continue to have perhaps an 80 percent match. Rather, they speaks only to what are the economic and political realities of today's budget problems.

After 3 years on the Budget Committee, after watching time and again the target of budget cuts being places like Montana, I simply

felt it incumbent upon me to relay to you the jeopardy that faces this State, and also to make you fully aware that Montana and other States do not cut the budget for rehab in a vacuum. It does have an effect in Washington, DC. We do look to see whether or not the States are picking up that which we are pushing to them. We, in turn, have to react because that is our job back there.

For my part, I believe the Federal Government does not do enough in this area. I am pleased that my amendment, as a member of the Budget Committee, to allow an increase to vocational rehabilitation services this year, was accepted by the House, the Senate, and the President. Vocational rehabilitation will be one of only a handful of social services which will receive an increase this year because of my amendment.

But we are out of money. The States have to do their share. To help the Federal Government? No, no; to help the citizens who need it. That is the point of this. I wasn't sure if my earlier remarks were being misinterpreted here or not.

Thank you all for being with us this morning.

[Whereupon at 11:55 a.m. the subcommittee adjourned.]

## METROPOLITAN ANALYSIS & RETRIEVAL SYSTEMS, INC.

Missoula, MT.

DEAR REPRESENTATIVE WILLIAMS AND MEMBERS OF THE COMMITTEE ON SELECT EDU-CATION: We are submitting this brief testimony in support of the re-authorization of the Rehabilitation Act.

Metropolitan Analysis and Retrieval Systems. Inc. (M.A.R.S.), as a corporation does not work directly in the field of rehabilitation; however, many of our clients, as well as M.A.R.S., are employers of rehabilitation clients. As an employer of the handicapped, we have become aware of the employment problems faced by these people. We and our clients have learned from experience that rehabilitation clients make competent, dedicated employees when they are given the opportunity. The Rehabilitation Act of 1973 brought about a period of transition in the field of

The Kehabilitation Act of 1973 brought about a period of transition in the field of vocation rehabilitation. Great strides have been made in opening up avenues for rehabilitation clients to live independent lives and be a part of the world of work. However, there still remains much work to be done in this area. Re-authorization of the Rehabilitation Act would permit the continued transitions for rehabilitation clients from a world of non-productivity and isolation into useful productive citizens. To a large extent the progress of rehabilitation clients is due to the very strong federal/state partnership, with the Federal government leading the way with entitlement programs. We do not believe that anyone can be naive enough to think that if this strong partnership did not exist that we would have any sort of equality between state rehabilitation programs. We urge the continuation of this state/federal partnership.

At the present time we are seeing the first recipients of PL 94-142 move from school to the world of work. It is imperative that these persons enter into the work force immediately, rather than live for an extended period of time on Federal programs where the quality of life is low and the person is unproductive and has no motivation to excel in life. Studies show that rehabilitation clients who spend only a few months on Social Security Insurance Programs become very difficult to place in the work force. Re-authorization of the Rehabilitation Act will greatly aid in job placement and independent living for these people.

placement and independent living for these people. We also believe that an on-going medical program should be available while the rehabilitation client is in a trial work period. Most rehabilitation clients enter the work on low entry level pay scales. Sometimes it takes more than one trial work period to find a working solution for these people. During this trial time, rehabilitation clients can lose their medical coverage under Social Security. To be without proper medical coverage can be very devasting for these clients. Rural rehabilitation clients are also desperately in need of care and outreach into

Rural rehabilitation clients are also desperately in need of care and outreach into their communities. In most instances they must leave their home community for care, counseling and employment. More emphasis should be placed on outreach programs to serve rural rehabilitation clients.

MA.R.S. recieves feedback from large and small firms all across the country. Many of these firms are users of the TUTC and JTPA Programs, and find them ex-



cellent placement tools for rehabilitation clients. We are repeatedly told that rehabilitation clients work hard to prove to themselves and their employer that they can get the job done. M.A.R.S. certainly finds our rehabilitation clients to be dedicated workers. We have a legally blind employee who is manager of In House Operations, a Client Specialist with a back injury and clerks with mental disabilities. These employees are some of our most productive and dedicated workers.

In closing, we would like to again stress the tremendous transition that is taking place in rehabilitation; the transition from disincentives to incentives is going to be the final step in the rehabilitation process. We feel the programs that can be coordinated with the Rehabilitation Act such as TUTC and JIPA will go a long way to wards supporting the transition from discentives to incentives. This country has invested a considerable sum of money developing a rehabilitation system that can transition the handiciapped into productive lives. That investment must now be supported by continued funding so that the system is not dismantled. We feel that, by supporting rehabilitation programs, TUTC and JIPA, this transition will be complete thus there will be a vast differnce in what the end result will be; independence for the disabled Americans.

HELENA, MT, August 20, 1985.

Representative PAT WILLIAMS, Montana Chairman, Subcommittee on Select Education; Washington, DC.

DEAR REPRESENTATIVE WILLIAMS: Thank you for allowing me to submit my views regarding the rehabilitation programs on the Federal and State levels. I feel that services for the head injured segment of our population are nonexistent, or at best if families do find programs, the costs are so astronomical that enrolling the injured person is out of the question. My experience with head trauma is that my husband a two years post injury. During the last two years I have been in situations that I rever knew existed. In a matter of minutes the bread winner and totally functional iead of the household was gone and I was left with picking up the pieces and naving no idea where to turn for help.

I believe that one of the most vital people that should be informed of all rehabiliation services is the hospital social worker. Information regarding who to contact should be made available to the families so that when the injured person is able to participate in an out of hospital program the families have that information. As the system is now, it is up to the family member to seek out what is available and from a lay person's point of view it is an overwhelming task.

Benefits through the Veterans Administration are very restrictive if the head njury is non-service related. Extended vocational rehabilitation programs are locaticated out of state and veterans are responsible for arranging and paying for off rehailitition campus living plus transportation to and from the facility.

Private programs for rehabilitative training such as the model head injury prorram located in Missoula, Montana charge \$18,000.00 for six months plus the inured person must pay for off campus living and travel to and from the center. Inurance coverage in our case specified that rehabilitation has to begin within one rear from onset of illness or injury, my hisband was not mentally capable for intenive rehabilitation, therefore this program is not available to us.

The program I did enroll my husband in was for the Developmentally Disabled. Ie did not belong in the surroundings but I was faced with the choice of placing im there or having him sit at home all day. He is now on a waiting list for up to ne year before job training will start through the D.D program. What does he do in he mean time? Continue as he is now, drawing Social Security Disability for the est of his life?

Head injured people remember what they were like before the illness. Their goals ire to be productive and to feel a sense of worth. I do not feel that these expectaions are out of line. There are no economically feasable services for the head inured. I recommend that special programs be implemented such as job retraining uited to their present abilities and dealing with ongoing short term memory loss. Why cannot the system help these under-served and neglected individuals attain heir goals?

 $\bar{5}30$ 

Sincerely,

MYRNA OMHOLT FOX.



#### PREPARED STATEMENT OF THE MONTANA STATE DEVELOPMENTAL DISABILITIES PLAN-NING AND ADVISORY COUNCIL AND THE MONTANA ADVOCACY PROGRA #/CLIENT AS-SISTANCE PROGRAM

#### PURPOSE OF THE COUNCIL

The state rlaining council is a citizen-based advisory group operating under the mandate of P.L. 98-527. Its 22 members work to improve the quality of life for persons with developmental disabilities. The Council administers federal funds, paid to the State, to make varied and significant contributions toward strengthening services for persons with developmental disabilities.

## PURPOSE OF THE ADVOCACY PROGRAM/CLIENT ASSISTANCE PROGRAM

The advocacy program pursues legal, administrative and other appropriate remedies to ensure the protection of the rights of persons with developmental disabilities living in Montana. The Client Assistance Program is a statewide program which assists vocational rehabilitation clients and client applicants in their relationship with the state rehabilitation and visual services and which ensures their rights under the Vocational Rehabilitation Act.

## POSITION ON THE REAUTHORIZATION OF DISABILITY LEGISLATION

Our organizations support the reauthorization without changes to the existing sections. The eriphasis on serving persons with severe involvement in their disabilities is a welcome mandate in the VRA; and it's one which should continue to prevail.

The EHA has provided important avenues for our citizens with handicaps and dis-abilities to benefit from patterns of life and from opportunities which those of us without hardicaps take for granted. Our agencies would like to see this Act increase its support of preschool services, transitional services (high school to community) and personnel development and preparation. And, in particular, it's this last feature for which there is, certainly in Montana, if not elsewhere, an urgent and pressing

we encourage the committee to work for an increase in the appropriation level We encourage the committee to work for an increase in the appropriation level we encourage the committee to work for an increase in the appropriation level fiscal burcen is reaching out and working with the combination of urban/rural/ remote populations.

# MONTANA ASSOCIATION FOR THE BLIND, INC., Sand Coulee, MT, August 18.

To Subcommittee on Select Education, Representative Pat Williams: This in response to your request for written testimony at the hearing to be held in

Bozeman on August 26.

As President of the Montana Association for the Blind and as President of the

As President of the Montana Association for the blind and as President of the Independent Living Project I am interested in the welfare of the disabled communi-ty but I am especially interested in the elderly blind in our state. I spent eight years working as a rehabilitation teacher for Visual Services in Montana. During that time I covered the High Line and had four Indian Reserva-tions. This gave me an understanding of the great distances and our sparse population.

These are some of the problems and possibly some solutions or at least suggestions.

(1) We need more training for our rural elderly blind and under the present situa-tion this is impossible. They need to learn simple skills to continue to live independ ently or at least semi-independently. District personnel cannot spend the tirge needed to teach all these skills. Home attendants and home health care personnel could be trained to teach some of these skills; such as cooking, shopping, home making skills, and some transportation. Some recreation is needed. Mobility and orientation are important for the individual to get around his own environment. (2) Workshops to train home attendants and home health care personnel should

be available. More money for transportation is needed.

(3) The reservations present a special problem. It is difficult to get the individual to keep appointments. I feel if more training were given to the home attendants and health care workers on the reservations it might bring better results. Some of our reservations are isolated and very large. Our state instructional staff and counselors do a good job but are limited by lack of more transportation money and time. The clients they work with need more follow up and more frequent calls to teach them



the necessary skills and then to follow up that training. If some time and effort and money could be spent training nome attendants and home health workers this might provide the needed follow up. We do need more instructional staff but budgets are such that that doesn't seem possible at this time. Some of us feel that if the mobility and orientation staff and the other instructional staff with the Visual Services Division and with the State School for the Deaf and Blind could work together this might provide more training for both the elderly blind and the younger students. We need more help with providing transportation for our elderly blind. This is a major problem in our state.

Some provision should be made for recreation for our elderly blind population. Many seldom get out of their homes or apartments. Simple arts and crafts are helpful:

In summary I would like to see more money and effort put into providing our rural elderly blind receive the training and help to become as independent as their environment will allow. We need to provide quality to their lives. Many of our elderly have visual problems and this will increase as people live longer so the problem will not decrease or go away.

VIRGINIA SUTICH.

#### SUMMIT INDEPENDENCE LIVING CENTER, Missoula, MT, August 21, 1985.

Representative PAT WILLIAMS, Subcommittee on Select Education, Helena, MT.

DEAR HONORABLE REPRESENTATIVE WILLIAMS: This letter is intended to provide support for the reauthorization of the Rehabilitation Act specifically in regard to the need for expanding Independent Living Title VII Part B Independent Living Centers and Part A Comprehensive Independent Living Services. As you know Independent Living is a consumer involved process that provides a

holistic approach to assure that people with severe diabilities can remain within

their own Lomes and participate in society as a whole. I am a disabled person and the Coordinator for the Summit Peer Counseling Pro-gram which provides me the opportunity to see and enjoy the many benefits resulting-from the Independent Center in Missoula and through-out the State of Montana. You may already realize that cur needs in Montana are compounded by the rural

nature of our State and the extreme lack of resources for people with severe disabilities

Currently the State has two Independent Living Centers-Summit trying to serve Western Montana and Montana Independent Living Project (MILP) trying to serve Eastern Montana. These centers are funded at \$150,000 per year and the minimal funds are in jeopardy without proper appropriation through the reauthorization of the Rehabilitation Act.

- I am personally advocating for increased funding for Part B Independent Living Centers in rural areas due to the long distances and therefore expensive service provision required to cover the area.

Please contact me at your convenience should testimony or further information be required.

Sincerely,

#### JOYCE KALMES.

#### PREPARED STATEMENT OF JEAN MEYERS, ASSOCIATE DIRECTOR, FLATHEAD INDUSTRIES FOR THE HANDICAPPED IN KALISPELL, MT

Mr. Chairman and members of the sub-committee my name is Jean Meyers, Asso-ciate Director of Flathead Industries for the Handicapped in Kalispell, Montana. On behalf of the Montana Association of Rehabilitation Facilities I want to thank you for the opportunity to provide written testimony as you prepare for the reauthoriza-tion of the Rehabilitation Act. I'd also like to express my appreciation for your plan-

Initially I will respond to a question raised by Congressman Williams which re-lates to the State/Federal paitnership. The Montana Rehabilitation Facilities pri-marily receive assistance and direction from the Rehabilitative/Visual Services Division, of the Department of Social and Rehabilitation Services. Our facilities have a strong relationship with State personnel who are responsive and effectively ad-minister provisions and funding allocations contained within the Rehabilitation Act.



The most effective state/federal relationship which directly affects our facilities is provided by personnel in the Denver Regional Office.

Our association supports the continuation of regional offices. Regional personnel have a comprehensive understanding of the Rehabilitation Act and rehabilitation services. We utilize their assistance for purposes such as, interpretation of legislation relating to Affirmative Action and 504. In the past, they have advocated on behalf of our rural facilities with the Washington Office and other branches of the Federal Government. They have specifically assisted some facilities in the planning and development of food service programs which provide employment for the handicapped.

It is important that the federal personnel involved with our facilities be knowledgeable of the rehabilitative process, specifically because many states in this region have dispersed populations. We believe that the regional office concept is the key link in the state/federal partnership.

The focus of the remainder of my testimony will address the special demands of rural rehabilitation, how well the Rehabilitation Act is working and recommendations regarding changes within the act.

The needs and issues experienced by the rural disabled present unique challenges to the rehabilitative structure and service delivery in states such as Montana.

In Montana there are seven rehabilitation facilities which provide services and training through an employment based model. During fiscal year 1985 these facilities served 1,221 individuals eligible for rehabilitation services, and 580 individuals eligible under the Developmental Disabilities Act.

A primary emphasis of a rehabilitation facility is to provide employment for the handicapped or to provide training which leads to competitive employment. Our vocational development programs include services such as, vocational evaluation, work adjustment, occupational skill training and short-term work experience. This is accomplished in a variety of settings such as sheltered workshops, work activity programs and community placements.

In addition to our work adjustment program, rehabilitation facilities offer social adjustment services which are designed to aid the individual in resolving problems in their daily life. These problems mey not be work related; however, they must be addressed in order for the individual to successfully achieve and/or maintain employment.

The following is a synopsis of current problems relating to the delivery of these specific services in rural locations:

(1) Montana has an agricultural base and lacks primary industry.

(2) This results in high unemployment within Montana's counties and creates an excessive labor pool. This has a direct bearing on our clientele's accessability to the job market.

(3) The geographic location affects our corporation's abilities to develop businesses and products which can augment state and federal funding and provide sites for training and employment of the handicapped. In many instances factors which contribute to this condition are due to high transportation costs and limited business markets.

(4) There is a distinct lack of technical resource personnel who understand the rehabilitative process and are able to assist in the development of new businesses.

(5) Amendments to the Rehabilitation Act of 1973 have broadened the definition of "Handicapped person." There are now special population groups which have historically been underserved. These include head trauma individuals and amputees as a few examples. Services are provided to these target groups side-by side with individuals who have severe mental retardation. As a result, the quality of employment and programmatic training frequently falls to the middle and generalizes to the lowest common denominator. I'm sure you are well aware of the distinct differences between individuals involved in the rehabilitation process versus a habilitative process. Therefore, many times an individual's self-concept is not enhanced by the comingling of training and services for these two distinct population groups. This may not be a localized problem specific only to rural states. However, the limited number of rehabilitation facilities and technical resources may exacerbate the situation. —

(6) There is a long waiting list of individuals requiring rehabilitation services. Although federal/state funding have increased, the amount has not been proportionate to the demand for service; as such, funding for expansion is necessary These problems are inherent in the rehabilitation structure. Legislation such as

These problems are inherent in the rehabilitation structure. Legislation such as the Rehabilitation Act intensifies our awareness of these needs. The act provides a definition for who we must serve, and identifies the types of services to be provided.



Two components of the act which directly affect our rehabilitation efforts and our ability to resolve the identified problems are contained in Section 304 and Section C-1 of Section 302. These sections deal with training and facility improvements. Previously the Act authorized funding for these items. Funding has not been available in our State since 1981 for training and technical assistance. The 1974 amendment to the Rehabilitation Act deleted Section C-1 of Section 302 involving facility improvement. In the past, Montana's facilities extensively utilized these programs. Following are specific examples of the value of these programs to rural rehabilitation areas and facilities. The technical assistance program can assist us in the following ways:

 (1) It provides an information clearing house which minimizes the cost of travel in Montona, the nation's fourth largest state.
 (2) It can assist rehabilitation facilities to develop strategies and expertise for spe-

(2) It can assist rehabilitation facilities to develop strategies and expertise for special population groups such as the visually and hearing impaired who need to be more frequently placed in a production setting. These strategies can access the individual's ability to work by adapting their environment and by training personnel involved with the individual.

(3) It can assist a facility to develop non-vocational activities which can optimally benefit the individual during slack business periods.

(4) Facilities must become more dynamic in specialized program development as a profile of the populations being served changes. We want to provide rehabilitation services and training which are intensely geared to the specialized needs of those we serve. In order to do this, facility personnel must keep current with knowledge and trends in the field of rehabilitation. Technical assistance can facilitate this development.

(5) It can also help an existing or new facility develop businesses to include manufacturing, subcontracting, etc. specific to the local area.

The facility improvement program not contained in the act can directly assist the rehabilitation facility by upgrading their services and programmatic equipment. If funding were authorized, rehabilitation facilities could better attain accessability for all disability groups. Rehabilitation engineering for adaptive equipment could be acquired to assist the handicapped individual in their work environment.

A third important component in the Act is contained within Section 316 and authorizes Special Recreational Programs important to the individuals personal a

thousand the second and the second a

In conclusion, the Montana Association of Rehabilitation Facilities feels the act is a comprehensive body of legislation. The Act provides us with very good direction and guidance as we attempt to meet the intent of the law. We recommend no significant changes be made to the Act with the exception of reauthorizing Section C-1 of Section 302 which deals with facility improvements. This would have a significant and beneficial impact for Rehabilitation facilities who provide training and services in a Rural setting. We also strongly advocate for authorization of funds in the technical assistance program and for those services which are not employment related such as Special Recreational Programs and expanded Independent Living Services. Thank you for inviting me to testify today, and thank you for your efforts in behalf of all the disabled.

> MONTANA STATE UNIVERSITY, DISABLED STUDENT SERVICES, Bozeman, MT., August 22, 1985.

To: Congressman Pat Williams, Chairman, Subcommittee on Select Education. From: Bob Frazier, Director, Disabled Student Services. Re: Request for Written Testimony Regarding the Reauthorization of the Rehabilia-

Re: Request for Written Testimony Regarding the Reauthorization of the Rehabiliation Act of 1973.

During the 1980 census, it was found that Montana lists 113,000 persons who have disabling conditions. That translates to approximately one in ever seven Montanans. When coupled with the fact that medical technology has advanced our ability to save people's lives, both with congenital and acquired disabilities, we should make



plans not to deal with what appears to be an every increasing population of disabled persons. The Rehabilitation Act will be one of the vehicles that allows us to provide services to these increasing numbers.

When the Rehabilitation Act was passed by Congress in 1973. a traditional service delivery model was chosen. For the most part, the system has been effective over the years but I have noted a decline in its effectiveness during the last several years. Many of the vocational programs still deliver services based on a counselor/ client format. We need to realize that the client consumer is an important part of every system and should not be just a recipient. Consumers have valuable information on how the system works, and need to supply us with as much input as possible on how to make the system better. After all, many of the people being served by the present system would not have survived their disabilities fifteen years ago. Because of the severity of their disabilities, many of the persons we seen now were not even being rehabilitated in 1973. Most quadriplegics were given five years to live and were told they were lucky to have oeen that long. Persons who were learning disabled were often seen as people who had limited mental capacities. Individuals who were spastic were many times kept in institutions so that able-bodied people would not have to deal with disability related problems.

At Montana State University we served 341 students with disabilities during the 1984-85 school year. Disabled students are comprised of twenty-six different disability groups including: visual impairments, quadriplegia, auditory impairments, amputees, paraplegia, learning disabilities, multiple sclerosis, muscular dystrophy, etc. To aid students we offer a wide range of services that assist in the rehabilitation process which include: reading and taping, liaison with state and fede. al agencies, recreational and social activities, alternative testing, accessibility planning, information and assistance to faculty and staff, informational resources to the public and private sectors regarding understanding of disability conditions, etc. During the five years the program has been in operation, the number of students using services has increased about three hundred percent and the retention rate has hovered between ninety and ninety-eight percent each year. Job placement figures have remained equal to that of the able bodied population at MSU.

There are a number of reasons for the success that the program has been able to achieve. In many ways we are on the cutting edge of both using and developing new technologies that assist people with disabilities. We "live" with students every day and know the ups and downs of disabiling conditions. We listen to our consumers on a continuous basis, seeking feedback on how to make programs and services better. Because of the size of our student population (about 375 in 1985-86), the opportunity exists and provides students with a good support group with whom to discuss the victories and defeats. We are able to create our own "safety net" that allows most students the opportunity to achieve their maximum potential and become highly marketable human beings.

To date, little direct funding is provided by the federal government to higher education for rehabilitation services. There are opportunities for competitive grants. However, many times these grants are for seemingly unimportant areas which will have little ' rect impact of the lives of disabled students. We presently receive all of our money to perate from state and private sources. I believe that with some direct support funded through the State Rehabilitation Services Office, that we could not only provide an increasingly higher quality of service, serve additional numbers, and also give disabled persons in Montana information that would increase their opportunities and improve their quality of life. Unfortunately, with our present increasing load of student consumers it will be difficult to do much more than status quo without additional dollars. I truly believe that in most cases, higher education is the key to independence for many persons with physical disabilities. Hopefully, Congress will provide the incentives to allow disabled people the chance to continue the ascent into th. mainstream.

<u>Thank you for the opportunity to provide you with information regarding the Re-</u> habilitation Act and higher education. If you have any questions, please feel free to contact me.



ROCKY BOY TRIBAL EDUCATION, Box Elder, MT. September 3, 1985.

Hon. PAT WILLIAMS,

Chairman, Committee on Education and Labor,

House of Representatives, Washington, DC.

DEAR REPRESENTATIVE WILLIAMS: On behalf of the Chippewa Cree Tribe, I would like to present our written comments regarding the reauthorization of the Vocational Rehabilitation Act of 1973.

As you are aware, the Chippewa-Cree Tribe has committed significant time and As you are aware, the Chippewa-Cree Tribe has committed significant time and effort to develop education and training opportunities for our tribal members in Rocky Boy. Recently, we have had the opportunity to comment on the supplemental appropriation for Vocational Rehabilitation funding levels; monies which we have also submitted competitive proposals for. In reviewing the proposed regulations for the reauthorization of this specific reha-bilitation act, I will comment on the following: The purpose of the title is to provide for the administration of programs designed to provide assistance to eligible American Indians in need of rehabilitation services but are unable to obtain needed services elsewhere. I strongly support federal sup-port for programs that will eventually assist our Indian people to a life of independ-ence. If there is a clear rationale for thering in the funding levels by fiscal year.

ence. If there is a clear rationale for tiering in the funding levels by fiscal year, then I endorse this process. However, I strongly feel that a basic 2% set-aside amount of vocational rehabilitation monies for American Indians, perhaps similar to that of the 1% set-aside Indian Vocational monies, would benefit the eligible pop-ulation in a more fitting manner. While I cannot speak of the need factor for all American Indians in general, I can speak to the need in Rocky Boy. That need em-phasizes increases in support for educational opportunities. We are not currently serving a segment of our populaiton that are in dire need of services—that of the handicapped Indian adult. Without the necessary 2% set-aside provision, this identified segment will continue to be overlooked. I further recommend that a provision be added to the proposed language of the Vocational Rehabilitation Act of 1973 to include matching monies by the Bureau of Indian Affairs. As stated many times, American Indians view education as the solution to the bulk of our problems. Now is the time to continue to support the first federal program, to but problems, how is the time to continue to support the first federal program, to my knowledge, that could greatly improve opportunities for al. Indian people. Your consideration of these issues will be appreciated. Thank you for providing this Tribe with an opportunity to comment on the Voca-tional Rehabilitation Act of 1973.

Sincerely.

PEGGY NAGEL Tribal Education Director.

THE CHIPPEWA CREE TRIBE OF THE ROCKY BOY'S RESERVATION, Box Elder, MT, September 3, 1985.

Hon. PAT WILLIAMS,

Chairman, Committee on Education and Labor,

House of Representatives, Washington, DC.

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American Indians in general, I can speak to the need in Rocky Boy. That need emphasizes increases in support for educational opportunities. We are not currently serving a segment of our population that are in dire need of services—that of the handicapped Indian adult. Without the necessary 2% set-aside provision, this identified segment will continue to be overlooked. I further recommend that a provision be added to the proposed language of the Vocational Rehabilitation Act of 1973 to include matching monies by the Bureau of Indian Affairs. As stated many times, American Indians view education as the solution to the bulk of our problems. Now is the time to continue to support the first federal program, to my knowledge, that could greatly improve opportunities for all Indian people.

Your consideration of these issues will be appreciated.

Thank you for providing this Tribe with an opportunity to comment on the Vocational Rehabilitation Act of 1973. Sincerely,

GARY EAGLEMAN; Chairman, RAYMOND PARKER, Member, JOHN HOULE, Member, John Sun Child, Member, DUNCAN STANDING ROCK, Member, Tribal Education Committee. ROCKY STUMP, Chairman, Chippewa-Cree Tribe.

GREAT FALLS, MT, August 13, 1985.

SUBCOMMITTEE ON SELECT EDUCATION, Washington, DC.

To whom it may concern:

I am submitting testimony about the kehabilitation Act and would also be interested in testifying.

I am a 27-year old quadriplegic who is in the process of moving from a nursing home to the above address; a private one-bedroom apartment which is an accessible and low-income rental. I'm very intersted in the needs of severely handicapped individuals who have left an institutional setting and want to live independently in an apartment or home in the community. I was out in an independent living setting before with minimal success, but had to return to a nursing home because of certain problems and needs that I would like to discuss now:

Question (1). What needs exist that cannot be met?

Answer. (a) Personal Care Attendants—for severely handicapped individuals, better supervision and coordination of personal care attendants (example, PCA working shifts). An increase in hourly payments would encourage PCA's to feel better about the work they do. (b) Therapy in Home—people who only have Social Security cannot afford to have

therapy in their home setting.

(c) Understanding of Medicaid Payments-I have always had trouble finding someone who will explain which of my needs will be paid for by Medicaid.

(d) Education in Home-to learn a skill in the home or earn a degree is difficult, but so is finding transportation to a Vocational Technical Center.

(e) Equipment Repair—if I did need my specialized equipment repaired for home or in educational pursuit, my environmental control unit repair will only be paid by Medicaid if I send it to the factory that made it. (f) Accessible and Low-Income Housing—there needs to be more one- and two-bed-

room apartments that meet this requirement.

(g) Transportation-there needs to be accessible transportation available, not just coordinated door-to-door by public systems. Question (2). What is the federal role in Rehab?

Answer. No comment.

Question (3). How does the federal, state, and private partnership work? Answer. No comment.

Question (4). What special Rehab needs exist in rural areas?

Answer: Refer to answers given in question #1.

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Question (5). What services do we need to provide for higher education and post employment services? Answer. In Montana, where it gets to be 30° below. I would like to have education in my home as I physically cannot move when my lody responds to the cold. Thank you for your time: Sincerely,

BOB DRAZICH.



# **REAUTHORIZATION OF THE REHABILITATION** ACT OF 1973

## TUESDAY, NOVEMBER 26, 1985

HOUSE OF REPRESENTATIVES, SUBCOMMITTEE ON SELECT EDUCATION, COMMITTEE ON EDUCATION AND LABOR,

Honolulu. HI. The subcommittee met, pursuant to call, at 10:10 a.m., in room 462, Prince Kuhio Federal Office Building, Honolulu, HI, Hon. Pat.

Williams (chairman of the subcommittee) presiding. Members present: Representatives Williams and Hayes.

Also present: Representatives Heftel and Akaka.

Staff present: S. Gray Garwood, staff director.

Mr. WILLIAMS. Good morning. My name is Pat Williams.-

I welcome each of you to the sixth in a series of hearings the Subcommittee on Select Education has been holding on the reauthorization of the Rehabilitation Act of 1973. We have been hearing from a variety of groups representing consumers, Federal and State administrators, private providers of the rehabilitation system, counselors, and others about the effectiveness of current rehabilitation programs and the future challenges of the system.

It is a pleasure to accept the invitation of Congressmen Akaka and Heftel to hold our second field hearing here in Honolulu. I also appreciate the presence of our good colleague, Congressman Charlie Hayes, from Illinois.

Vocational rehabilitation is the major Federal job-related effort serving persons with disabilities and providing support services to allow people to work. Vocational rehabilitation has made a major contribution to keeping people self-sufficient and independent. For all of us concerned about the Federal deficit, we are encouraged by the cost effectiveness of vocational rehabilitation.

We hope to keep this system working well for those in need of its services. We also wish to ensure that it continues to operate in a cost-effective manner. That is why we solicit the opinions of folks such as you. Your views will be most helpful to us as we reauthorize this important legislation.

Our data indicates that the unmet need is enormous. Disabled people suffer between 50 and 80 percent unemployment. Thus, despite our successes, we have a long way to go in this State-Federal partnership to develop the most comprehensive and effective program.

Today, we are particularly interested in hearing from the perspective of people who work with vocational rehabilitation in a set-

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ting that is geographically different. Hawaii is an island State which can mean unique demands for rehabilitation services. All of us in the Congress are very concerned the F deral rehabilitation program be designed to meet the needs of your State, as well as all of the other 49.

Mr. Hayes.

Mr. HAYES. Thank you, Mr. Chairman.

I don't have any opening statement.

Mr. WILLIAMS. Mr. Akaka.

Mr. AKAKA. Mr. Chairman, I thank you and Congressman Hayes for coming to Hawaii and taking the time to hold a hearing on the reauthorization of the Education of the Handicapped Act and Rehabilitation Act of 1973. As you will hear, Hawaii is a unique place. We take pride in the diversity here; and yet, we have many types of problems that are similar to problems throughout our country and throughout the world.

I am happy you are here because it provides us an opportunity to have dialog with you, with your community and with Congress and to tell you about some of our distinct needs of the people here.

This is an avenue of presenting Congress to the people of Hawaii and to tell the people here that Congress wants to hear from you and of your specific needs. Also, it is indicative of Congress that they desire effective and equitable laws.

Last week I think you all know that the House and Senate conferees for the Department of Labor, Health and Human Services, and education appropriations bill agreed to appropriate \$1.362 billion for rehabilitation services and handicapped research, which is \$145.6 million more than the administration request, and \$1.411 billion for education for the handicapped, which is \$104.9 million more than the administration request. These actions are an affirmation of the importance in moving forward on the education of the learning disabled and in maximizing the handicapped person's potential for employment and independent living. Congress concurs that the initial investment is well worth the long-term benefit.

It is also befiting to note that we will be celebrating the 10th anniversary of the enactment of the Education of Handicapped Act, commonly known as Public Law 94-142, and that will take place on Friday, November 29. With the passage of this legislation, all handicapped children were assured a free, appropriate public education, no matter what their disability, no matter how severe their disability. The impact of this legislation is impressive. 4,128,009 handicapped children were served last year alone; 465,763 education professionals were trained to work with handicapped students; and over 7.5 billion Federal dollars were appropriated in the last 10-years.

But all these figures and dollar amounts do not tell the whole story. Since enactment of the Rehabilitation Act of 1973 and the Education of the Handicapped Act, we are asked to look at the handicapped in the same light that we see the nonhandicapped—as human beings with individual differences, unique needs and unique potentials. America's society has been greatly enriched by providing the means for the disabled to contribute to the social and economic progress of the United States.



Mr. Chairman, I look forward to hearing the testimonies given today on the special education rehabilitation programs in the State of Hawaii, and again I want to thank you and to say mahalo nui loa for taking an active interest in investigating the needs of our State of Hawaii.

Thank you very much.

Mr. WILLIAMS. Thank you.

Our first witness today is the administrator for vocational rehabilitation, Dr. Nishioka.

Doctor, if you will come to the witness table.

We have this morning six witnesses, and this afternoon we will hear from seven or eight witnesses. In order to give them all an appropriate amount of time and also allow the members to question, if we have questions, I request each witness to keep their remarks to no more than 8 or 10 minutes. If you begin to go over that there will be a little reminder, and we would ask you to summarize.

Your complete testimony will be put in the record. You may read or summarize as you wish.

Doctor, we are glad to have you with us today. You may proceed.

## STATEMENT OF TOSHIO NISHIOKA, ADMINISTRATOR FOR VOCATIONAL REHABILITATION, STATE OF HAWAII

Dr. NISHIOKA. Mr. Chairman and members of the committee.

My name is Toshio Nishioka and I am the administrator of the Vocational Rehabilitation and Services for the Blind Division in Hawaii. I am delighted to be invited to provide testimony on the reauthorization of the Rehabilitation Act of 1973. My testimony this morning is a summary of the testimony that was submitted to you last week. The Vocational Rehabilitation Program started in Hawaii in 1936. Next year, 1986, we will be celebrating our 50th year of serving handicapped persons in this State.

The Vocational Rehabilitation Program, under the Vocational Rehabilitation Act, is working very well in Hawaii. During the past year, vocational rehabilitation counselors working out of branch offices located on the islands of Oahu, Maui, Kauai, Hawaii and Molokai served 6,983 handicapped persons and rehabilitated 726 into gainful occupations.

The division works cooperatively with and purchases services from many public and private agencies in the community for the rehabilitation of disabled persons.

Vocational rehabilitation counselors provide guidance, counseling and job placement of handicapped persons. Training of clients are provided by programs under the Job Training Partnership Act, public and private business and technical schools, colleges, universities, private rehabilitation facilities and employers.

In addition, the division provided direct services to 891 blind and visually impaired persons last year. Services included personal and social adjustment training, low vision clinic, sheltered employment and vending stand operations.

The division is working cooperatively on three rehabilitation projects. They are the Hawaii transition project, to improve the rehabilitation of handicapped students; the deaf/blind project, to im-

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prove the rehabilitation of Jeaf/blind persons, with the department of education; and the Rehabilitation and Research Training Program to improve services to disabled persons in the Pacific basin with the University of Hawaii.

To improve services to clients, rehabilitation personnel have been trained to keep up-to-date with changing technology, to learn the latest technique in service delivery and information on improved job development and placement. Training of State agency staff, sheltered workshop personnel and other professional and managerial staff in the rehabilitation community are authorized under the act.

As you can see, provision of vocational rehabilitation services to handicapped persons in Hawaii under the Vocational Rehabilitation Act of 1973. has been very successful. The well balanced approach to serving and rehabilitating handicapped persons under the act has enabled us to rehabilitate thousands of handicapped persons in Hawaii.

I would now like to express some of our concerns and needs in serving handicapped persons in Hawaii.

At the present time we are serving only 18 percent of those who need and can benefit from vocational rehabilitation services.

- Additional funds are needed to serve persons with brain injuries, psychiatric problems, learning disabilities, severely disabled persons for independent living services and for supported employment services.

We are receiving increasing numbers of persons with brain injuries and severe psychiatric problems but cannot serve many of them because we do not have the resources to help them become employed.

There are 2,203 students who are in special education classes and who are 16 years and older but we are serving only 500 of them.

There are approximately 16,955 very severely disabled persons in Hawaii. The independent living programs under title VII, parts A and B, are serving only about 500 of these very severely disabled persons. There is a great need to serve more of these people including 120 identified elderly blind who are not now being served. Independent living services to the elderly blind, is authorized under title VII, part C, but not funded as yet. As Congressman Akaka mentioned, it will be funded for this coming year.

Many of these very severely disabled persons can become gainfully employed through services under the independent living program, basic vocational rehabilitation program and through supported employment.

To serve as many of these handicapped persons who are not now being served, there is need for Congress to increase funding for programs under the Vocational Rehabilitation Act. These programs provide individualized vocational rehabilitation services through a network of public and private community-based service providers, staff training program to assure quality services, research and special project programs to improve services and independent living services to severely disabled who are not yet ready for vocational rehabilitation services.

The Rehabilitation Act of 1973, as amended, is a good act in providing a most complete and well-balanced approach to the rehabili-



tation of handicapped persons. We recommend extension of the Rehabilitation Act.

Thank you for the opportunity to appear before this committee. I would be happy to answer any questions.

# [The prepared statement of Dr. Toshio Nishioka follows:]

#### PREPARED STATEMENT OF DR. TOSHIO NISHIOKA, ADMINISTRATOR, VOCATIONAL REHABILITATION AND SERVICES FOR THE BLIND, HAWAII

Mr. Chairman and Members of the Committee, my name is Toshio Nishioka and I am the Administrator of the Vocational Rehabilitation, and Services for the Blind Division in Hawaii. I am delighted to be provide testimony of the reauthorization of the Rehabilitation Act of 1973. The Federal/State rehabilitation program began in 1920. In Hawaii, the Vocational Rehabilitation program started in 1936. Next year, 1986. we will be calebrating our 50th year of serving handleaned persons in this 1986, we will be celebrating our 50th year of serving handicapped persons in this state.

In order to explain how well the Vocational Rehabilitation Act is working in Hawaii, I would like to share with you the activities and our accomplishments in serving handicapped persons in the state last year under the Rehabilitation Act. The Division served 6,983 handicapped persons and rehabilitated 726 into gainful

employment. The average weekly earnings at case closure was \$135.

Of the 726 handicapped persons rehabilitated, 400 or 55% were equally divided between persons suffering from orthopedic, psychological or emotional problems. Two hundred ninety-four (294) or 40% referred themselves for services and 158 or 21% were referred by educational institutions.

Vocational Rehabilitation Counselors working out of branch offices located on the islands of Oahu, Maui, Kauai, Hawaii, and Molokai provide guidance, counseling and job placement in every county to disabled persons. The Division works cooperatively with and purchases services from many agencies

in the community for the rehabilitation of disabled persons.

1. Division staff serve on three of the four Private Industry Councils under the Job Training Partnership Act. The Division has entered into a Memorandum of Understanding with the Honolulu Job Training Program which clearly sets forth our responsibilities and enhances our working relationship.

2. The Division has entered into a total of 25 Unpaid Work Experience Agree-ments with five private sector employers and 20 federal Department of Defense employers. This year 43 clients participated in the unpaid program to develop their job skills and work habits in a "real work" environment.

3. The Division entered into a partnership with Leeward Community College (LCC) and the business community through the Business Advisory Council to devel-op and implement a program at LCC to train the severely disabled as computer programmers

4. The Special Education-Vocational Rehabilitation Work-Study Program (SEVR) is a cooperative effort of the Department of Education and the Division. The purpose of this program is to provide, within a public school letting and the community, opportunities for handicapped youths to develop and to gain experiences essential for ultimately securing and maintaining successful employment. The SEVR pro-gram served 42 schools throughout the State and provided services to approximately 500 students. One hundred forty-seven (147) students completed school this year and schieved their vocational goal. Of the 726 rehabilitated this year, 116 of them were SEVR students.

5. Last year the Division purchased on a contractual basis \$651,529 (45% of the case service funds) worth of vocational rehabilitation services from se en sheltered workshops throughout the state. The specific services num se en snene su evaluation, work adjustment, occupational skills training, and job placement. hundred thirty-one (531) clients were served in the workshops. These 531 clients resented 9% of all clients served by the Division. One hundred fifty-seven (157) abilition aleman and its in the workshops. habilitation closures were credited to the workshops and these represented 23% the rehabilitation closures achieved by the Division. Of the 157 clients closed as related to the second habilitated, 59% were classified as severely handicapped or severely disabled, 490 were closed as competitive employment workers, and 51% as sheltered employment workers. In FY-1986 the Division is purchasing approximately \$735,000 worth of to-cational rehabilitation services. The minimal expectation is 141 clients closed as rehabilitated.

6. We also purchased vocational and technical training services from other public and private training institutions.



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7 We are working jointly on three projects with the Department of Education and the University of Hawaii. They are the Hawaii Transition Project, to improve the rehabilitation of handicapped students, and the Deaf Blind Project, to improve the rehabilitation of deaf blind persons, with the Department of Education; and the Rehabilitation and Research Training program to improve services to disabled persons in the Pacific Basin with the University of Hawaii.

in the Pacific Basin with the University of Hawaii. Last year, the Services for the Blind program served 891 blind and visually impaired persons.

1. The Adjustment Services Section taught 72 severely visually disabled persons to live more independently through training in such areas as mobility, typing, braille, abacus, personal time and home management, financial management, social skills and recreation. Client survey on adjustment services revealed that 92% were very satisfied and 8% were satisfied with the services provided.

2. The Low Vision Clinic prescribed optical aids for 172 persons to make maximum use of their residual vision for reading and distance viewing.

3. The Workshop for the blind served 46 persons in extended employment. Gross sales totaled \$510,548.

4. The Blind Vending Stand Program employs 30 legally blind and visually impaired persons to operate 31 vending facilities throughout the state. A total gross sales of \$3.2 million was generated during the year. Average annual earnings were \$26,415. Sales tax generated by the vendors totaled \$16,549.

5. The Services for the Blind Program works with and benefitted from a wide range of 27 different voluntary services from 93 volunteers and four groups. Special recognition was given to Hawaiian Electric Company for conducting cooking classes to over 300 blind persons for 35 years. Chinatown Lions Club was recognized for providing a recreational bowling program to approximately 20 persons weekly since 1980.

The Division is committed to continuously improve services to disabled persons in Hawaii. In November 1983 the Management Control System (MCS) was implemented. We are one of 13 state vocational rehabilitation agencies to implement this system. The purpose of this system is to meet the intent of the Rehabilitation Act of 1973, as amended, of providing quality vocational rehabilitation services to eligible persons with disabilities to assist them toward employment.

Prior to program implementation a pre-test case review was conducted. A year later a post-test case review was conducted and the results indicated significant improvement in performance in all areas covered by the program.

To improve services to clients, rehabilitation personnel are trained to keep up to date with changing technology, to learn the latest technique in service delivery and information on improved job development and placement. Training of state agency staff, sheltered workshop personnel and other professional staff in the rehabilitation community are authorized under the Act. We, in Hawaii, depend heavily on the University of Hawaii-Manoa Rehabilitation Program for appropriate and needed training. The University has two basic sub-programs under the direction of the Counseling and Guidance Department of the College of Education. They are the Rehabilitation Counselor Education Masters Degree and the Rehabilitation Continuing Education Programs.

The University, through a sub-contractual arrangement with Rehabilitation Coctinuing Education Program (RCEP) IX, San Diego State University, has been providing continuing education to practitioners in the field such as our agency staff for the past two years. Prior to this other arrangements were possible under prior rules and regulations.

To improve the technical and managerial skills, Hawaii VR managers receive training under the Rehabilitation Administration and Management Programs of the University of Oklahoma. Funds for this program are authorized by the Act.

As you can see, provision of vocational rehabilitation services to handicapped persons in Hawaii under the Vocational Rehabilitation Act of 1973, as amended, has been very successful. Rehabilitation services are provided through multiple approaches by public, private non-profit, and private for profit community based service providers. To improve services to handicapped persons, training of staff and research projects are available under the Act. We feel that the balanced approach to serving and rehabilitation handicapped persons under the Act has enabled u- o rehabilitate thousands of handicapped persons in Hawaii. Because we feel they the Vocational Rehabilitation Act of 1973, as amended, is a good Act, we recommend extension with no major changes.

I would now like to express some of our concerned and neces in serving handicapped persons in Hawaii.



There is every probability that the number of disabled persons will increase as advances continue to be made in the medical sciences in raving lives and extending life expectancy.

At the present time we are serving only 18% of those who need and can benefit from vocational rehabilitation services. This is based on the 1980 census where 38,181 or 5.9% of non-institutionalized and handicapped persons, who were between the ages of 16 and 64 in Hawaii, were identified.

Additional funds are needed to serve persons with brain injuries, psychiatric problems, learning disabilities, severely disabled persons for independent living services and for supported employment services.

We are receiving increasing numbers of persons with brain injuries, especially from the Rehabilitation Hospital of the Pacific, but cannot serve many of them because we do not have the resources to help them become employed.

Twenty-one percent of our caseload are cases with psychiatric problems but there are many more, especially the severely psychiatrically disabled that we are not serving because of inadequate resources.

Of the 2,203 students who are in special education classes and who are 16 years and older 1,469 or 68% are identified as learning disabled. Referrals of students will grow because the special education program has already identified at least 1,000 students in each age group from 9 to 15. At the present time we are serving only 500 special education students and approximatley 10% are learning disabled.

There are approximately 16,955 very severely disabled persons in Hawaii. The independent living programs under Title VII, Part A & B, are serving only about 500 of these very severely disabled persons. There is a great need to serve more of these people including 120 identified elderly blind who are not now being served. Independent living services to the elderly blind, is authorized under Title VII, Part C, but not funded as yet.

Many of these very severely disabled persons can become gainfully employed through services under the independent living program, basic vocational rehabilitation program and through supported employment.

Supported employment services include intensive, on-going support to individuals who are very severely disabled. These persons need this service in order for them to engage in part-time or full-time employment and receive wages above or below the minimum wage. This support is expected to endure throughout the period of employment without which employment would be impossible. Funds for supported employment are needed but there are no funds authorized for this service under the Rehabilitation Act.

We have problems that are unique to Hawaii that created very real challenges for us in the area of staff training. We are an island state, separated by great distances from the mainland. We have differences in terms of culture, economic base and historical experiences. We find that as much as we are dependent on the mainland resources to meet our needs, we may not and do not realistically depend on them. The earlier mentioned factors cause difficulties in timely and substantial communication, coordination and involvement between parties separated as we are. Mainland resources are not always the best or the most relevant to our needs.

Training costs are great for those whose needs are not easily met locally such as mobility specialists, which is a one-of-a-kind specialist, who serve the blind. Also, for the same costs, what may be brought from the mainland are not as richly varied and qualitatively good as we have had from locally run programs. Locally run programs have the advantage also of being able to be very easily accomodating and responsive to change and emergent unanticipated events.

The University of Hawaii's funding through the subcontractual arrangement is a very uncertain and precarious one. We are not sure annually what may be anticipated for the coming year resulting in difficulty in keeping staff and activities going on on a continuing basis.

Hawaii needs a steady and adequate funding source to provide for the unique training needs to continuously upgrade services to handicapped persons.

To serve as many of these handicapped persons, who are not now being served, there is need for increased funding by Congress to provide for individualized vocational rehabilitation services, training programs, research programs, independent living services programs and special projects programs. There is also need for national leadership by the current administration especially in fostering closer working relationship with other human service agencies from

There is also need for national leadership by the current administration especially in fostering closer working relationship with other human service agencies from the national level down to the community level as no one agency can provide all the rehabilitation needs of disabled persons, especially the severely disabled. The current administration is providing this leadership in the school to work transition and supported employment programs.



We feel that the Rehabilitation Act of 1973, as amended, is a good Act in providing a ~ st complete and well balanced approach to the rehabilitation of handicapped persons. We recommend extension of the Rehabilitation Act.

Thank you for the opportunity to appear before this committee. I would be happy to answer any questions.

Mr. WILLIAMS: Thank you, Doctor. Since you began your testimony, our colleague, Cecil Heftel, has joined us. Congressman, it is good to have you with us. As I mentioned to Dan before you came in, we are delighted to be able to accept your longstanding invitation to bring this subcommittee here to Honolulu, and to hear from you constituents.

Mr. HEFTEL. Thank you very much, Pat. I would ask your consent to place my statement in the record.

Mr. WILLIAMS. Without objection.

[The prepared statement of Hon. Cecil Heftel follows:]

#### OPENING STATEMENT OF HON CECIL HEFTEL, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF HAWAII

Thank you, Mr. Chairman, I would like to first thank you and the committee for coming to our Island State to see and hear firsthand what our needs and concerns are in the areas of education for the handicapped and rehabilitation training. We are a long way away from the mainland and particularly from Washington, and sometimes it is difficult to get the attention of those who write and implement the laws.

Although you have only been here for three days, Mr. Chairman, I am sure you have already noticed the mixture of ethnic backgrounds in our State. We are very fortunate to have such a blending of cultures because the end result is an enrichened society from which all of us who live in Hawaii profit. We are proud of our ethnic heritages and of the fact that we can maintain individual lifestyles while at the same time share so many common goals and ideals.

As a result of this uniqueness, it should not be surprising that our problems are sometimes different than those of our fellow Americans on the mainland, and that we must therefore deal with them in a different way. I am sure this theme will underlie the testimony we hear today.

The Education for the Handicapped Act, better known as P.L. 94-142, and the Rehabilitation Act have provided important funds in our state. We have used them to implement programs that help identify those who have handicaps that are not readily apparent; to develop programs or rehabilitate different kinds of handicaps; and to carry out rehabilitation and special education programs. Adequate funding for these programs is absolutely essential. Dollars spent to help people become productive members of society are only a fraction of the costs of having to institutionalize them for what can amount to a lifetime. Our entire society benefits when we can assure all our citizens that they will have an opportunity to lead productive and meaningful lives.

With these opening remarks, Mr. Chairman, I now our witnessees. Again, I would like to thank you and the time to come to our state to hear our needs and work with the committee during the coming months as reauthorization of these laws progresses so that we can assure that this legislation is responsive to and reflective of our continually evolving needs. Thank you.

Mr. HEFTEL And then to share, I think, a thought and understanding that we all have.

About the most efficient way we can spend people's dollars is to make our citizens self-supporting, gainfully participating in the life of their society, community and family. And so even though we have an administration that thinks only in terms of efficient use of dollars, at least in their rhetoric, it is obvious to all of us, I am sure, that when we have youngsters who are handicapped, the most efficient way and also the most humane, the most common sense way to treat those young people is to treat them as potential



individuals who serve fully in their communities, given the kind of training and opportunity they must start life with first.

And it is in this sense that this hearing and the kinds of things being done through the leadership of people like Pat Williams can achieve a better understanding of how we both serve our people and serve our economic needs. If we ignore young people, if we don't give them what they must have to fit into a society and to become gainfully employed, we destine them to a life of inactivity, to a life in which society some way must support them.

There is nothing more expensive than the latter.

I would like to take a moment to share with you the kind of understanding we all gain from our own personal experiences. I lived some 6 months in a hospital and know what all those problems are about, know what hospitals and doctors, the whole medical world, is about. Then I found myself in a position where I couldn't move without help, where I couldn't stand, I couldn't sit, I couldn't do anything without help. I was close to being simply a vegetable. I found out that you can go from the vegetable state to being perfectly normal and fully acclimated in our society. I know that there were times when a lot of people, not because I was so young but because I was so old, said "What are you doing all this for? You are not going to get back to normal, why put yourself through all the grief and pain?

The point being the system-the system-had to pay a lot of money to rehabilitate me. Now I am rehabilitated, but that kind of experience makes you realize what it means if you don't take care of these young people initially.

At some of the rehab centers where I was located I saw young people come in who had been in devastating accidents, who were going to be comatose, were going to be unable to be normal throughout their lifetimes.

There were a couple that acted as though they would never function again, but they were brought down to rehab every day. They were physically brought down. They couldn't move, they couldn't talk, they couldn't do anything. Because I went to the same rehab center twice, when I went back the second time, after I had some additional surgeries, and this was perhaps 7 or 8 months later, one of the young people I saw walk in looked familiar, no longer a shaven head—she originally had had her head shaven—I 'ooked at her, I walked up and I said, are you so and so. She said yes, I am. That young person who could do nothing for herself 9 months

later walked into the rehab room continuing rehab.

Somehow we have got to understand that if we don't spend the kind of money it takes for people to assimilate in our society, we will spend a 'undred times more and they won't be able to function as human beings. So the kind of leadership my colleagues, Mr. Akaka, Congressman Hayes and Pat Williams, are trying to bring to the Congress and administration-is an understanding of why it is economically efficient, and in terms of human values mandatory, that we provide a common sense method of education for our young people who are handicapped, so they can spend a lifetime of participating instead of being a burden on the society, themselves and their families.



I am delighted I am here and I am delighted I have had the opportunity to address you all.

Mr. WILLIAMS. Thank you.

Questions, Mr. Hayes.

Mr. HAYES. Maybe one.

I was just looking at Mr. Nishioka's statement, which is pretty specific. You said there are approximately 16,955 very severely disabled persons in Hawaii, the independent living program under title VII, part A and B, are serving only about 500 of these severely disabled persons.

So there is a great need to serve more of these people, including the 120 identified elderly blind who are not now being served.

I guess you are conscious of the fact what you say, you already were inadequately funded. The prospects of the future, if the administration has its way, it may be you will be in a position to serve less than you are actually serving now, maybe have part of the program which is now being funded with Federal funds completely eliminated.

There is that danger and fear on the part of some of us who are part of this committee. My specific question is, where else do you get money? Are there other sources of funds? I noticed the state supplies a certain amount of money, but there is a cap on that as to-how much did your particular department expend last year or this year in funds and what is needed to continue what you are doing now in terms of dollars?

Dr. NISHIOKA. This past year the program expended \$6 million for rehabilitation of the 726 persons in gainful occupations.

Now, you mentioned the independent living program serving 500 of these people. One of the ways-there are several ways we can attack this problem, although we won't be able to serve all these people. There may be a duplication of services by different agencies; and we are working very closely with other agencies so there is no duplication of services.

And the other area that we are trying to get funds again is through the State. The State Legislature has been rather generous with our program because I think our funding is something like 38 percent State funds and 62 percent Federal funds.

Mr. HAYES. Thirty-eight percent-

Dr. NISHIOKA. Approximately. And 62 percent Federal funds. Mr. HAYES. You are aware of the fact, I am sure, that the Congress, when we reconvene next week, I believe it is, will undoubtedly be discussing the debt limit against a backdrop of Congress' report on the proposed Gramm-Rue nan legislation, which seeks to transfer power, I guess, is the President to devise a ways and means as to which programs should be cut to reach zero debt by either 1990 or 1991.

Given these kinds of discretionary powers and position of the President and what I consider and Members of Congress-I think it is sort of nonpartisan in some respects when you really look at the vote-the insensitivity they have toward these kinds of programs is really presenting a real challenge to those of us who, like Chairman Pat Williams here, are trying to conserve and preserve some of these programs.



The thought and the possibility of maybe increasing the amount of money is almost beyond juestion. What we had hoped to do I guess, is try to maintain as there we can as much of the funds from the Federal Government as necessary in order to continue, which means we got to dig deeper in to some of the private sectors to get the money as a result of our efforts to reduce the deficit.

I thank you, Mr. Chairman.

Mr. WILLIAMS. Mr. Akaka.

Mr. AKAKA. Thank you very much, Mr. Chairman.

Dr. Nishioka, thank you for your testimony. Your testimony reveals that you feel that your programs have been successful.

Mr. NISHIOKA. Yes.

Mr. AKAKA. Yet you have served about 18 percent. Is that 18 percent of those who are handicapped or 18 percent of the population here?

Mr. NISHIOKA. Eighteen percent of the handicapped population. That is based on the 1980 census. These are people between the ages of 16 and 65 and who are not institutionalized, so it comes to something like 5.9 percent of the State population, which is a little lower than the national average. The national average is something like 8.5 percent. So I guess we are healthier people.

Mr. AKAKA. How does 18 percent compare nationally?

about 10 percent of the people:

Mr. AKAKA. So what you are telling me now is 18 percent is above the national norm of service?

Mr. NISHIOKA. That is correct.

Mr. ARARA. I also read where you do coordinate services. You do use other agencies of the State here, and you should be commended for that. I notice also that you have a program that is called the Hawaii transition project—

Mr. NISHIOKA. That is right.

Mr. AKAKA. One of the programs you are working with is the Unive sity of Hawaii, Pacific basin project. What department are you working with in the university?

Mr. NISHIOKA. With the medical school. On the Research and Training Program with the department of education under transition, the blind project also.

tion, the blind project also. Mr. Акака. What kind of services are you providing in that Pacific basin?

Mr. NISHIORA. We are not providing direct services to the Pacific basin, but the fact that with the research project being funded, I met many of these people in the South Pacific, and I found they had great need, so working with them because of their needs, I offered our services.

For example, the people running the Vocational Rehabilitation Program, South Pacific, felt they needed some kind of training, not the kind of training that going to the mainland will help them, but more in terms of down-to-Earth training. So we offered—Samoa took advantage and the Northern Marianas and referred counselors to Hawaii, and I sent them to the island of Kauai to get training in rehabilitation in the rurai area—Kauai—and their they went back, and I am very happy they got that training by our staff in Hawaii.





Mr. AKAKA. You indicate here you are engaged in the rehabilitation and research training out in the Pacific to give services to the people there. My question was, what services are being given by these trainees?

Mr. NISHIOKA. Before Hawaii—the project did provide services in the rural areas for the home care training and also the working on this research and vocational rehabilitation referral system for Hawaii and the Pacific basin. This research project that is going on right now is the assessment of itilization of health services by profound deaf in Hawaii. That is a research project going on, and I am pretty sure once the project is completed, we will be able to follow up on the results of that project.

But as far as all other areas, as to what the Research and Training Center Program is doing, I think the research training people and staff can explain the details of that. I am one of the advisory committee members to the program.

Mr. AKAKA. You are also working with the department of education for the visually handicapped. How many programs do you have in the department of education? Is that a high school

Mr: N'SHIOKA: We have at the present time a work-study program that we are working on with the department of education. This is where we work with the secondary education people in the high schools from age 16 and over, students, to help them from school to work. So we work with the school to—while they are still in school with the counselors involved and help develop the UP [Individual Education Program]. So they gain work experience in school on campus and during the senior year of causius, and they take over from that point on:

But we found that there is a lot of severely discound students that under the present Rehab Act you have to have a vocational potential. Many of these people don't have the potential so, therefore, these people are more or less falling in between the cracks.

Again, through the transition program we are trying to develop a system where we can call different agencies involved. Again, this is where we are tryin o save money too. At the present time, the students go through the school system; and when you get the students after they graduate, we have to do another evaluation in a workshop. What we want to do is develop a system within the school so they can do this work evaluation within the school system.

Then, again, to do that, you have to have all the policy changes made within the DOE, and that is why this project is getting the members from the board of education, the superintendent's office, and all the different agencies together to kind of look at this—to be part of this research project and demonstration project so that the policy changes can be made so that the students can receive better services faster and better quality services, too, by all the different agencies working together. Because no one agency can do the work.

Mr. AKAKA. I thunk you very much, Dr. Nishioka.

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Mr. WILLIAMS. Cecil.

Mr. HEFTEL. Thank you:

<u>Doctor, I think it is important to continue from right where we</u> are at now: Do you feel that we are maximizing our economic assistance and our available programs in the sense that the individ-



ual dealing with one source and one contact is able to receive all of the training and all of the assistance needed? Are we forcing the individual to go to different agencies to deal with different people and to actually add both to the cost and inefficiency of the pr gram we are administering?

As an example, when a student is in school, do we conduct the programs in such a way that everything that needs to be done goes through the school so that the student has no reason to go anywhere else or the assistance needed, and is that what you are trying to achieve is what you are just telling us?

Mr. NISHIOKA. I lost your-

Mr. HEFTEL. If you are a handicapped student of 16 and you go to a high school and we have provided the funding, transportation and the ability to participate in the school system, is the system structured so that a handicapped child receives all of the assistance he or she needs, all the training he or she needs, through the auspices of the school he or she attends as opposed to having to go to other agencies to do it?

Mr. NISHIOKA. The student dcesn't get all that from the DOE, and we again try to coordinate services.

Mr. HEFTEL. Yes. But, in other words, are we set up so that regardless of who provides the service, once you are involved with the school system, the school system takes over responsibility for coordinating and making available to the student all of the assistance needed, or does the student have to go to other offices, to other places to deal with other people?

Mr. NISHIOKA. That is the system today.

Mr. HEFTEL. And you are telling us that is inefficient? Or at least I would think you would be telling us it is inefficient.

Mr. NISHIOKA. I wouldn't say it is inefficient. I think we try to have one agency take over everything, but because—I guess they call it turf—different funding scurces to run the program, and, therefore, coordination has been a problem in the past.

But it would be good——

Mr. HEFTEL. Is it still a problem?

Mr. NISHIOKA. It is still a problem, but it is something that can be resolved, and this is where we are working cooperatively with all agencies—when I say many agencies, there is a lot of agencies like the department of education, vocational rehab, there is private agencies in a community that is involved, the parents are involved, that we all need to work together cooperatively.

Mr. HEFTEL. Well, of course, 1 am trying to take it from the standpoint of the student. That person should theoretically be able to go to one institution, to one type of service center, and particularly if that individual is already going to a public school. It would seem that we would want all of what that student needs to be made available through the single source or contact on the part of the student. Who coordinates it, what is done to efficiently present it to the student makes no difference to that student.

But the moment the student has to go to multiple locations when we are still talking about coordinating a single source, I think we are losing time and money, and I think we are not maximizing what we can do for the student. I guess my question to you is: Do you think that we need a change in the way handicapped programs



are administered, particularly where the student is at an age bracket where they would be in a public school, so they can get all of what they need from a single source?

--Mr. Nishioka. If you can do that, that would be fine. But at the same time, dealing with the present setup—let me explain it. The special education long-range program in this area, I guess, is to have a coordinator who will-

Mr. HEFTEL. Let me ask you: You are talking about something in the future. Is what, what we have in place, or the future?

Mr. NISHIOKA. No, it is no place, it is in the future. Mr. HEFTEL. So for howeve hany years, 30 years or 40 years, 20 years, 10 years, 5 years, any timeframe you want to use, with the knowledge that was needed-we have never done it as of this date, is that correct?

Mr. NISHIOKA. That is correct.

Mr. HEFTEL. Do you think it is coming quickly now, or do you think it is still in the discussion stage for a long period of time? Mr. NISHIOKA. It should be-it is in the discussion stage at the present time, but I think it would be dependent at the same time, again, because of the mancial crunch. We have to still come up with some alteractive ways of doing what you suggested over there:

Mr. HEFTER. There isn't any more efficient way to do it than that?

-Mr. NISHIOKA. We recognize that, so that is why it is recommended somebody within the system must follow the person right through the system.

Mr. HEFTEL. If what you are telling me is we have a financial crunch, it would seem, Mr. Chairman, that is all the more reason why we have to do this. Because we can't affer t to lose any dollars of assistance through duplication, and additioned in the system, and also because of the way the system responds and reacts to the recipient. I think it is very devastating constimes to expose the resipient to multiple forms of direction, contact and different locations.

Again, drawing on personal experience, everything I had to do was under one roof, it is a good thing. I don't know how I would have survived otherwise. So I just think it is something we need to be aware of, namely that Federal funding, with State funding, with multiple-State agencies, doesn t necessarily produce the most effient use of the dollar or most effective service to the recipient.

I am glad that you mentioned we uld be doing it. By the same oken, it is a little distressing to remize we are still only talking about it. Thank you very much.

Thank you, Mr. Chairman.

Mr. WILLIAMS. Doctor, thank you for being here and providing us vith your testimony and answering our questions.

Mr. WILLIAMS. I will now ask the second panel to come forward: Jean Rogers, Dr. Izutsu and Dr. Okamoto.



### STATEMENTS OF TERENCE A. ROCERS, DEAN, SCHOOL OF MEDI-CINE, AND PRINCIPAL INVESTIGATOR, REHABILITATION RE-SEARCH AND TRAINING CENTER; SATORU IZUTSU, CODIREC-TOR, REHABILITATION RESEARCH AND TRAINING CENTER; AND GARY OKAMOTO, CODIRECTOR, REHABILITATION RE-SEARCH AND TRAINING CENTER

Mr. ROGERS. I am Dr. Rogers: With your permission, I would like to follow the other two witnesses because that is the format of my testimony:

Mr. WILLIAMS. That is fine. Why don't you take the table with them, and we will call on you last.

Dr. Izutsu and Dr. Okamoto are codirectors of the Rehabilitation Research and Training Center. Dr. Rogers is the dean of the school of medicine and principal investigator of the Rehabilitation and Research Center. Let's start with you.

Mr. Izutsu. We will start with Dr. Okamoto, if you don't mind. Mr. WILLIAMS: We will do it any way you fellows want to do it.

Dr. OKAMOTO. Congressman Williams and members of the Subcommittee on Select Education, on behalf of my clinical and administrative colleagues, I wish to thank you for this opportunity to describe the impact of the Rehabilitation Act of 1973 on the development of comprehensive rehabilitation to the severely disabled in Hawaii and the Pacific basin.

Supported by the Division of Vocational Rehabilitation, State of Hawaii, and justified by the Rehabilitation Act of 1973, the Rehabilitation Hospital of the Pacific received public moneys to modernize its facilities in the late 1970's. This and other major contributions fueled an ambitious building program that ended in 1984.

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Since 1953, the bospital has admitted and discharged over 20,000 disabled patients and currently averages 800 admissions per year. The mean length of stay, 30 days, is nearly 2 to 3 weeks lower than the late 1950 averages. About 95 percent of patients who complete the inpatient program return home and thereby avoid long-term institutionalization. This extraordinary record is the result of our referring acute modical surgical hospitals and physicians who support medical rehabilitation.

- Inpatients represent <u>Biosters</u> discreters and disabilities that reflect an aging, trauma-prone society. Stoke accounts for 40 percent of admissions; brain injury, 15 percent; spinal cord injury, 15 percent; complicated fractures, artificial joints—prostheses—and amputations, 20 percent; and other impairments of the neurologic, skeletal or muscular system, 5 percent.

Eighty to eighty-five percent of patients live in Oahu; 10 percent, neighbor islands of Hawaii, Kauai, Lanai, Maui, and Molokai; 1 to rcent, Micronesia and American Samoa; and 1 percent, mainland United States. Fifty-five percent of patients are 65 or older;

and 3 percent, under age 20. Fifty-three percent are males. Ethnically, part-Hawaiin and Hawaiian patients comprise 12 to 13 percent of patients admitted. Over 80 percent of other patients



are Caucasians, Japanese, Filipino, and Chinese. While native Hawaiians as a group are not under- or overrepresented, at this time, their rate of involvement in each category of physical disorder or disability is not yet known.

Directed by a physiatrist or a physician specialist in medical rehabilitation, an interdisciplinary team evaluates and manages the acute disabled patient. The team's primary goal is returning the patient home through maximizing the patient's potential to ambulate with aids, care for self, communicate vorbally or nonverbcontrol bladder and bowel, prevent pressure sores, maintain sound nutrition, practice safety techniques, adapt recreational activities, and adjust constructively to disability. Thus, the team facilitates a patient's functional recovery to live as independently as possible.

In addition to the physician specialist, the interdisciplinary team consists of rehabilitation nurse, occupational therapist, physical therapist, speech and language therapist, clinical psychologist, prosthetist and orthotists, recreational therapist, nutritionist and vocational evaluator. A rehabilitation engineer, unfortunately, is not yet on our roster. The relative involvement of each team member varies from patient to patient, disorder to disorder, disability to disability.

Reclizing that the transition from hospital to home was in itself a unique phase in medical chabilitation, the Rehabilitation Hospital of the Pacific established a comprehensive outpatient center in early 1984. It brought the specialized, intensive, comprehensive interdisciplinary management of inpatients to the outpatient setting The discharged patient was assured of continuity in rehabilitation. It also enabled the staff to offer other patients quality rehabilitation without costly hospitalization.

In its newly remodeled facility, the outpatient center has a kitchen and bathroom for patient and family training; artificial limbs and braces for amputee and paralyzed patients; biofeedback and computerized devices for speech therapy, muscle relaxation, cognitive retraining and motor reeducation; and other equipment replicated from the inpatient therapy units.

On a smaller scale, a satellite clinic was set up in late 1984 to better serve the densely populated, rapidly growing area west of Honolulu. The demand was unexpectedly high and led to a doubling in size, staffing and services.

While the comprehensive outpat: ...t center and satellite clinic account for over 20,000 visits per year, neither meets the special needs of disabled patients who were injured on the job and whose goal is to return to work. Unlike most inpatients, these patients tend to suffer from injuries to the low back, upper back, neck, shoulders or hands.

Other young adults disabled by accidents or diseases may sufficiently improve from inpatient or outpatient rehabilitation and be ready for prevocational evaluation in anticipation of gainful employment eventually.

These patients require a different order of specialization in staff, facilities and  $\epsilon$  upment for evaluation and treatment. Furthermore, for individualized restorative plans to be efficacious, the input of employers, insurance payors, labor unions, and workers' compensation coordinators is critical.



Recognizing this special population of disabled patients, the Rehabilitation Hospital of the Pacific established the Injured Workers' Center in early 1984. Currently over 1,000 patient visits a month occur in the center's newly renovated facility. Interestingly, 20 percent of them are related to hand injuries and the majority; low back pain.

A disabled patient may participate in one or more of the following services: physical evaluation, multimodality treatment, work hardening, work capacity or tolerance, back school, injury-prevention and vocational assessment. Its state-of-the-art technology is different from the equipment and techniques utilized in the inpatient and other outpatient programs. Aided by a computer bank, a patient's comprehensive work profile can be matched with specific jobs:

Complementing the Injured Workers' Center is a newly organized chronic pain program with inpatient and outpatient services. Based on the most current model for pain rehabilitation, the program uses cognitive and behavioral techniques to teach pain management skills, increase physical activity, reduce dependency on medication, decrease frequent physician and health care utilization, improve spousal relationships and prepare for return to work.

Other resources are available to the staff and patients at the hospital: the heated pool for therapy, the greenhouse for relaxation; the outdoor mobility course for exercise, the sports court for wheelchair recreation, the driver's simulator for handicap driving, the electrodiagnostic laboratory for neurophysiologic assessment, the urodynamic laboratory for testing abnormal bladders, and the volunteer program that involves over 47,000 hours of time unselfishly donated by nearly 700 lay-volunteers annually.

A system of patient consultation, professional education, and program development on the neighbor islands of Hawaii has begun: Presently, physiatrists or specialists in rehabilitation lecture physicians and evaluate patients on Kauai, Maui and Hawaii. Under contract, physical therapists regularly visit Kula Hospital in rural Maui.

The Rehabilitation Hospital of the Pacific has a public responsibility to train and educate professionals. Our educational events have nearly quadrupled in the past 2 years and audiences have come from a wide spectrum of health and human services. The hospital clinical staff has intensified its collaboration with other community professionals and organizations to improve the relevance of its educational participation. The hospital is a major training site for virtually every professional discipline in clinical rehabilitation in the State of Hawaii. Rotation through the hospital is, in fact, a mandatory part of the medical school curriculum.

Research and training as a priority was given a significant boost by a cooperative agreement between the John A. Burns School of Medicine and the National Institute of Handicapped Research in March of 1984, due largely to the leadership of Dean Terence Rogers: A major Rehabilitation Research and Training Program in the Pacific basin was thus established and will be described in detail by my colleague, Prof. Satoru Izutsu, Ph.D. Officed at the hospital, the R?&T program has already enriched the clinical staff and environment in the spirit of the Rehabilitation Act of 1973.



In conclusion, the Rehabilitation Act of 1973 has had a profound effect on the historical development of the Rehabilitation Hospital of the Pacific and the role of medical rehabilitation in vocational services and independent living for disabled peoples in Hawaii and the Pacific basin.

Our message to the Subcommittee on Select Education is clear. Your congressional colleagues need to understand that modern medical rehabilitation is a powerful method by which disabled citizens can return to societal productivity by avoiding long-term institutionalization, by living at home or in a group residential setting and, when appropriate, by working at a paying job.

In part, through your subcommittee's support, we can meet the challenge posed by the Rehabilitation Act of 1973 with innovation and dedication.

[The prepared statement of Gary A. Okamoto follows:]

#### "REPARED STATEMENT OF GARY A. OKAMOTO, MD

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patients and two outpatient programs for special populations of chronically disabled patients. It is the only medical rehabilitation facility within the Pacific Rim. Since 1953, the hospital has admitted and discharged over 20,000 disabled patients and currently averages 800 admissions per year. The mea. length of stay 30 days, nearly two to three weeks lower than the late 1970 averages. About rinety-five percent of patients who complete the inpatient program return home and thereby avoid long-term institutionalization. This extraordinary record is the result of our refer-ring acute medical surgical hospitals and physicians who support medical rehabilitation.

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Ethnically, part-Hawaiian and Hawaiian patients comprise 12-13% of patients ad-mitted. Over 80% of other patients are Caucasians, Japanese, Filipino, and Chinese. While Native Hawaiians as a group are not under or over represented, at this time. their rate of involvement in each category of physical disorder or disability is not yet known.

Unlike acute or emergency care in which patients may be passive partners during diagnosis and treatment; rehabilitation is a participatory process. Cultural and language differences can be formidable for the non-English speaking patient and the English-speaking. American-trained clinical staff. In fact, the medical rehabilitation paradigm itself may be culturally bizarre to the patient and family. We know that this issue of communication and appropriate rehabilitation deserver more of our at tention.

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That even subtle fiscal reforms proposed by the Health Care Finance Administration can potentially annihilate comprehensive medical rehabilitation and secondarily adversly impact on vocational and independent living programs.

That research and training can generate solutions to perplexing problems we face with our disabled citizens. To the extent that all of us in this room have, are, or will suffer from one of more disabilities and experience significant handicap in our life time, we will benefit from the governmental and private investment in research and training.

Finally, that our geographic and cultural diversity create unique problems that are not readily solved by formulas effective in cities on the mainland. We, however, do not possess all the resources and look to the federal government for assistance. In part, through your Subcommittee's support, we can meet the challenge posed by the Rehabilitation Act of 1973 with innovation and dedication.

Mr. WILLIAMS. Dr. Izutsu.

Mr. Izursu. Congressman Williams and members of the subcommittee, as Dr. Okamoto mentioned, the Pacific Rehabilitation Research and Training Center began in 1984, and it is housed at the Rehabilitation Hospital here in Honolulu. At this time on behalf of the rehabilitation community, I would like to thank you and your subcommittee for your efforts in the establishment of the R&D Center in the Pacific.

My oral presentation will include four areas: One, orientation of the areas (the Pacific we have been mandated to serve, major findings to ite, training and research projects we are undertaking, and recommendations. We serve Hawaii, Guam, American Samoa, and Micronesia. For today's presentation, I will concentrate on Micronesia, which is the most complex of the areas covered by the Pacific R&T Center.

There are approximately 2,100 islands throughout Micronesia. And these 2,100 islands, only about 100 are inhabitated. We cover over 2 million square miles, mostly ocean. The population, excluding Guam and Hawaii, is 165,000 plus, and this includes American Samoa, the Federated States of Micronesia, the Republic of Belau, the Commonwealth of Northern Marianas, and the Republic of the Marshal Islands.



This gives an illustration of the expanse that we cover. Hawaii is on the top here. Samoa is on the bottom here, Guam is here. The Pi. lippines is only about 500 miles due west of Belau. We are located between the latitudes 0 to 20 degrees north and latitude 130 to 170 degrees. To show a better perspective of where we are, this is Australia, Japan is up here. Philippines is here, and this is the area that we cover.

- My plane, it takes 15 hours to travel from here to Saipan with all the intermediary stops. Our eight-person a lvisory committee is composed of representatives from each of the jurisdictions, and as Mr. Nishioka mentioned, he is a member of that advisory committee.

The major findings to date are as follows: For example, health manpower, there is lack in all categories. Doctors, we have just 0.64 for every 1,000 population. That means we have 106. Nurses, we have only 6,900, which is 3.6 for every 1,000. Physical therapists, for example, in Micronesia, we only have one, and she is about ready to retire next year. We have a prosthetic technician who lives on Majuro, and he was trained in Honolulu many years ago.

The disabled population. Accurate statistics of the prevalence of disabilities aren't available. The numbers recorded by the various agencies have been collected but do not reflect population prevalence. However, it is known that certain prevalent conditions, such as otitis media and meningitis cause disabling conditions.

In addition, it has been well established chronic conditions, such as diabetes, heart conditions, alcohol and drug abuse, hypertension, stroke and pulmonary problems, all on the increase in the Pacific, are affected by the rapidly changing social, cultural, and economic factors which, in turn, have implications for rehabilitation.

Services Hawaii and Guam have rehabilitation services comparable for the most part to the United States, mainland United States, and in Micronesia and American Samoa there are a combination of services, such as public health, programs for the elderly, vocational rehabilitation, special education, Head Start, and there are international services which are provided by WHO, the South Pacific Commission and UNICEF is in the planning stages of offering services.

Some of the special considerations in providing rehabilitation services in the Pacific Islands are, for example, the median age is only 17.1 years. Fifty percent are under 20 years of age. There is relocation of working age percentages from remote islands to urban centers, which are causing family and societal disruption. It is a subsistence economy with high ut employment among the well population. Politically, all areas are going irrough political reorganization, and each one is trying very hard to become independent of the United States.

Culturally, it is multilingual and multicultural. There are at least nine separate distinct languages. And we are always cognizant of the fact Micronesia has been occupied by four different countries since the time of Magellan—Spain, Germany, Japan, and now the United States, each superimposing its cultural characteristics.

In the health and medical area, there are serious sanitation problems, there are indigenous health practices, there are dietary



changes leading to the increase of certain conditions. For example, diabetes was rare in 1940; it is now a leading cause of amputation. Leprosy is epidemic in Somoa, chronic otitis media is common, leading to hearing problems. Common dental eye disease, such as acromyopia, is prevalent.

Alcoholism and drug abuse are very serious problems in most areas today. There is increase in accidents due to the introduction of motor vehicles. For example, this is one of the leading causes of hospitalizations in the Feder ited States of Micronesia.

Now, in the area of rehabilitation, there are some factors we live with. There is a low priority of rehabilitation for Government funding, there is a lack of coordination of efforts between agencies dealing with rehabilitation, there is a local belief that off-island treatment is better than local treatment, there is a lack of respect for instruction provided by local trainers where off-island instructors are valued.

There is an expectation of the elderly and the ill, that their family will provide. The rehabilitation is seen as probably unnecessary work. There are environmental barriers to mobility of the disabled. To address the above findings, the following programs have been implemented since our beginning a year ago, and here are the examples of the research and training.

I would like to address—I would just go down very quickly and address two areas. In the research area, the satellite communication, client tracking, multiagency rehab data system, and vocational rehab, medical rehab, special education referral systems and assessment methods, prevalence of disability, and utilization of services by the profoundly deaf and the study of Hawaii's elderly, over-88 Japanese.

In training rehabilitation technicians, home care training, care for the elderly, continuing education of physicians in rehab, the use of satellite equipment and computers and the proper use, care, and storage of autolaryngeological equipment. The two that I would like to address in this listing are the satellite communication. We have installed now a number of stations throughout Micronesia. Nine stages are upgradec ... nd we have created three new stations.

With the use of ATS-1 it was possible to have voice and hard copy communication from far away, because all of these areas are equipped with computers. The ATS-1 is down. We have been working with Senator Inouye's office in trying to get to NASA to see whether the have time on another satellite that they are presently we the hope that that system will be up by the end of the pring of 1986. That would then mean that medical emergencies as well as followup, conference calls, and continuing education, can be conducted through these satellites.

In the area of training, we have concentrated in training renabilitation technicians to be trained in occupational therapy techniques, in place, in location, so they need not travel to Honolulu or the mainland to be trained. The areas that we have been training and looking at are pediatric rehab, family training so that in the remote islands, which is sometimes days away from the main urban hospital home care training and adult rehabilitation and with great concentration on the use of locally available material, and in most cases what we try to do is be technologically appropri-



ate so that the expense of importing material and equipment will not be so high.

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As I mentioned, we have been concentrating on home care training because of the remoteness of some of the outer islands. We feel that essentially what we will need to do is really train the family members to care for their handicapped on their islands and in their homes.

In conclusion, then, the Pacific Rehabilitati n Research and Training Center is in its second year, emphasis has been placed on having the representatives of the people in the Pacific area identify their needs and priorities relating to improving services of disabled persons through rehabilitation research and training. It has become evident a program, such as R&T centers, is essential in filling some of the gaps in the continuum of services from a disabling condition to becoming deinstitutionalized of the mentally retarded into less restrictive environments, the transition from inpatient rehab services to the home, the rapidly increasing cost of all types of rehabilitative care, and the disproportionate numbers of handicapped individuals who encounter difficulties with the legal system.

The following is recommended to the Subcommittee on Select Education: One, to continue the R&T initiative in the Pacific basin. This program could be a vital link for the Micronesian disabled in the transition from trusteeship to free association with the United States.

Two, to encourage Government agencies and programs to increase their efforts and coordination communication to avoid duplication and strengthen outcomes by combining resources.

Three, to promote the monitoring and dissemination of federally funded program outcomes so that all may benefit; and, finally, four, to continue to be sensitive to the advice of resident professionals and lay persons who can provide direction in defining culturally relevant, technologically appropriate protocols which vary so widely in Guam, American Somoa, Micronesia, and Hawaii.

[The repared statement of Satoru Izutsu follows:]

PRET CRED STATEMENT OF SATORU IZUTSU, PH.D., CODIRECTOR, THE PACIFIC REHABILITION RESEARCH AND TRAINING CENTER, JOHN A. BURNS SCHOOL OF MEDICINE

#### INTRODUCTION

The Pacific Rehabilitation Research and Training Center began on March 1, 1984 under a Cooperative Agreement between the Department of Education (National Institute of Handicapped Research) and the John A Burns School of Medicine at the University of Hawaii.<sup>1</sup> Rehabilitation activities at this Center are related to medical rehabilitation, vocational rehabilitation, and special education.

The goal of the Center is to improve rehabilitation services for handicapped persons in the Pacific through innovative, culturally relevant, and technologically appropriate research and training. Also emphasized are the development of: a sound data base, appropriate manpower, improved communication, interagency cooperation, and standards for evaluation of programs.

Within the broad goal, priorities are recommended. r the Pacific Basin by an eight member advisory committee composed of representatives appointed by the respective chief executive officers from each involved political entity. When setting



<sup>&</sup>lt;sup>1</sup> The Center is located at the Rehabilitation Hospital of the Pacific. This has furthered the relationship of the University with a community-bas. I teaching institution especially devoted to the rehabilitation of the physically handicapped.

policy or planning and implementing programs for the diverse Pacific areas, unique political, demographic, cultural and medical factors are considered with input from the areas of concern. A copy of the RR&T brochure is attached. Following is the annotated list of activities undertaken to date by the Pacific RR&T Center since its inception in March 1984.

inception in March 1984. The Pacific RR&T Center is responsible for an area which covers 2 million plus square miles, mostly ocean. There are over 2,000 islands inhabited by approximately 1.3 million people. Only 165,000 plus people live on 100 islands outside Guam and Hawaii. There are about 110 doctors 610 nurses, 19 vocational counselors and aides, 5 physical therapists and aides; 6 occupational therapists and aides, 1 speech therapist, 247 special education techers and aides, and 1 prosthetic technician outside of Hawaii and Guam. Disease which commonly cause disabilities are otitis media and meningitis, diabetes, hear structions and hypertension, alcohol and drug abuse, stroke, pulmonary problem. And leprosy.

When the Center began, the Advisory Committee determined that initial efforts will be in Micro resia where there is a dearth of rehabilitation services.

The findings ... Micronesia to date can be summarized as follows:

There is a lack of indigenous manpower trained in rehabilitation.

It appears that rehabilitation programs have had low priority for government funding.

Coordination of services provided by agencies involved in the various aspects of re habilitation needs to be examined for effectiveness.

There is the expectation of the elderly and the disabled that the family will provide and that rehabilitation is unnecessary

There is a lack of respect for instruction provided by local trainers who may be able to teach rehabilitation techniques to others after their own training.

Off island instructors and off islands treatment are valued

Whatever training is conducted must allow for repeated demonstration and practice of the task(s) to be mastered.

One time experiences or reading about techniques do not seem to result in learning

Material and equipment utilized ordinarily in the U.S. mainland and Hawaii do not survive the harsh tropical weather as well as the terrain of the atolls and islands of the Western and South Pacific.

#### L TRAINING .....

Training is a major emphasis of the Hawaii RR&T Center because a significant obstacle to effective rehabilitation ii. Micronesia is the lack of trained, skilled rehabilitation workers (physicians, OTs, PTs, vocational rehabilitation counselors and administrators, special education teachers, speech therapists, signers, audiologists and prostheticists).

#### A. Rehabilitation training programs

The RR&T has initiated two training programs to address the manpower needs of the Pacific Basin, especially in Micronesia—the training of rehabilitation technicians and the training of nurses in home health care.

On these islands, hospital stays are short largely due to the preference of the patients to be treated at home rather than in the hospital. Patients, once discharged from the hospitals, are usen unable to return to the clinics for rehabilitation services either due to the lack of transportation and/or their homes are on remote outer islands. Therefore, the availability of individuals trained in basic rehabilitation services is essential for assisting the family in providing programs initiated during the in-patients stay.

Four students have completed the first rehabilitation, technician training course and are now operating clinics in the islands of Belau, Pohnpei, Majuro and Ebeye. Twenty-five nurses of the Federated States of Micronesia have completed the home health care training program. These training courses are scheduled to be replicated in the other states of Micronesia in 1986. By October 1986, nurses on each island will have received training in basic rehabilitation techniques and there will be an RR&T trained rehabilitation technician to function as the "Master" rehabilitation provider.

The trainees have come to the training program with varied backgrounds. Some have had previous paraprofessional training, others have had no medical training. Generally, previous medical experience has focused on acute care. Because there is a lack of knowledge in the islands on the importance of rehabilitation, these concepts have been included in the RR&T training plume. In addition, in-service train-

ing on the general philosophy of rehabilitation and the role of the reliabilitation technician have been given to service providers who would with the disabled in the hospitals, health clinics and the community.

#### B Care for the clderly

This activity was initiated by Neighbor 'sland ("tral) professionals in Hawaii who requested training of health workers and lay person. In the care of confused and impaired elderly persons. (The proportion of persons 65 years old and older in Hawaii is increasing more rapidly that in any other State).

The RR&T Center funded a team of professionals who were already conducting monthly presentations on aspects of elderly care on Oahu under the auspices of another agency to repeat the programs on the Neighbor Islands. Plans are for professionals to make presentations at community meetings on Maui, Kauai two areas of the Bir, Island, Hilo and Kona. When feasible, the programs are videotaped for future use.

#### C. Continuing education for physicians in rehabilitation

Continuing education of physicians on rehabilitation topics is ongoing by the RR&T. The Medical Director and other specialists participate in continuing medical education activities in Hawaii (Oahu and Neighbor Islands), American Samoa and Micronesia. Subject matter covers a broad range of the assessment and management practices in rehabilitation and is tailored to the levels of expertise and needs of the various areas. In addition to physicians, training is offered to physical therapists, occupational therapists, speech pathologists, special education teachers, clinical psychologists and social workers.

#### D. Proper use, care, and storage of stolaryngological equipment

This activity was planned to assess the status of otolaryngolopical equipment purchased for Minume 10 years ago. Six locations were selected for assessment and recommendation an, Yap, Truk, Pohnpei, Majuro, and Belau. A qualified operating room nurs in the Queer's Medical Center, Honolulu traveled to these locations to assess condition of the equipment. Following her recommendations, RR&T provided the hospitals with myringotomy sets and audiometers and sont a nurse qualified in otolar mogological procedures to conduct inservice training for the personnel assigned to care, maintain, and account for the instrumen's. A maintenance procedure manual was also developed for each of the Micronesian hospitals for instructional purposes with an audiotape recording of instructions.

#### II. RESE

### A. Pacific micronet-Satellite communication

A major priority established by the RR&T Center Advisory Committee was to improve satellite communication capabilities in the Pacific which would facilitate planning, coordination and implementation of health and educational activitie. The satellite will be used for continuing education, and planeting of individual health programs for disabled persons as well as for expediting action in medical emergencies. With the assistance of persons in the Pacific areas with satellite expertise and experience, a comprehensive plan was developed for upgrading the system.

Nine stations were upgraded and placed in operational order. Stations in areas where electrical power is unpredictable were provided with solar power panels. Eleven stations were equipped with computers and printers for sending and receiving hard-copy messages and three complete, new stations were installed. The nine improved stations are in Guam, Saipan (2), Kosrae, Belau, Yap, Majurio, Truk, and Pohnpei. The three new stations are at the Guam Memorial Hospital, LBJ Tropical Medical Center in American Samoa and the Rehabilitation Hospital of the Pacific in Honolulu.

The RRST Center has assisted in two training efforts in the use of 'he satellite and computer equipment. The first was held in Guam, February 25-28, 1985 and was a joint effort of the Western Pacific Special Education Consortium and the University of Guam. The second was conducted by a consultant who trained the satellite operators in each location. The RR&T is presently engaged in conducting evaluative research on use of the satellite system (Micronet) before and after the system upgrade. The RR&T is also active in alerting key persons in Washington regarding the importance of this type of communication in the Facific and it requesting that alternatives to replace the ATS-1-satellite be explored. Recently, Senator Daniel Inouye of Hawaii has notified the RR&T Center of NASA's continuing efforts to establish communication routes related to available satellite, in the Pacific.



#### B. Rehabilitation client tracking system

The Data Tracking research project has been initiated in the Federated States of Micronesia and is being conducted by the Community College of Micronesia. A faculty member of the Special Educat on Department is coordinating project activities. The initia' objective is to establish a unique client identification method to facilitate tracking disabled children so they will not be lost to services. This projec will bring together special education, vocational rehabilitation and medical rehabilitation data into or e, computerized data base.

#### C. Vocational rehabilitation, referral system/assessme - ethods

The goal of this study is to describe and refine both the referral and the evaluation processes of the vocational rehabilitation system in the Pacific Resin. This critiques of vocational rehabilitation practices on a national level super trias against island populations. Because of multicultural sattings within a fit Basin; separate territorial profiles are being developed to provide inform at is relevant to the local cultures: Where appropriate; this includes the development of local norms on select psychometric instruments and interview protocols for functional assessment. This study being implemented by professionals at the Injured Worker Center of the Rehabilitation Hospital of the Pacific.

#### D. Medical rehabilitation, referral system/assessment methods

This completed study (September 1985) explored the mechanisms b, which patients from the various Pacific areas are referred to Honolulu for medical reliabilitation. The study describes the system a it is operating today and identifies gaps in service and possible solutions to problems. The study outlined problem areas in the referral system including: high costs, poor documentation and follow-up, lack of communication between physicians, inappropriate equipment and unrealistic recommendations for the care of rehabilitation clients and lack of understanding of the role of rehabilitation among Pacific area professionals. Because of the above constraints, people who could benefit from rehabilitation services do not have the opportunity to reach their potential stage of recovery. The Medical Referral Clearinghouse of Region IX Public Health Services which is being installed at a Hawaii hospical is a proposed partial solution to some of the problems of referral. However, the level of funding and the planned duration of the project seem limited.

#### E. Special education, referral system in Hawaii

This study will design, develop and implement research to describe the Special Education referral system in the State of Hawaii. Methods and patterns of referrals will be analyzed to identify gaps in service or failures of the referral system. Alternative ways to conduct referrals will be recommended, if needed. This began November 1, 1985 and will take approximately four months to complete.

#### F. Prevalence of disability in Hawaii

The RR&T is collecting data on the prevalence of disabilities in Hawaii and elsewhere for use as basic; background material for its various projects. One project involves obtaining the Department of F the Surveillance data on impairments. The first study is an aggregate of data iro disability prevalence at three points lence changes over time. A specialist the RR&T.

#### G. Utilization of services by profoun \_\_\_\_\_ deap

This assessment began in the summer of 1985 and the continue through December to survey of the profoundly deaf in Hawaii will scribe their service unit tion attents and determine if they underutilize the user is trypothesized. I omit, dations for solutions will be provided. The survey is a face-to-face interview by specially trained deaf interviewers. The researcher for this project is a graduate student at the University of Hawaii and a certified signer.

#### H. Study of Hawaii's Japanese well elderly

The Well Elderly research is investigating a ramdom sample of 1025 first Japanese immigrants to Hawaii and comparing them to a similar population in Japan. It will examine physical and social/behavioral issues related to longevity in two groups. It is anticipated that the findings may provide clues to factors related to life styles in an ethnic group which may promote healthy, long lines.

#### I. Risks of hip fracture in the elderly

He and ther fractures are leading causes of pain, fear, restection of activities at the rmong older persons. This is a collaborative effort with the Osteoporosis Cent in Rawaii which is partially funded by the National Institute on Aging (NLA, The research will study bone mineral content of elderly persons with fractures. The purpose is to establish baseline data which will lead to an a and specific indicator of hip fracture risk and to the development of pressive

interventions: The current NIA funding does not provide for this in portant in N-01gation. The project will begin in RR&T Year 02 and extend to Year 03.

#### J. Hawaii spinal cord registry

The RR&T and the Rehabilitation Herbital of the Pacific are collaborating to ur date and re-establish a Spinal Cord Registry. Will provide important knowledge on: course of recovery, associated comprisations, treatment comparisons relating to length of hospitalization, estimated comparative costs and demographic data for planning. The data will be used by practitioners, researchers, planners and administrators.

#### K. Managers of group homes for men ally retarded

The Department of Housing and Urban Development and the Association of Retarded Citizens (ARCH) are constructing new homes on Oahu and Kauai (for 73 retarded persons who will be discharged from the State institution for the mentally retarded) but there are no qualified home managers. This RR&T project is a collaborative effort with ARCH in which a competency-based corriculum will be developed and training will be conducted for managers of group homes for the mentally retarded. Thirty home minagers and day treatment personnel and one inter-disciplinary team will complete the preliminary training. The project will begin in RR&T Year 02 (1985) and continue into Year 03 (1986).

#### L. Uniform actional data system

This project is part of the validity and reliability study of the data system and assessment instrument developed by the NIHR funded tash force in Buffalo. New York headed by Carl V. Granger. This is a collaborative effort in which RR&T will hire two consultants to assess ten consecutive patients admitted to the Rehabilitation Hospital of the Pacific. The patients will be reassersed at specified intervals and the completed forms will be returned to Buffalo, N.Y. for inclusion in their study.

#### III. OTHER ACTIVITIES

A: The RR&T Advisory Committee meets at least annually to critique activities and suggests new projects. The Hawaii Committee meets the month prior to the annual RR&T Advisory Committee to enable to recommend projects which are then referred to the full committee. For example, the Hawaii group met in August and the RR&T Advisory Committee meeting was in Honolulu September 9th and the 1985.

E. Each month the RR&T conducts a Journal Club Meeting when a staff member or an invited guest speaks on a relevant, current journal article or rehabilitation topic of interest. It is open to all interested persons in the Rehabilitation Hospital

C. The RR&T circulates a newsletter, a least six times a year, to a mailing list of 220 in order to keep persons in related fields current on the activities of the RR&T Center.

D. A directory of rehabilitation services in the Pacific is being finalized and will be available in the near future.

E. The Pacific Rehabilitation Research and Training Center supports the presentations of workshops; when the opportunity arises, which relate to the go. Is and objectives of the Center and are pertinent topics. To date the program has part, ly funded an aphas workshop (Honolulu), a presentation on disability and sexuality (Honolulu), a discussion of appropriate rehabilitation technology (Hilo), and an inservice training in techniques to facilitate adult learning.

F. RR&T has provided opportunities for three graduate students at the School of Public Health (University of Hawaii) to conduct relevant research on rehabilitation topics and to fulfill their practical assignments at the Center. Another graduate student is a part-time employee.



#### IV. CONCLUSION

The Pacific Rehabilitation Research and Training Center is in its second year. Emphasis has been placed on having the representatives of the people in the Pacific areas identify their needs and priorities related  $\omega$  improving services to disabled persons through rehabilitation research and training in the Pacific Basin. It has become evident that a program such as the RR&T Center is essential in filling some of the gaps in the continuum of services from a disabling condition to that of becoming an able citizen in his/her community.

ing an able citizen in his/her community. The Pacific RR& Center will continue to pay special attention to insues related to the needs to develop rehabilitation manpower and the need for continued education in this area; the projected demands for renabilitation of elderly persons: the deinstitutionalization of the mencally retarded into less restrictive environments; the transition of disabled persons from school to work and living in the community; the transition from in-patient rehabilitation services to the home; the rapidly increasing costs of all types of rehabilitative care; and, the disportionate number of handicapped individuals who encounter difficulties with the legal system.

The following is recommended to the Subcommittee on Select Education:

1. To continue the RR&T initiative in the Pacific Busin. This program could be a vital link for the Micronesian clashed in the transition from trusteeship to free association with the United States.

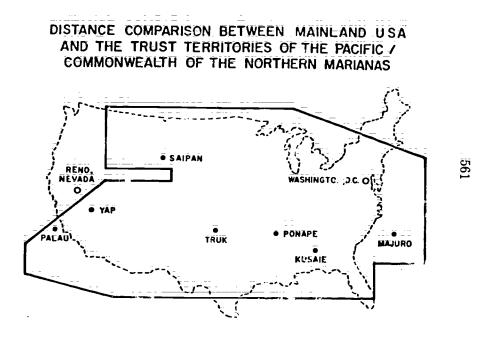
2. To encourage government agencies ....a progration increase their efforts in coordination and communication to avoid duplicat and strengthen outcomes by combining resources.

3. To promote the monitoring and dissemination of federally funded program outcomes so that all may benefit.

4. To continue to be sensitive to the advice of resident professionals and lay persons which can provide direction in defining culturally relevant and technologically appropriate program goals which are so varied in Guam, American Samoa, Micronesia and Hawdii.

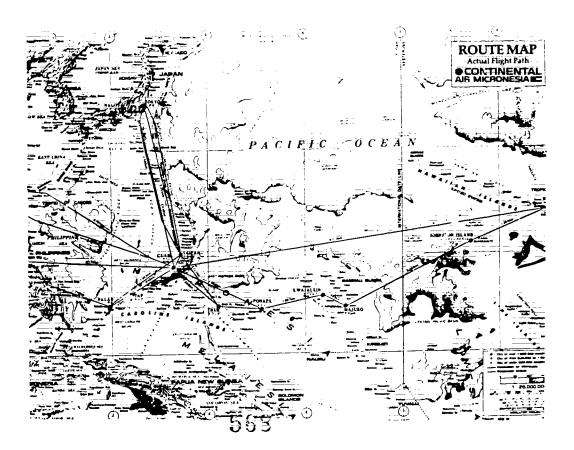












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# REHABILITATION RESEARCH AND TRAINING

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### RESEARCH

FACIFIC MICRONET - SATELLITE COMMUNICATION

FEHABILITATION CLIENT TRACKING SYSTEM

MULTI-AGENCY MEHABILITATION DATA SYSTEMS

VOCATIONAL REHABILITATION TO THE THODS

VEDICAL REHABILITATION REFERRAL SYSTEMS / ASSESSMENT METHODS

SPECIAL EDUCATION REFERRAL SYSTEMS / ASSESSMENT :#THOOS

PREVALENCE OF DISABILITY IN HAWAII

UTILIZATION OF SERVICES BY THE DUNDLY DEAF

STINDY OF HAWA. 'S JAPANESE WELL-ELDERLY

RISKS OF HIP FRACTURE IN THE ELDERLY

HAWAII SPINAL CORD 72" ISTRY

MANAGERS OF GROUP HEARS FOR MENTALLY RETARDED

UNIFORM INSTITUTAL SATA . STEM

#### TRAINING

REHABILITATION TECHNICIANS

HOME CARE

CARE FOR THE ELDERLY

CONTINUING EDUCATION OF PHYSICIANS IN REHABILITATION

USE OF SATELLITE EQUIPMENT AND COMPUTERS

PROPER USE, CARE AND STORAGE OF. OTOLARYNGOLOGICAL EQUIPMENT



# REHABILITATION TECHNICIAN TRAINING



HOME CARE







FAMILY TRAINING



USE OF LOCALLY AVAILABLE MATERIAL



# $\overline{5}\overline{6}\overline{5}$

# VOCATIONAL REHABILITATION REFERRAL SYSTEM. ASSESSMENT METHODS & ASSESSMENT NORMS



Functional assessment and work samples allow for accurate job placement



Production in a workshop setting



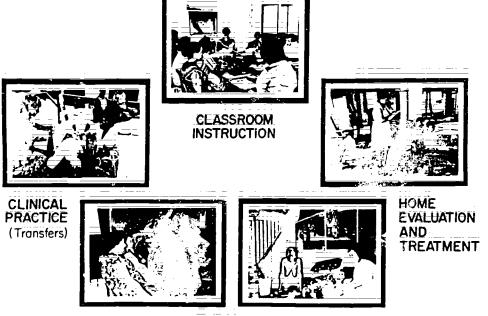
Storefront in an American Sampa Vorkshop



Inter-Island travel between work and home



# HOME CARE TRAINING



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### 567



# RR & T

UPGRADED NINE STATIONS:

|      | V |
|------|---|
|      |   |
| • •7 |   |

| KUP 77 | Univers iv of Guam<br>Martica, Guam                |
|--------|----------------------------------------------------|
| KUP BI | Educe on Office                                    |
| KUP 7: | Commun 1) College of NMI<br>Sarban, CNMI           |
| KUP 40 | TTPI Education Dif.                                |
| KUP 61 | - Bureau of streadium<br>Koror, Republic Belau     |
| KUP 51 | Department of it ducation<br>Calories, top         |
| KUP 4I | Department atE a cashan<br>Majuta, Marshall slands |
| KUP 3I | Department of Eq. ation<br>Morn, Truk              |
| KUP 2I | Com College of Micronesia<br>relianta, Follogi     |

# RR & T EQUIPPED THREE NEW STATIONS:

KUP 77 - Remote Guam Mem<u>u vi riospital</u> Agana, Guam

KurxxX Rahab Rehabilitation Hospital of the Pacific Honolulu ----LBJ Hespital Pāgō Pāgō; Amēr in Sāmōā







Mr. WILLIAMS. Thank you. Mr. Rogers.

Mr. ROGERS. As mentioned, I am the dean of the school of medicine, and it is my responsibility to negotiate our affiliation with the Rehabilitation Hospital of the Pacific, and my pleasure to appoint Dr. Okamoto to our faculty as the chief of our division of physical rehabilitation medicine. Likewise, on behalf of the wider university and Pacific community, I negotiated the initial cooperative agreement with the National Institute of Handicapped Research, which supports the Rehabilitation Research and Training Center just described. As you can tell, these are highly developed professionals, and so my supervisory role is limited.

I might mention that some-the satellite communication thing should have taken a year of paperwork, but Dr. Izutsu had it working before we found out the paperwork was needed, and I personally respect and enjoy hat kind of activity.

Currently I am working with our faculty to increase the amount of time for the rehabilitation in the training of premedical students and house staff. In this context, we have a strong affirmative action policy for the recruitment of native Hawaiians and other Pacific islanders into this medical school. We have a full year of remedial premedical work and a decelerated track to the medical doctor program. This is of particular relevance to the testimony you will hear later from our Hawaii colleagues this afternoon. Under these programs we have graduated 64 native Hawaii medical doctors since 1975.

The Rehabilitation Research and Training Cevier permits our university and the rehabilitation hospital to carrout our self-de-termined missions to provide technical and educational leadership in developing all aspects of rehabilitation in those areas described by Dr. Izutsu

On behalf of all of us, I would like to ackness lige the concern, sensitivity and generosity of spirit displayed by ur subcommittee and the Congress, in general, with respect our handicapped fellow citizens:

Without suggesting there is anything removely original in the idea, I see down the road the real successes in the field of rehabilitation come from programs which prevent the handicapping conditions in the first place, from -ubella vaccination to relentless traffic !aw enforcement:

We note, for example, that mental retartation may be broadly attributed to three causes: idiopathic developmental defects, interruption of the oxygen supply during a crucial few minutes during parturnica, and to genetic defects. In major centers a delivery room with the superb coordination of a corps de ballet can present many of the delivery accidents, and the analysis of pedigrees of afflicted families, supplemented by chromoson analysis, sensitive counseling and aniniocentesis offer strong preventive hopes for genetic syndromes.

I need not emphasize the high cost of providing these state-ofthe-art services to remote locations where facilities and staff are already in short supply. But our responsibility, as just described, is f: ung, even beyond the scope of the word "rural." the of our research and training responsibilities for the near

future will be to upgrace the skills and responsiveness of midlevel



practitioners in child birth and develop a comprehensive working epidemiology of potentially hereditary mental retardation in Micronesia. All of this has to be accomplished through the application of appropriate training, appropriate level of training and technology, rather than by endeavoring to suplicate the fantastic services available in major U centers.

The development of this kind of training, we submit, is itself a research project.

# [The prepared statement of ference A. Rogers follows-]

#### PREPARED STATEMENT OF TERENCE A. ROGERS, DEAN, JOHN A. BURNS SCHOOL OF MEDICINE

I am Terence Rogers, the Dean of the John A. Burns School of Medicine at the University of Hawaii It was my responsibility to negotiate our affiliation with the Rehabilitation Hospital of the Pacific and to appoint Dr. Okamoto to our part-time faculty as the Chief of our Division of Physical and Rehabilitation Medicine. Likewise, on behalf of the wider University and Pacific Community I negotiated the initial Cooperative Agreement with the National Institute for Handicapped Research which supports the Rehabilitatici. Research and Training Center described by Dr. Izutsu. Accordingly, my full support for the testimony they have offered may be taken for granted. As they are both highly developed professionals my responsibilities with respect to them are not supervisory in the conventional sense.

Currently I am working with our faculty to increase the amount of time for rehabilitation in the training of Pre-M.D. students and house-staff. In this context, we also have a strong affirmative action policy for the result of Hawaiians and other Pacific Islanders into this medical school. We have a full year program of remedial premedical work, taught by the vedical school textility and designed to make such students more competitive applica. A or medical school textility and designed to make decelerated (5 year) track to the M.I and for such educationally disadvantaged students who are admitted to medica. This is of relevance to the testimony you will hear later from our Hawaiian community. Under the programs just described we have graduated 64 Hawaiian M.D.s since 1975.

The Rehabilitation Research and Training Center funding permits our University and the Rehabilitation Hospital to carry out our self-determined missions to provide technical and educational leadership in developing all aspects of rehabilitation in American Samoa, Guam, Micronesia, as well as in our own State: On behalf of all of us, I would like to acknowledge the concern, sensitivity and generosity of spirit displayed by your subcommittee and the Congress in general with respect to our handcapped fellow citizens.

Without suggesting there is anything remotely original in the idea, the real successes in the field of rehabilitation come for programs which prevent the handicapping conditions in the first place, from rubella vaccination to relentless traffic law enforcement. We note that menual retardation may be broadly attributed to three causes; idiopathic developmental defects, interruption of the oxygen supply during a crucial few minutes during parturition, and to genetic defects. In major centers a delivery room staff with the superb coordination of a curps de ballet can prevent many of the delivery accidents, and the analysis of pedigrees of afflicted families, supplemented by chromosomal analysis, sensitive counseling and amnior entesis offer strong preventive hopes for genetric syr dromes.

We do not need to emphasize the high cost of providing these state-of-the-art services in remote rural locations where facilities and staff are in short supply and thinly scread, but our area of responsibility. As described in previous testimony is far-flung even beyond the scope of the term "tot !" One of our research and training responsibilities for the near future will need to upgrade the skills and responiveness of mid level practitioners in child birth and a comprehensive "working" epdemiology of potentially hereditary mental retardation in Micronesia. All of this nust be accomplished through the realistic application of appropriate training an i echnology rather than by vainly endeavoring to duplicate the services available in najor U.S. centers. The development of this kind of training, we submit, is itself a

Mr. WILLIAMS. Questions? Mr. Hayes.



Mr. HAYES. You know. I have listened to what amounts to some very educationally revealing testimony from all three witnesses I never realized the magnitude of the problem in terms of the geographic area you have to cover. I was just listening today on some program on television this morning where I think the average age life expectancy for females in Honolulu is something beyond 80.3 years, or something, and males is 74.3, something like that, as compared to Washington, DC, the seat of our Capitol, living some 10 years less.

I listen to the problems we have with the handicapped, I wonder how do you account for this longevity? I was almost telling my wife we need to start moving.

Mr. ROGERS. Sir, the number is askewed by Japanese ladies. They go on and on and on. If you take those out of the population, we don't look that different.

Mr. IZUTSU. As one of our scientists in psychology mentioned, if you want to live long, you ought to be Japanese and live in Hawaii. He can't guarantee anything else.

Mr. HAVES. In a more serious vein, though, I notice the acute shortage of doctors and nurses and other technic a. Is that shortage due to the lack of funds or what? To what eacher is the Burns Hospital supported with Federal funds? I am not guite sure:

Mr. Rogers. Yes, sir. I did not include it ir my testimony for reasons of brevicy. But we accept Micronesians into our medical school, but of those we have graduated, only two have gone back. And I can't blame them individually. They go to California, or worse, and that is it. In consultation with the Micronesian political leadership, we are going to start a program for training so-called medical officers whose qualifications will be valid in Micronesia, whose training will be realistically based on their educational base, and the first \$2.5 million is appropriated in the last Congress, but the Office of Manegement and Budget is still being difficult about the apportionment. Once that breaks loose, we are ready to go with that.

Also, there are National Health Service Corps assignees in Micronesia, and our medical school has a contract with HHS to supervise and support and generally provide continuing education for them.

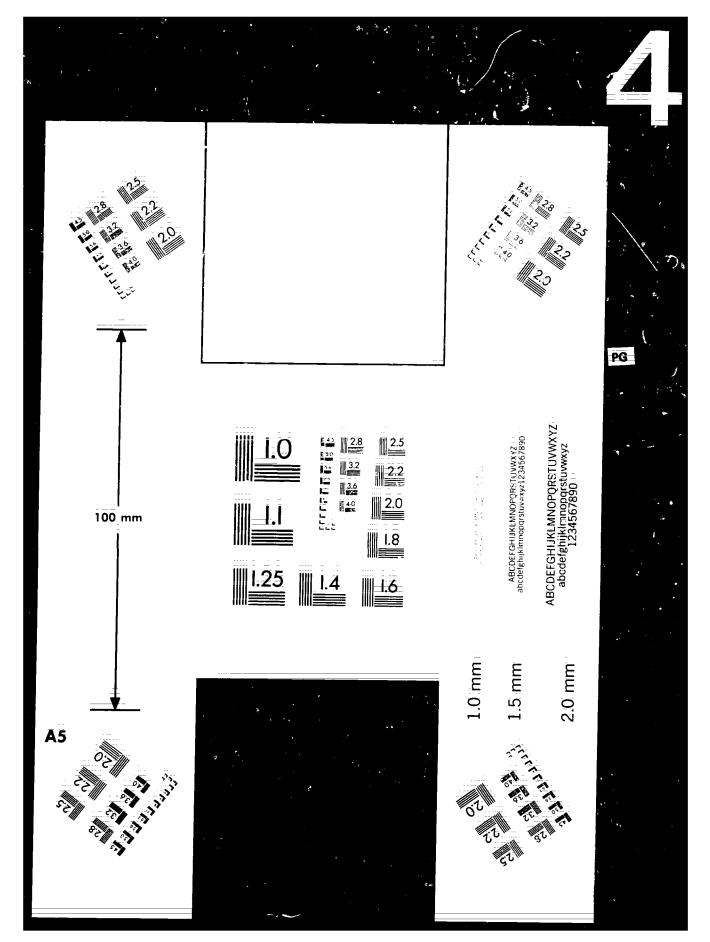
Mr. HAYES. I note for fiscal year 1985, the hospital received in the Research and Training Center \$61,685. I guess you also received some basic State grant money. Just how much of that did you have to raise independent of those two sources, the state and Federal Government, for the preration of the medical center? What was your total expenditure?

Mr. Rocets. Our total budget for our medical school operation is about \$13 million, of which about \$8 million is from the State and

other \$5 million, plus or minus a half-million, is almost entirely Federal.

There are occasional relatively small grants from the Robert Wood Johnson Foundation or other such private—but it is entirely through the State legislature and the Congress that we are able to finance our—

Mr. Hayes. Are Medicare and Medicaid funds available?





Mr. ROGERS. Yes, they are in Hawaii and Guam, but not in Mi cronesia because the hospitals do not qualify, sir:

Mr. HAYES. Thank you.

Mr. WILLIAMS. Mr. Heftel.

Mr. HEFTEL I am just delighted to see at least two of you three gentlemen. We usually end up meeting in Washington, sometimes in Honolulu. Dr. Ckamoto, you and I got to get to know each other better so we are in equal familiarity with each other.

I wonder, Doctor, if you could give us some insight into how effective we are at setting up a system that brings a quality student, patient or recipient to a single source in a single geographic location, where the system takes over from there so that that individual doesn't have to figure out what to do, and the family doesn't have to figure out what to do for all of that which is needed. Because I think that might be one of the more critical things we may be accomplishing in structuring what we deliver to that citizen.

I wonder if among you three gentlemen you could focus on that, because I know 1. m prior testimony we are still in the discussion stage as to something that should be fairly obvious, that when a student goes to the school, it should all be there and the student shouldn't have to do anything more in terms of how you get delivery to him. I wonder if you could address that for us, one or all of you, not in the sense of criticism, but in the sense---

Mr. Izutsu. That is a very valid question. In our concern with Micronesia, Samoa and Guam, Guam is pretty much independent, but when we look at Samoa and Micronesia, they look—Hawaii is looked at as a single system of referring difficult patients here. There are a multitude of problems with that in terms of once we get through with the rehabilitation level, to send them back into their environment, which may not be appropriate as far as what we have done here.

The whole training net only goes with the client, we have to train the entire family and support system so one client can go back into that environment. It poses a tremendous problem. That is what we are trying to tackle. We have here at Gary's hospital, for example, a one-stop where they can come in and go through the whole rehabilitation services under one roof, but this is not possible in the area of Micronesia.

Mr. HEFTEL. May I inject the next question, and this may be better addressed to Dr. Rogers, I am not sure. What about the more localized issue that I was addressing from the prior testimony; namely, the student who needs the continuation of rehabilitation and training who is handicapped, trying to come into the system, that is at least coming to a public school facility, how do we make that the sum total of what that individual must do, just as we do it for the individual who comes to the Research Hospital of the Pacific. Once you come to that institution, the institution takes over.

Now, how does that get translated into the school system so that when the student comes to school, the school takes over and in an efficient, dollar-efficient, human resource efficient manner delivers what is needed to that individual? Are you able to address that, at least in part? Because I think that is one of the things we have to focus on as we go forward.

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Mr. Rogers. Yes. Well, in Micronesia----



Mr. HEFTEL. Remember, we are talking now about Hawaii.

Mr. ROGERS: Oh, about Hawaii.

Mr. HEFTEL. What I am addressing, because it is where you have the bulk of the population, it is where I heard that we have not yet reached the point where when that handicapped student comes into the school system, the system takes over for the student.

What I heard was the different services are still talking to each other about who should take over what and how the student is not receiving the single-source assistance that should be available at the cchool in Hawaii. That is what I would like to target, if you have an observation.

The fact that you don't have an observation or that you don't immediately have a profile indicates to us we must have a long way to go in terms of what we are doing and the way we incorporate with the school system in Hawaii the needs of the retarded student who reaches that school. We are only reaching 18 percent to start with, and that 18 percent is not able to then let the system take over from the school. You have to do that, and then go out into the system to find out the rest of what you need to know to get it done.

It seems to me it is not beneficial to the student or recipient, and it is very inefficient the way we use our dollars. It may well be I am asking the wrong panel, because you don't focus on that, but it is certainly a problem I guess we are all going to have to find out more about based on the prior testimony I heard, which is why we are still talking—it is as though we are still talking about the Rehab Hospital of the Pacific and getting through with what you need by going through, and you are still talking about incorporat ing all the other medical services and all the other hospitals in the area in terms of how that person was going to receive treatment.

Mr. ROGERS. It is quite clear your consciousness has been raised even if you went about it the hard way.

Mr. HEFTEL. The very hard way. But it has been raised, believe me. And I know what the one-stop service, if you will, means and what the absence of it means. We can barely move a block when you have to be taken in and out of a wheelchair, special cars, it goes on and on. If you can't do it in the one block and the one method, it is very debilitating to the patient or to the recipient.

Mr. ROGERS. I would say in Hawaii that for the severely traumatized patient, or whatever, that, as Gary described, it is one—all under one roof at Rehab up to that point, at which—Rehab Hospital, I mean, of course—up to that point at which the patient may leave the hospital.

After that, I would say that your implicit general criticism that the system is fragmented is a valid criticism, and it is actually one of the components of our cooperative agreement with NIHR, to make, if you like, a research project, the rationalization of what has been from my point of view as a psychologist, an overcategorization of rehabilitation and voc rehab services.

And I would agree that in Hawaii obviously the school is an appropriate focus because this is where the rehabilitation largely takes place. Well, we came here to tell you we were doing good, and you pointed out to us somewhere we could do better.

Mr. HEFTEL. The reason I am so concerned with the issue is that it is after you leave that which has already been coordinated;



namely, the traumatic center, if you will, you then go into the real world to function, and now if it is in a training syndrome or learning syndrome where you are going to live with certain handicaps, you need a single source of trained coordination and motivation, learning for the patient, the student, and if you don't have that within a school structure where the patient has already reached the school, then there is a dissipation of energy, of deliars and a debilitating effect upon the student.

I think that we are perhaps not addressing the right forum for this because you are doing it in the area you function in. I don't think you are doing it in the area after they leave you, if you will, and I guess that is what really concerns me in terms of what I have learned in the past few years.

I think it is something we have to address in Hawaii. It is not something the panel can address here, other than where we in the federal system can legislate effectively for programs designed to coordinate all of the things needed by the recipient out of the school system where the person is in the school system, and it is just something for us to know we still must do or achieve, because we haven't. You have achieved it in the area in which you function, but once the patient leaves you and becomes hopefully a functioning person, we don't have to become a part of the system once we leave you.

Mr. WILLIAMS. Cec, you seem to be preparing a one-stop rehabilitation service. Now, for those young people—let's use young Americans—who are attending school, are you suggesting that the physical plant for the rehabilitation be located within the school?

Mr. HEFTEL No; what I am trying to suggest is when the student comes to the school who is handicapped and has a multiple series of needs, that all the direction, all the coordination flow through that school, through that system the student is already in, so if that student needs a rehabilitation effort outside of the building, that is all coordinated through the school system.

If that student needs contact with counseling and motivation, that is done within the school. So that student, whatever the needs are, they flow in and out of the school rather than the parents and the youngster trying to find out where to go and what to do.

Because the school, unless it is equipped to do this, which is one of the things I am trying to address in our dialog, leaves them without finishing the process, and it is costly all the way around, because when you leave there and you now find the coordinator somewhere else, you realize how expensive it is for the system and you leave the school to go someplace that has a coordinator, that has to start the learning process about you all over again.

One of the things you learn is once you leave one location and go to another, for any reason, they start the process of learning about you all over again. If you go to five centers, and it can happen, it will duplicate five times what has been done the first time. If you only did it the first time and they coordinated where you go and what you do, you save wear and tear on the individual.

What you go through each time, they put you through the testing and the interrogation and the whole process, and when you do it with a younger person who has a handicap, you multiply the burden upon that young person.



I think somewhere we have to realize we are not using an efficient system for those dollars, or we are not efficiently addressing the problems of the student.

Now, medically they could tell you how disastrous it would be if that person came to your hospital and had to go independently to five other medical sources, making appointments, getting there, going through five times the same routine, and the history taking and understanding of the patient. That is where my concern comes in. And you can quickly see it in what the gentleman addressed to us previously, when Dr. Nishioka was speaking about the fact they are still talking about it in relation to the school system.

Obviously, he was telling us something we ought to be listening to very intently, because he is telling us we haven't yet gotten to the point where we have coordinated those functions. It isn't something we can address here, but we need to understand it, so when we allocate dollars to the system, one of the things we want to motivate the school and States to, is coordinating for the handicapped student these functions once they come into the school system.

Mr. WILLIAMS. Quite often such duplication and the completion and repletion of forms is thought to be required by the Federal Government. However, when our oversight committees take a look at the reasons for such bureaucracy, we find there are no federal regulations that require whatsoever.

There are local requirements. The Federal Government is responsible for our share of bureaucracy, but let me tell you, it is a much smaller share than you think. You are responsible for more of it—I am not pointing it at these three fingers along here, I am pointing out here. Let me assure you—

Mr: HEFTEL: The system out there:

Mr. WILLIAMS. That great system. Somebody said to me, "Why did you run for Congress?" I said, "I want to find out who 'they' are."

Do you know who they are? You. Washington does not require all of the requirements for redtape, paperwork and bureaucracy. Nor is Washington responsible, by the way, for the great cost overruns that you read about in the Defense Department. Private industry located in places like this and in places like my own State of Montana are responsible for such overruns or duplication of bureaucracy.

Dr. Okameto, as you were closing your testimony, you said that even subtle fiscal reforms proposed by the Health Care Finance Administration can potentially annihilate comprehensive medical rehabilitation.

Can you expand on that for me?

Dr. OKAMOTO. Yes. As I am sure you are aware, the whole Medicare trust fund is in danger of bankruptcy.

One of the areas that the Health Care Finance Administration has looked at carefully is the use of Medicare dollars going to the area of long-term care institutionalization, rehabilitation, psychiatric care and to a minor degree, pediatrics.

My concern is that because less than 1 cent out of every dollar, as I have been told, of the Medicare dollar actually goes into what I described earlier as acute medical rehabilitation, the general political interest and governmental research that has gone into un-

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derstanding what acute medical rehabilitation is all about has been very, very small compared to the enormous amount of attention that icute medical-surgical medicare hospitalization received.

Of the proposals that have come out of the lack of information about what medical rehabilitation can do for disabled people is a proposal to lump, aggregate, collapse medical rehabilitation into long-term care, nursing home industry payment systems.

If that were done, what we know as acute medical rehabilitation: that is, getting people through medical rehabilitation from hospital to home, I think will be destroyed, since most rehab units and most rehab centers, free-standing centers in the United States, depend heavily on Medicare dollars.

As our society sees itself growing older, the major physical disability that we will begin to face, and we are already feeling that, will be awesome. And if our goal is to help these citizens avoid institutionalization to maintain their productivity, we need to maintain the integrity of medical rehabilitation. That is why I make reference to that.

Mr. WILLIAMS. Gentlemen, we very much appreciate----

Mr. HAYES. I want to satisfy my own curiosity, and I direct my question to you, Dr. Rogers.

There seems to be some similarity of the problem faced here in terms of, I notice you say over a 10-year period, I think only 64 medical doctors graduated from the institution, is that correct?

Dr. Rovers Sixty-four native Hawaiians.

Mr. HAYES. I want to know if you have the same problem among blacks, which I am most familiar with. There is an increasing shortage of black students, hence graduate medical doctors, created as a result of the cost involved to go to school and the limited amount of Federal moneys available in most instances for them to go. Many of them are disadvantaged and have no other source that would enable them to go to school.

Another problem, which I know you may not know too much about, is that being a doctor is not as enticing in some instances as it used to be; the whole question of liability insurance, which I never knew about, has become a great problem.

But I was just wondering if the lack of great numbers of Hawaiians entering school--you mentioned there will be other testimony coming later from institutions, but is that due to lack of funds? What is the reason why your school could only graduate over a 10year period 64 medical doctors

Dr. ROGERS. Yes, sir. No, there is no-I should mention. first of all, when I refer to other testimony, that will be from Hawaii civic organizations, not institutions. We are the only game in town for inedical education.

No, there is no shortage of applicants, and actually I do know the deans of the three black medical schools very well, and we

Mr. HAYES. You mentioned, by the way, a strong affirmative action program.

Dr. ROGERS. And we have a strong affirmative action program. Perhaps I could cut through a lot by saying a slightly self-serving thing. We had a meeting of those schools with large minority populations, and I was asked to be the keynote speaker because of the





success of our program of retaining minority students. Lou Sullivan and the other guys were there.

Our program has been possible through the HCOC program administered by Dr. Simpson, as you know. But also our own state has been very supportive of this.

Our tuition—I mean, the students scream about it, but by mainland standards, it is unique. We are merciless with relatively prosperous Hawaiians about supporting Hawaiian youngsters going to medical school. It is a small place.

Mr. HAYES. Thank you very much

Mr. WILLIAMS. Again, gentlemen, thanks for being with us today. Our final panel this morning will be Kristie Mills, representing the Hawaii Center for Independent Living, and Patti Henderson, executive director, Protection and Advocacy.

Ms. Mills, if you will begin first.

# STATEMENT OF KRISTIE MILLS, HAWAII CENTER FOR INDE-PENDENT LIVING; AND PATTI HENDERSON, EXECUTIVE DIREC-TOR, PROTECTION AND ADVOCACY

Ms. MILLS. My name is Kristie Mills. I will be summarizing our written testimony as the executive director, Erica Jones, could not be here today.

Hawaii's Centers for Independent Living, and I may refer to it as HCIL, has operated since June 1981 as the nonprofit statewide corporation run by and for the disabled. Our goals are to enable people with disabilities to live independently in their communities, to educate our communities concerning the problems of people with disabilities and to advocate for their civil rights.

Since opening we have provided community-based support services to disabled people and their families through referrals from public and private service providers as well as self-referrals. We began to educate our communities on the cost effectiveness of Independent Living for people with disabilities in terms of both doilars and human lives.

Although Federal title VII parking money makes up one-third of our budget, we have succeeded in developing a broad base of funding.

The remaining two-third of our budget is comprised of the following sources: State grant-in-aid, State purchase of service contracts, fee-for-service contracts, United Way, county general revenue-sharing funds, private grants and foundations and special events and contributions.

HCIL's continuing goals are to enable people with disabilities to gain and maintain independent life styles in their communities and to educate the community concerning the problems and rights of people with disabilities.

In order to accomplish these, our goals and our services—I am just going to list them for time purposes—are peer counseling, housing assistance, financial counseling, location of personal care attendants, outreach and public education, information and referral, support for legal rights in all consumer areas under section 504 and Public Law 91-142, Independent Living skills training and jcb readiness training.



According to the 1980 cenus, the number of non-institutionalized disabled persons age 16 to 64 years old equalled 38,181 with 16,455 of these determined severely disabled. It has been HCIL's initiative to provide services to this population statewide. To this endeavor, we have expanded our services and gained recognition as providing a viable alternative to institutionalization.

In the past 4 years, the total number of clients has shown a steady increase from around 90 in 1981, in a l-year period, to projecting about 570 at the end of 1985. Complete demographics are included in our written testimony.

HCIL's operation is governed by a board of directors, a majority of whom are persons with disabilities; 80 percent of our staff have personal experience with disability and are responsible for administering HCIL's programs.

Thus, we attempt to not only serve disabled but we employ disabled. This enables us to have firsthand knowledge of how the Rehabilitation Act directly impacts on its target population.

Presently, the State division of vocational rehabilitation acts as the conduit for both our State and Federal funding.

HCIL's relationship with the division has been a mutually coperative one. However, we would like to see an operation developed four centers to receive direct funding from the commissioner.

HCIL has received an appropriation directly from the state legislature to fund HCIL, which is provided through DDR, and the focus of these funds are for deinstitutionalization, maintaining deinstitutionalization and promoting the full integration of the disabled in the community.

The population targeted for funding includes the severely disabled and elderly who may or may not have potential for gainful employment.

It is critical that Independent Living scivices be seen as viable alternatives for the State's disabled to deter institutionalization. In order for this to occur, Independent Living moneys cannot be regulated and awarded solely upon an employment and rehabilitation model, but also consideration must be given to support of community services.

In our testimony, we addressed certain areas of the act. One of those is the State plan.

-Currently there is a need for guaranteeing and substantially involving disabled people representing Independent Living in the development of the State plan. It is not being done at this time.

Since this is the document that plans and develops policies and methods for expanding and improving services to handicapped idividuals, it is reasonable to assume the Independent Living consumer participation would be advantageous.

Our suggestion would be for Independent Living Centers to be involved in an advisory capacity in developing and signing off on the State plan.

A suggested addition to the Rehabilitation Act, section 706, State plans would be the inclusion of language that allows for DDR to sign off athority on part A services only with 90 percent of these funds applied for purchase of service, activity and 50 percent of that applied to nonprofit Centers for Independent Living that meet eligibility standards.





In the area of employment, and I feel like this has been covered pretty well by the division of vocational rehabilitation, I think we sull consider there are some concerns here because although training and employment is a major part of the Rehabilitation Act, it seems our statistics may be low. About a quarter of the disabled determined employable are not working and the other quarter may be working, but in sheltered employment. That is a concern for us.

As far as architectural and transportation barriers, one barrier in Hawaii is in the area of transportation. On Cahu there is a transit system which has a long history if inability to meet the needs of the disabled. It is still unable to provide total transportation needs geographically but does not provide evening or weekend services; and consumers feel it is unreliable and time consuming. There is testimony as a result of many public hearings that documents this.

On the neighbor islands, there is even a greater barrier because there is no public transportation, period, let alone transportation for disabled, which leaves the disabled and elderly on those islands literally geographically isolated from equal access to their communities.

Another major barrier to Hawaii's disabled is the area of housing. The average nationwide occupancy rate for rentals is between 5 and 6 percent, while in Hawaii, the rate is between 1 and 2 per cent. And here in Hawaii, an average studio apartment in Wakiki could list for \$450 a month.

For those people who are on Federal subsidy programs and who are receiving certificates to supplement their rents, they can wait up to 6 to 12 months to get that certification and our staff say that it is like finding a needle in a haystack. Section 8 is very difficult to find landlords that are willing to accept currently.

- So housing overall is a real barrier to disabled, not just in being able to locate housing but also affordability as well as accessibility.

In conclusion, I thank you for this opportunity to present testimony in that the good work that the Rehabilitation Act has generated will be expanded and continually improved.

We would like to especially underscore the importance of the original interpretation and full intent of section 504 and the four major points that I would like to leave for your attention are, one, a disabled voice in the State plan; two, control over our own lives and disabled people; three, disabled productivity based not solely upon employability but also as our ability to contribute as citizens in our community, whether that be by civic duty, volunteerism, leadership, et cetera; and, four, equal access for disabled to transportation, housing and employment.

Given the needed support services, disabled persons can truly be deinstitutionalized and maintained in their communities.

Thank you.

Mr. WILLIAMS. Thank you.

[The prepared statement of Kristie Mills follows:]

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PREPARED STATEMENT OF KRISTIE MILLS, HAWAII CENTER FOR INDEPENDENT LIVING

In response to your invitation to testify before the Subcommittee on Select Education, I submit our agency's testimony. As a Title VII program recipient, we welcome this opportunity to present our views on the workability of the Rehabilitation Act of 1973.

Hawaii Centers for Independent Living (HCIL) has operated since June 1981 as a non-profit, statewide corporation run by and for the disabled. Our goals are to enable people with disabilities to live independently in their communities, to educate our communities concerning the problems of people with disabilities, and to advocate for their civil rights. Since opening, we have provided community-based support services to disabled people and their families through referrals from public and private service providers as well as self-referrals. We have begun to educate our communities on the cost-effectiveness of independent 1 ...ng for people with disabilities, in terms of both dollars and human lives.

Although Federal Title VII Part B money makes up about one-third of our Sudget, we have succeeded in developing a broad base of junding. The remaining two-thirds of our budget is comprised of the following sources: State Grant-in-Aid, State Purchase of Service Contracts, Fee for Service contracts, United Way, County General Revenue Sharing Funds, Private grants and foundations, Special Events and contributions.

HCIL's continuing goals are to enable people with disabilities to gain and maintain independent lifestyles in their communities, and to educate the community concerning the problems and rights of people with disabilities. In order to accomplish these goals, our program provides the following services to the disabled and their communities:

A. Peer Counseling—Emotional support, problem-solving and adjustment for the newly disabled and/or deinstitutionalized clients, individually or in groups. B. Housing Services—Help in locating accessible, affordable housing; working with landlords to accept disabled tenants; help with minor building modifications; consisting now sources of bouring double housing and maintaining a building modifications; generating new sources of housing; developing and maintaining a housing roster.

C. Financial Counseling-Help in accessing income sources for which a client may be-eligible; help-in budgeting.

D. Personal Care Attendants -Recruiting, training, screening and referring personal care attendants to clients requiring personal care services; training disabled clients in supervision of attendants.

E. Outreach and Public Education-Participate in and initiate conferences, conduct workshops and accept speaking engagements to raise public awareness; locate those in hospitals and other dependent situations who want and need our intervention; publication of a newsletter; providing input and direction to local, state, and federal lawmakers on legislation supportive of our needs and rights. F. Information and Referral—Provide information on available resources to cli-

ents, concerned others, service agencies, and the general public to prevent gaps in and duplication of services to the disabled

G. Support for Legal Rights in all consumer areas under Section 504 and P.L. 94-142.

H. Independent Living Skills Training-Training in specific skill areas using individual methods as appropriate for client needs.

I. Job Readiness Training-Prevocational-counseling directed to people who are

not yet ready for Department of Vocational Rehabilitation services. According to the 1980 Census, the number of non-institutionalized disabled per-sons aged 16-64 years old equalled 38,181 with 16,455 of these determined severely disabled. It has been HCIL's mission to provide services to this population statewide. To this ordeneer HCIL To this endeavor HCIL has steadily expanded its services and gained recognition in the state as providing a viable alternative to institutionalization. In the past four (4) years, the total number of clients served statewide has shown a steady increase:

| 1981 (7-month period) | Clients<br>99 |
|-----------------------|---------------|
| 1982                  | 287           |
| 1983                  | 429           |
| 1984                  | 483           |
| 1985                  | 500           |

Additionally, HCIL has implemented a program evaluation system according to Section 711(c) of the Rehabilitation Act of 1973. The following client demographic information reveals the numbers and types of handicapped individuals served:

| 5.           |      |      |      |       |     |      |      |      |      |       |       | Percent |
|--------------|------|------|------|-------|-----|------|------|------|------|-------|-------|---------|
| 17 and below | <br> | <br> | <br> |       |     | <br> |      |      |      |       |       | 2.0     |
| 18-29        | <br> | <br> |      |       |     | <br> |      |      |      |       |       | 23.5    |
| 30-49        | <br> | <br> | <br> |       | • • | <br> |      |      | •••• | ••••• | ••••• | 36.2    |
| 50-64        | <br> |      |      | ••••• |     | <br> | •••• | •••• |      | ••••• | ••••• | 15.6    |
| 65 and over  | <br> | <br> | <br> | ••••• |     | <br> |      |      |      |       | ····· | 22.6    |

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| Sex: |                                                            |
|------|------------------------------------------------------------|
|      | Male                                                       |
|      | Female                                                     |
|      |                                                            |
| hsa  | bilities                                                   |
|      | Visual impairment                                          |
| ]    | Hearing impairment                                         |
| ]    | Hearing impairment<br>Physical and neurological impairment |
|      | Mental disability                                          |
|      | Mental retardation                                         |
| 1    | agening disability                                         |
| ;    | Madically disabling conditions                             |
|      | Medically disabling conditions<br>rely disabled            |
|      |                                                            |
|      | icity                                                      |
|      | Caucasian                                                  |
|      | Filipino                                                   |
|      | Japanese                                                   |
| (    | Chinese                                                    |
| j    | Hawiian/part, Hawiian                                      |
| ī    | Portuguese                                                 |
|      | Korean                                                     |
|      | amoan                                                      |
| ì    | Puerto Rican                                               |
|      |                                                            |
|      | ilack                                                      |
|      | South-East Asian                                           |
|      | ndian/Alaskan                                              |
| 1    | lispanic                                                   |
| i    | vixed                                                      |
| ē    | )ther                                                      |
| ì    | Jnknown                                                    |
|      | 2 HALLOW H                                                 |

HCIL's operations is governed by a Board of Directors, the majority of whom are persons with disability. Eighty percent (80%) of its staff have personal experience with disability and are responsible for administering HCIL's program. Thus, HCIL attempts to not only serve disabled, but also employee disabled. This enables us to have firsthand knowledge of how the Rehabilitation Act directly impacts on its target population.

From the perspective of a consumer, community-based center, HCIL requests your attention to the following matters:

### HCIL-DVR PARTNERSHIP

HCIL contracts to provide services to the handicapped and is reimbursed by Federal and State funds which are disbursed through the State Division of Vocational Rehabilitation (DVR). In this capacity, HCIL does not have direct contact with the Federal administration but utilizes DVR as its primary liaison. Although HCIL's relationship with DVR has been a mutually cooperative one, we would like to see an option developed for Centers to receive direct funding from the Commissioner.

Federal administration but utilizes DVR as its primary haison. Although ACIL's relationship with DVR has been a mutually cooperative one, we would like to see an option developed for Centers to receive direct funding from the Commissioner. The State has set up an organizational structure whereby the Department of Social Services and Housing (DSSH) includes not only DVR, but also the Criminal Justice and Public Welfare divisions. This has limited DVR fiscally from contracting and expanding its services for the disabled. Therefore, it was necessary for HCLL to approach the Legislature for Grant-in-Aid funds to subsidize our program. However, during present fiscal year, and next fiscal year the Legislature has appropriated monies through the DVR for the purpose of funding our program. The focus of these funds is for deinstitutionalization, maintaining deinstitutionalization and promoting full integration of disabled and elderly who may or may not have potential for gainful employment.

gainful employment. It is critical that Independent Living services be seen as viable alternatives for the State's disabled to deter institutionalization. In order for this to occur, Independent Living monies cannot be regulated and awarded solely upon an employment and rehabilitation model but also consideration must be given to supportive community services.

### STATE PLAN

Currently, there is a need for guaranteeing and substantially involving disabled people representing Independent Living in the development of the State Plan. Since



this is the document that plans, develops policies and methods for expanding and improving services to handicapped individuals, it is reasonable to assume that Inde-

Improving services to handicapped individuals, it is reasonable to assume that Inde-pendent Living consumer participation would be advantageous. One suggestion would be for Independent Living Centers to be involved in an advisory capacity, de-veloping and signing off on State Plans. A suggested addition to the Rehabilitation Act, Sec. 706-State Plans would be the inclusion of the language that allows for DVR to sign off authority on Part A services only with ninety percent (90%) of these funds applied for Purchase of Serv-ice activity and fifty percent (50%) of that applied to non-profit Centers for Inde-pend. ent Living that meet eligibility standards.

#### SPECIAL NEEDS GROUPS

In the provision of services HCIL has become increasingly aware of the need for expanded, improve rehabilitation opportunities for some special needs groups. One of these groups are individuals suffering from traumatic organic brain syndrom. Although there exists in the State a few neurolinguistic experts, the resources available are very limited. We are seeing more and more of these clients in our agency and are acutely aware of the lack of available services.

Another special needs group is the spinal cord injured. Although, the State has a recognized rehabilitation hospital, its services are limited by DRG regulations. An average of 100 newly injured persons are discharged from the hospital annually. For these people with supportive families discharge into the community may be a smooth transition. However, for those people who lack family support, discharge into the community if often traumatic. HCLL's mission is to ensure community support for these persons who choose indpendent living rather than institutional care. It is our growing experience that disabled individuals lack the knowledge, skills, and coping mechanisms for successful independent living.

In conclusion, society must face the reality that as medical technology becomes more advanced, people are surviving that previously due to the severity of their medical conditions were not expected to live. The challenge is to advance the services at an equal rate to accommodate these persons. In order to accomplish this, a full commitment is required by the Administration and Congress, not just in theory, but in priority funding as well.

### EMPLOYMENT OPPORTUNITIES

As of September 1985, the monthly average unemployment rate for the State of As of September 1985, the monthly average unemployment rate for the State of Hawaii is 5.9% compared to the national average of 6.9%.<sup>1</sup> Additional information reveals that according to the 1970 U.S. Census, over sixty percent (60%) of Hawaii's disabled population, 16 to 64 years, were able to work. Of these, seventy-six percent (76%) were in the working force. During the fiscal year, 1980, DVR placed 662 handicapped persons in the competitive employment of which 149 persons were in sheltered employment. However, according to the Hawaii State Employment Serv-ice, 2,285 or 31% were claimants of benefits due to lack of employment. Although the handicapped appear to be competitive once in the job market in

ice, 2,285 or 31% were claimants of benefits due to lack of employment. Although the handicapped appear to be competitive once in the job market, in 1970, twenty-five (25%) of the handicapped, 16 to 64 years, able to work were not in the labor force. One factor may be that although the handicapped have increased 'heir educational level over the cars, compared to the total population, they have less education and training. For example, in fiscal year 1980, thirty-six percent (36%) of the handicapped applicants did not graduate from high school. Similarly, twenty-five percent (25%) had some education beyond the twelfth (12th) grade—still, comparatively a smaller percentage of thirty-two percent (32%) for the total popula-tion. Training and employment for the disabled is a major goal under the Rehabili-tation Act. Although Hawaii continues to make progress towards this goal, the fact remains that one-fourth (¼) of the disabled determined employable are not working, and one-fourth (¼) of the disabled placed are in sheltered employment. Additionally, equal opportunities for all disability groupe needs consideration

Additionally, equal opportunities for all disability groups needs consideration when statistics show that placement for mentally retarded persons constituted only 7% and mentally restored 8%. Fenales make up one-third ( $\frac{1}{2}$ ) of the total handi-capped placement compared to two-thirds ( $\frac{2}{3}$ ) for males.

In order to illustrate the unique employment needs of disability groups, one disability group for example is the deaf population. As deaf children graduate from the Department of Education (DOE) programs, generally they lack the educational skills to compete with the hearing world. Most of them will not choose higher education





<sup>&</sup>lt;sup>1</sup> Hawaii State Labor Board.

and those that do, will seek to attend Gallaudet College in Washington, D.C. For the majority, employment is difficult due to language barrie.s. In addition, those who secure employment, complain of jobs that offer them no advancement. Civil Service offers some opportunities and the Post Office, for example, has succeeded in employing the deaf. However, rules and regulations stipulate that special consideration in hiring the deaf may only be granted when they are referred through DVR. Since not all deaf individuals who apply for Civil Service positions meet DVR eligibility criteria, the result is some individuals are denied access.

#### ARCHITECTURAL AND TRANSPORTATION BARRIERS

Under the Rehabilitation Act there is established the Architectural and Transportation Barriers Compliance Board functioning to investigate and prepare plans to guarantie adequate transportation and housing for handicapped individuals. Upon investigating Hawaii's compliance, there are some basis barriers to Hawaii's disabled. One barrier is transportation which impedes the mobility of the handicapped and aged. On the island of Oahu there exists a para-transit system, which has a long history of inability to meet the disabled needs. It serves the island geographically on a very limited basis, there is not evening or weekend service, and it is unreliable and time consuming. One person traveling ten (10) miles can expect to possibly sit in the van for  $1\frac{1}{2}$  - 2 hours both coming and going from work. The paratransit system is poorly coordinated, overbooked and basically unable to meet the disabled persons, 0 to 100 years. For those disabled who depend upon the para-transit system for work-related transportation, it can actually impede employability.

Numerous public hearings have taken place over the years with testimonies and evidence substantiating the problem of transportation on Oahu. Neighbor island experience even greater barriers with no public transportation systems. This leaves the disabled and aged literally geographically isolated from equal access to their communitities.

Another barrier to Hawaii's disabled is in the area of housing. The average intionwide vacancy rate for rentals is between 5-6% while Hawaii's rate is between 1-2%. Additionally, low rent rates are rare with an average studio apartment in Waikiki listing for \$450/month. For those individuals who apply to public or federal rent subsidy programs, the wait can be between 6-12 months. If, for example, a person is awarded a Section 8 certificate for subsidized housing their task of finding a landlord/unit meeting criteria is like "finding a needle in a haystack." The community has become less and less receptive to Section 8 recipients due to the stringent guidelines. Eighty percent (80%) of the disabled and elderly served by HCIL earn \$5,000 or less annually with incomes between \$297-\$350/month. Fifty percent (50%) of HCIL clients requesting assistance in locating housing and one-third ( $\frac{1}{2}$ ) of these are Section 8 recipients. Accessible, low-income housing presents further barriers with few buildings meeting accessibility standards. When buildings do have units built to meet minimal standard, there is no enforcement or priority given to guaranteeing that the units are made available to the disabled.

Accessibility and housing barriers continue to be a major handicapping condition faced by persons with disabilities in Hawaii. It is our recommendation that the Board investigate and prepare plans to address these concerns.

Board investigate and prepare plans to address these concerns. In conclusion, HCIL welcomes this opportunity to present testimony in the hope that the good work the Rehabilitation Act has generated will be expanded and continually improved. We would like to especially underscore the importance of the original interpretation and full intent of Section 504. Without this piece of legislation, we as representatives of disabled consumers would have no mechanism for guaranteeing equal participation in our community. Thank you for allowing us this opportunity to present our comments and recommendations.

Mr. WILLIAMS. Ms. Henderson.

Ms. HENDERSON. Greetings, and welcome to Hawaii, Mr. Chairman, and Mr. Hayes.

It is a distinct pleasure for me to have the opportunity to present testimony not only on behalf of the Protection and Advocacy Agency, and the client assistance program locally, but also nationally, since I also serve on the two national boards. So my remarks



<sup>&</sup>lt;sup>2</sup> Seattle, Washington Federal Loan Bank Association.

are going to be somewhat broader than specifically related to Hawaii, if you will.

The Rehabilitation Act of 1973 with its amendments, mandating that client assistance programs be established throughout the United States, is one of the most significant and important pieces of legislation that has been implemented in many years. This is so for many reasons, but particularly in that this is a client-centered program that works to enhance the client's ability, enables them to become participating, contributing members of society.

The Client Assistance Program has proven itself nationally and is meeting the mandate and intent by Congress. Despite delay, it is functioning in every jurisdiction and working to meet client needs, and in partnership in most areas with the local State departments of vocational rehabilitation.

Clients are currently being served and difficult problems being solved, most often through mediation and negotiation directly with VR counselors and VR state administrations.

Nationally, CAP's have been compiling their first annual reports so we don't have real broad data to give you. An evaluation, fully and comprehensively, should be forthcoming and presented to your committee in April 1986.

One of the most crucial results due to the implementation of CAP is we are addressing the entire rehabilitation process. This is from the entry level to and through the full appeals process.

This is the first time in the long history of the irradiation process clients in fact have had objective and outside assistance through other specific client assistance program advocates and representatives. As a result, a very significant piece of information has been uncovered nationally. That is, the administrative appeals process is cumbersome and in dire need of attention.

Currently, the law requires the VR director has the final word and acts at the end of the appeals process. We feel the director should be involved.

However, there needs to be a new mechanism initiated nationally and in place in every single State that enables the client to file an appeal after the director has formulated an opinion at the end of the process.

What has been happening in some States is the CAP has been successful at every stage of the process, and when it ultimately gets to the director's desk, all the results that have been gotten for the client have been reversed.

I would like to strongly recommend and urge that this be added, an initiation of a mechanism that will address the needs of the client by allowing them the opportunity to file an additional appeal to an objective body, and this is allowed in many other State and Federal processes, so this is not a real creative or original idea, that will allow them to appeal further and to also go to court if necessary.

The next item under that would be to have the whole system reevaluated so that it is totally client centered and client directed. I will now comment upon and delineate other crucial and national interests and concerns that are more and more critical from State to State.



First of all, the current law stipulates that the State is the designated payee. There is an urgent need to change this so that the designated agency is the payee. Funds can then be transmitted directly to the client assistance program regardless of whether they are internal to the VR system or external.

The current system has caused many, many problems throughout the United States and in the territories. Funds are not received by Washington in a timely manner; the State itself experience a delay and ultimately there is a further delay from the State-designated payee or the Governor's office directly to the various individual client assistance programs.

There are some States to this date that have not received their fiscal year 1985 funds, and the Federal fiscal year ended September 30, 1985. Therefore, some programs have been fiscally limping along and valiently attempting to comply with the law through creative borrowing even from their local banking institutions and other programs.

This has, of course, created major problems for those programs that are independent, unaffiliated and are totally responsible for running their own shops, if you will. They do not have thousands of dollars of letters of credits that they can depend on.

The specific problems are maintaining quality staff when there are no funds. If most States are complying with regulations, they are in the middle of external audits by certified CPA's, so therefore, the CPA's are further confounded and confused by these delays.

So hopefully, by changing the law, that will enable the cash-flow to come to the designated programs throughout the United States and the services can be continuing and flowing in an orderly manner.

The other issue is that it appears the rehab services administration is attempting to narrow the scope of services to clients in key areas. The client assistance programs around the country recommend that the CAP clients and potential CAP clients, not only for CAP services but for VR services be able to be assisted with any issue or problem as it relates to their ability to function and participate in society.

Particularly crucial are those areas under the Social Security Act and the work incentive, sections 16 and 17, as well as the employment issues that Kristie alluded to earlier under section 504.

People should be able to get help and assistance, whether it is through extra coaching and training support staff so they can be employed and maintain employment. They should be able to be assisted if they have been discriminated in employment under the CAP and VR program.

The other crucial issue is the fiscal authorization level, and I feel that that is totally inadequate not only for Hawaii but for the other minimum allotment States. The law States that the caps should be statewide. It is impossible in minimally funded States that not only includes Hawaii, it includes Montana, Missouri, Utah, Vermont, American Samoa, Northern Marianas, and it goes on and on. So the majority of the States are minimum funded States and since they cannot be statewide on the minimal location they are really in essence in violation of the law. It is our conten-



tion respectively that the States cannot operate and provide any quality service, an individualized service, to persons.

Each State and territory definitely has its own unique needs, but key to the services of every single client assistance program in the Nation is that they're built to attract and maintain dedicated quality professional staff and to provide the individualized personalized services that are needed. No State can do this on \$50,000 and no territory on \$30,000.

I would like to comment further on Hawaii's unique needs. Geography alone is highly unique in that even within the State six populated islands are separated by water. Providing services and training statewide is impossible. Travel is time consuming and expensive. This factor alone would increase operating costs to Hawaii's cap above similar costs to mainland States where expensive area travel is not required to reach all of their State residents. The average cost of a single round-trip ticket to a neighbor island is between \$60 and \$100. We are also, of course, far from the mainland and air travel there is very expensive.

The cost of living is considerably higher than in any other State. Just as an example, the Federal Government here grants a cost-ofliving allowance yearly that is 15 percent higher in Hawaii's Federal Government system than the same Federal employee in Washington, DC, receives. Hawaii is the second most expensive place to live in the Nation. Rent, just for an example here, for office space averages between \$1.50 and \$2 a square foot. Rapid increase in rent costs have been definitely predicted and indicated.

Finally, based on the foregoing, we highly recommend the Federal authorization should be at least \$10 million, with a respective minimum allotment to States and territories at \$150,000 and \$90,000 respectively.

Another key issue that I would like to bring up today is a special work group was convened by the Rehabilitation Services Administration in August 1984 to recommend changes in VR service to improve services for the chronically mentally ill. It was observed that the State VR agencies frequently utilize old and traditional community-based rehabilitation facilities, particularly sheltered workshops, for provision of services to those with chronic mental illness, even though most of these facilities are geared to work with persons with mental deficiencies or physical disabilities.

Traditional rehabilitation practices and intervention mechanisms proven to be successful in working with persons with less severe and stable disabilities often are definitely not appropriate rehabilitation modalities for persons with chronic mental illness. State vocational rehabilitation agencies nationally continue to utilize them in working with this particularly disabled population. I would really like to point out that this recommendation, and these recommendations that resulted from this work group, have not been implemented to date.

As a result of these problems, people with disabilities will often languish in the system until one of several things happen: No. 1, they find their own job with no help from VR, they tire of the nonservice services and stop trying, or hopefully their counselor places them. The fact the counselors know little nationally about the whole issue and ramifications of disabilities, the effort to utilize



new techniques and technology or available expertise in conjunction with the general lack of attention given to the whole point of VR, which is placement, contribute to the alysmal placement record for people with severe or developmental disabilities in employment or workshops. Severely or developmentally disabled adults are most typically placed as homemakers.

\_\_\_\_I would like to add followup services are virtually nonexistent. This is true despite the fact most jobs are lost in the first week or two and irrespective of the insignificant issues which arise for people who may not have worked outside the home for a long time, if at all. The fact there are inadequacies in the system is well documented and needs to be addressed

The issues and concerns I have just delineated for you bring me to my final point to the issue of section D in the law that specifically addresses the needs of severely disabled persons. We urge that the Congress take a very, very close look at implementing this section which is under the comprehensive living section of the act. Implementation of this will allow for a definitive, specific mechanism to reach the severely disabled and severely handicapped and impaired person. This includes the elderly, the blind, the mentally ill, the developmentally disabled as well as many of the spinal cord injured persons.

The vocational rehabilitation system with the newly mandated and innovative client assistance programs throughout the country is the only federally supported system with a broad enough mandate to truly make substantial contributions to the lives of people with disabilities by helping them to overcome obstacles that have prevented them in the past from being full participating members of society and definitely responsible for their own economic self-sufficiency.

I thank you very much for this opportunity to bring key issues to your attention. I sincerely urge you to address them, and I would be happy to answer any questions.

[Prepared statement of Patty M. Henderson follows.]

## PREPARED STATEMENT OF PATTY M. HENDERSON

Greetings and welcome to Hawaii.

As the director for both the Client Assistance Program and Protection and Advocacy Agency in the State of Hawaii, and, as the Region IX board representative to the National Association of Protection and Advocacy Systems and Client Assistance Programs, I am particularly pleased to have the opportunity to present testimony regarding the reauthorization of the Rehabilitation Act of 1973.

The Rehabilitation Act of 1973 with its amendments and mandate that Client Assistance Programs be established throughout the United States is one of the most significant and important pieces of legislation that has been implemented in many years. This is so for many reasons, but particularly in that this is a client centered program that works to enhance the client's ability, enables them to become participating, contributing members of society.

The Client Assistance Programs has proven itself nationally and is meeting the mandate and intent by Congress. Despite delay, it is functioning in every jurisdiction and working to meet client needs, and in partnership in most areas with the local state departments of vocational rehabilitation. Clients are currently being served and difficult problems being solved, most often through mediation and negotiation directly with VR Counselors and the VR state administrations. Nationally, CAPS are currently compiling their annual program performance reports and are gathering data on the events and activities of their first year in operation. An evaluation should be forthcoming on CAPS and will be presented to your committee in April, 1986. One of the most crucial results due to the implementation of CAP is, we



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are addressing the entire rehabilitation process, from entry level, to and through the appeals process. This is the first time in the long history of the rehabilitation process that clients have had objective and outside assistance. through Client Assistance Program staff advocates and personal representatives. As a result, a significant piece of information has been uncovered nationally. That is, the administrative appeals process is very cumbersome and is in dire need of attention 'urrently the law requires that the VR director have the final word and action at the end of the appeals process. We feel the director should definitely be involved in the appeals process. ess, however, there needs to be a mechanism initiated and in place in every state that enables the client to file an appeal after the director has formulated an opinion at the end of the process. What has been happening in some states is the CAP has very successful in assisting clients with the current appeals process until the final stage where the directors dismiss and reverse the preliminary decisions that were made in the client's best interests. On behalf of clients and Client Assistance Programs nationally, I would urge that this cumbersome process by improved upon by: 1. Initiation of a mechanism that will address the reeds of the client by allowing them the opportunity to file an additional appeal to an objective body at the end of

the appeals process or to go to court if necessary and if the case warrants. 2. In general, the entire process should be revaluated so it will be more objective, impartial, client-centered and directed.

I will now comment upon and delineate other crucial, national issues and concerns that are becoming more and more critical from state, to state, to state, and need to be addressed now.

1. Current law stipulates that the state is the designated payer here is an urgent need to change the law to state that the designated agency · payee so that funds can be transmitted directly to the Client Assistance Pr n, bt it an external or internal program.

The current law and system has caused serious problems througout the United States and Terriories and particularly here in Hawaii. Funds are not received from Washington RSA in a timely manner, the state experiences a delay, and ultimately there is the further delay from the state designated payee or Governor's Office to the Client Assistance Program. There are some state designated Client Assistance Programs that to this date have not received their fiscal year 1985 (and the '85 fiscal year ended, September 30, 1985) funds for operating their programs, yet they have continued to fiscally limp along and valiantly attempt to comply with the law through creative borrowing from their local banking institutions and from other programs. This of course has created major problems particularly for the independ-ent, unaffiliated. Client Assistance Programs as they are totally responsible for operating their own organizations and do not have letters of credit anywhere. The specific problems are of course maintaining quality staff when there are no funds, major accounting bookkeeping, cash flow and operational problems. For programs who are currently in the middle of yearend audits by certified public accountaria, the problems and concerns are compounded. When looking at this problem from the outside, the solutions seem simple; currently they are not. By changing the law so that Client Assistance Programs can be the designated payee, as in the Protection and Advocacy Systems across the country, all of the cash flow and operational problems would be eliminated.

2. Currently, it appears that the Rehabilitation Services Administration is at-tempting to narrow the scope of CAP services to clients in certain areas. Client Assistance Programs around the country recommend that CAP clients should be able to be assisted with any issue or problem as it relates to their ability to function and participate in society. Particularly crucial areas that need to be addressed are Social Security and work incentive issues under Section sixteen (16) and nineteen (19) of the law, and employment issues under Section 504 of the Rehabilitation Act.

3. The current national fiscal authorization level for Client Assistance Programs is totally inadequate. Client Assistance Programs that are designated to receive the minimum allotment of \$50,000 or \$30,000 for the territories, are havely able to keep their doors open unless they are greatly augmenting their CAP allocation from other sources. The law states the CAP program should be statewide. This is totally impossible in minimum states and territories such as Montana, Hawaii, Missouri, Utah, Vermont, American Samoa, Northern Marianas, etc. These minimum states are forced to be in violation of the law.

It is not contention respectively that states and territories cannot operate at the current level of funding and provide effective and quality service to individuals. Each state and territory has its own unique needs, but key to the services of every single Client Assistance Program in the nation is their ability to attract and maintain dedicated, professional staff and to provide individual, personalized quality



service to clients. No state can do this on \$50,000. No territory on \$30,000. It has been the philosophy of Federal and State vocational rehabilitation agencies that quality service is what they are about. Even more so is this the philosophy of the newly mandated Client Assistance Program throughout the nation that operate under the same Act.

I would like to comment further on Hawaii's unique needs. Geography alone is highly unique in that even within the state, six (6) populated islands are separated by water. Providing services and training statewide is impossible. Travel is time consuming and expensive, yet very needed. This factor alone would increase necessary operating costs to Hawaii CAP above similar costs in mainland states, where expensive air travel is not required to reach all of their state residents. The average cost of a single round trip ticket to a neighbor island is between \$60 and \$100. We are of course far from the mainland and the availability of support services. Travel, as you know, from Hawaii to the mainland is very expensive. Many mainland cities have available national centers, large universities and other projects that deal with issues related to rehabilitation and disabled persons. Often, we must rely only on our own resources.

The cost of living is considerably higher in Hawaii than almost in any other state. The federal government for example grants a cost of living allowance yearly that is fifteen (15) percent higher in Hawaii's federal government system than the same federal employee in Washington, D.C. receives. Hawaii is the secon 4 most expensive place to live in the nation. Rent for office space averages between \$1.50 and \$2 a sq. ft. Rapid increases in rent costs have been predicted. The State of Hawaii Data Book for 1980 estimates the overall cost of living in Hawaii is approximately 25-30 percent higher than the average cost of living on the mainland. Hawaii has a further diversive ethnic, cultural and linguistic group of people that comprise Hawaii's population. Because of the different cultural traditions in the various groups, the attitudes of the community towards disabled people are very diverse. It is estimated that over eight (8) percent of the population do not speak English, and a much larger percent do not speak English as a primary language. Therefore, to provide scrvices to non-English speaking people requires an additional effort not required in many other states where English, or even English and one other language, are spoken by almost the entire population.

Hawaii's population is increasing very rapidly, especially from immigrants from foreign countries. In 1980, Hawaii's population was estimated to be 942,300, which is an increase of more than twenty-two (22) percent since 1970, when the population was 769,913. From 1968 to 1978, the number of immigrants from foreign countries as a percent of the population increased from 6.5 percent to 7.8 percent. Therefore, a significant number of people that reside in Hawaii are immigrants from foreign countries. The number of new immigrants admitted into the country who reside in Hawaii increased from 3,825 admitted in 1967, to 7,825 admitted in 1977. Further, the number of persons becoming naturalized citizens in Hawaii increased from 1,902 in 1967 to 4,532 in 1977. Therefore, Hawaii's position relitive to other states that have experienced a decline in population, or a lower rate of increase in population than Hawaii, has changed and should be reevaluated in light of recent population then Hawaii in Hawaii, and the unique problems they present for providing services to those who are disabled. No one ethnic group constitutes a majority of the population in Hawaii. In 1978 it was estimated that 26.2 percent of the population was Caucasian, 25.2 percent of the population was Japanese, 19.7 percent of the population 4.3 percent of the population was Chinese, and 15 percent of the population was other ethnic groups.

Finally, based on the foregoing, we highly recommend the total federal authorization should be at least ten million, with the respective minimum allotments to states to be at no less than \$150,000, and territories at \$90,000.

4. A special work group, convened by the Rehabilitation Services Administration in August 1984 to recommend changes in VR Service to improve services for chronically mentally ill adults observed that:

State VR agencies frequently utilize traditional community based rehabilitation facilities, particularly sheltered workshops, for provision of s rvices to those with chronic mental illness, even though most of these facilities are geared to work with persons with mental deficiencies or physical disabilities.

Traditional rehabilitation practices and intervention mechanisms, proven to be successful in working with persons with less severe and stable disabilities, often are not appropriate rehabilitation modalities for persons with curonic mental illness,



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yet State vocational rehabilitation agencies continue to utilize them in working with this disability population.

I should point out that of the recommendations which resulted from this work group, none have been implemented to date.

As a result of these problems, people with severe or developmental disabilities will often languish in the system until one of several things happen: (1) they find their own job with no help from VR, (2) they tire of the non-service services and stop trying, or (3) their counselor places them. This brings me to my next point which is the inadequacy of placement and follow-up services. The fact that counselors know little about developmental disabilities, the lack of

The fact that counselors know little about developmental disabilities, the lack of effort to utilize new techniques, technology or available expertise in conjunction with the general lack of attention given to the whole point of VR—placement—contribute to the absymal placement record for people with severe or developmental disabilities.

Severely or developmentally disabled adults are most typically placed by VR in sheltered employment or as homemakers. Even among the competitive jobs into which a developmentally disabled client might be placed, they are traditionally low paying, menial jobs with little or no opportunity for advancement and are substantially below the individual's capability.

I should also add that follow-up services are virtually nonexistent. Once a client is placed on a job, he or she enters a status 22. In order to move from status 22 to a status 26, successfully rehabilitated, a client must remain on the job. Most often, the only time a client hears from his or her counselor after placement is at the two month period—the purpose of the contact being to verify continued employment. This is true despite the fact that most jobs are lost in the first week or two and irrespective of the significant issues which arise for people who may not have worked outside the home for a long time, if at all. The fact that there are inadequacies in the system is well documented and needs to be addressed.

5. The issues and concerns in #4 above bring me to my final point of the issue of Section D in the law that specifially addresses the needs of severely disabled persons. We urge that Congress take a very close look at implementing this section which is under the Comprehensive Living Section of the Act. Implementation of this will allow for a specific mechanism to reach the severely disabled and severely handicapped and impaired individual.

The Vocational Rehabilitation system with the newly mandated and innovative Client Assistant Program, is the only federally supported system with a broad enough mandate to make substantial contributions to the lives of people with disabilities in this country by helping them to overcome obstacles that have prevented them in the past from being full participating members of society and responsible for their economic self sufficiency.

Thank you very much for this opportunity to bring key issues, concerns and recormendations to your attention.

i sincerely urge you to address them and assist in bringing about the needed change.

Mr. WILLIAMS. Thank you. Mr. Hayes.

Mr. HAYES. Thank you, Mr. Chairman.

We have benefitted by very comprehensive and well-prepared written testimony, which I intend to study and scrutnize at the conclusion of the hearing.

There is one question that I am going to raise of Ms. Mills so as to give me some clarity. Can you tell me the distinction between competitive e.nployment and sheltered employment?

Ms. MILLS. Sheltered employment is generally an organization like the Goodwill Industries, your Salvation Army Industries—are you familiar with that—where somebody is employed but maybe at less than a minimum wage, or they are evaluation training, and if they are employed, which there is a small percentage which are, it will always be at that minimum wage. So they can be anywhere in that process and we considered sheltered employees for division of vocational rehabilitation.

They would not close their services until somebody had gone all the way through the process of evaluation, assessment and train-



ing, and then if they are placed in the shelter workshop the workshop sets, through the Department of Labor, a standard or rate of fee, which can be below minimum wage:

Mr. HAYES. Thank you, Mr. Chairman.

Mr. WILLIAMS. Ms. Mills, does the Center for Independent Living have any suggestions for us as to how we might improve accessibility or affordability of housing for persons with disabilities?

Ms. MILLS. I guess that which you have some controls over is the housing subsidy programs. When I talk about the section 8 certification, I know you have some controls over setting some regulations on that, and that specifically is one area we are having trouble utilizing. We are having trouble assisting a client, and once they have waited their period of time they get their certificate. What they have to do is go out into the community and convince a landlord to rent to them and then they have to meet the standards of section 8.

One of those standards, to me that just doesn't make any sense, says that somebody can't—an individual cannot share—well, when you have already such a high cost of living—and I share—that is the only way I can survive in Hawaii, is to share a three-bedroom apartment at \$750 a month, because I can't afford that. But when you have a section 8 certificate, two unrelated people cannot share. To me that kind of regulation inhibits the ability of somebody to successfully find housing.

Also, I'm not sure, in all honesty, how the States interpret the regulations, but sometimes they go in and place such strict guidelines on a landlord that, you know, if they have a loose piece of tile in their entryway they will say you don't meet certification until you fix that. It makes a landlord not want to bother with the program. The competition here is so fierce, why should they deal with section 8?

Section 8 will not give them their deposit money up front. Landlords want these deposit money because they can get interest in their savings account. Section 8 will guarantee it. And in the end, if they want it back—let's say a tenant has done damage, so they want to use that—they have to get proof of costs, then section 8 will reimburse. Landlords don't want to deal with all that. If there is anything you can do on a Federal level with those kinds of restrictions, that would be helpful. About one-third of our housing recipients are under certification, so that's a large population we are talking about.

Mr. WILLIAMS: Thank you.

Ms. Henderson, you mentioned the necessity of a good followup but the unfortunate lack of it. There is a statement toward the end of your testimony in which you say most jobs are lost in the first week or two. Is that documented?

Ms. HENDERSON. Yes.

Mr. WILLIAMS. Are you referring to all employment?

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Ms. HENDERSON. In general, yes.

Mr. WILLIAMS. And the followup doesn't occur until, I believe your testimony said, the first month?

Ms. HENDERSON. Two months.

Mr. WILLIAMS What happens to the bulk of those people then with regard to counselor contact who have lost their job within that 2-month period?

Ms. HENDERSON: Well; I could only answer specifically for myself: from my own information on that. No. 1, if a client is successful in getting the job; and say it is lost within that first 2-week period and the counselor doesn't follow up until 2 months afterward, you have to begin the whole process again.

Mr. WILLIAMS. Can you trigger a situation where the counselor intervenes back into your difficulty after a person has lost their job? Is there a mechanism by which the counselor can come back and assist you?

Ms. HENDERSCN. There could be if there was more direct counselor followup. Once the person has been placed in the employment situation.

Mr. WILLIAMS: The person could contact the counselor, and that would trigger the counselor in helping to become active again in having that person retain that job or provide him with another job, would it not?

Ms. HENDERSON. That is, of course, a possibility. But you are putting it back on the person who needs some ongoing support in that first 3 or 4 weeks, especially if they have been out of the job market. When I was alluding to that I was raying I think we maybe also need some coaches, some employment coaches along the way until they are more secure within their new employed status; because they have probably been out of the work force for a lot of their adult lives:

Mr. WILLIAMS. Is employment the primary goal of rehabilitation, and should it be?

Ms. HENDERSON. It certainly appears to be the primary goal of the whole rehabilitation process. I think it might depend on what you mean by should that be the only goal of it.

Mr. WILLIAMS. Should it continue to be the primary goal?

Ms. HENDERSON. I don't feel it should be the primary goal. I think something that would enable a person to contribute to society other than just, say, a number, an amount of dollars is equally important, whether that be in day activity programs, sheltered workshop programs, or what have you. They may not be able to go out and compete in the so-called marketplace like the rest of us. Many can and many, many severely disabled cannot. Even with the recommendations of the supportive counselor, all the way up to where they got the job in the first place.

Mr. WILLIAMS. Ms. Mills, should a job be the primary success or cri<sup>+</sup>-ria of one who is in Independent Living?

Ms. Mills. I don't think so. I think you have to look at individuals and their ability to be productive members, and I think, you know, I think our major criticism of sheltered employment is when people end up stuck, that there is no movement through that. I think there should always be a goal for individuals to continue trying to improve their participation.

For someone who has moderate mental retardation sheltered employment is appropriate, then fine, but can they continue, is there a mechanism where they can continue advancing, you know, so that they are not stuck in one corner of a sheltered workshop. I



have worked in them, not as an employee but I've worked as a staff member so I'm real familiar with them, I see lots of people who get stuck there.

The more productive you are, the more you are stuck there. Those sheltered workshops need those employees and they need to pay them under a minimum wage. That is what I would like investigated and looked at.

Ms. HENDERSON. If I may, I would like to support Ms. Mills' last statement, because that is definitely true, that people do end up getting stuck, if you will, in sheltered workshop situations, particularly when they start becoming more productive and may then be able to go out and compete in the marketplace and get a job, because they are so beneficial to the system.

Mr. WILLIAMS. Well, you both have been very helpful to this subcommittee and we appreciate your testimony and the testimony of all those who have provided it for us this morning. This afternoon at approximately 1 o'clock, this subcommittee will convene to hear the education of the handicapped reauthorization testimony. Thank you all.

# [Additional material submitted for the record follows:]

### PREPARED STATEMENT OF THE COMMISSION ON THE HANDICAPPED

The Commission on the Handicapped is pleased to have this opportunity to respond to the House Subcommittee on Select Education's request for testimony concerning the reauthorizations of the Rehabilitation Act of 1973 and the Education of the Handicapped Act.

Our Commission is not a direct service provider. However, we are mandated by the State of Hawaii to review and assess the problems and needs, and the availability, of adequate services and resources for disabled persons in Hawaii including those related to vocational training and rehabilitation and education.

### THE REHABILITATION ACT OF 1973

In response to your questions relating to how well the Act is working and how the State-Federal partnership is evolving, we are of the opinion that our State is progressing satisfactorily. However, we do believe that efforts should cortinue to be directed towards not only reauthorizing the Act but to also ensuring that the delivery of services to disabled clients continues to keep pace with our changing world. We are becoming more cognizant of the emergence of a new group of clients re-

We are becoming more cognizant of the emergence of a new group of clients requiring more complex vocational rehabilitation services than those traditionally provided. This group encompasses individuals with learning disabilities, mental illness and head injuries. We recommend that guidelines be developed towards ensuring that these disability groups be more equitably processed and that employment goals be developed to parallel their capabilities.

With respect to other suggestions relating to changes, we would strongly recommend that vocational rehabilitation services for clients include closer monitoring and follow-up once clients are placed in employment situations. It has become increasingly apparent that follow-up services are a most vital component in ensuring that job placements are long lasting. In addition, VR services for extended supported employment services for severely handicapped adults are often not feasible due to the time limited nature of VR services as presently structured. This should be adjusted accordingly.

We would like to also suggest that Congress take an active role in clarifying the intent of Section 504 of the Rehabilitation Act to broadly define "program or activity" and "reasonable accommodation". The lack of clear intent and guidelines has severely hampered the full implementation of Section 504.

### THE EDUCATION OF THE HANDICAPPED ACT

With respect to assessing the need of reauthorizing the discretionary programs under the Education of the Handicapped Act, it is our firm belief that the Federal government should not discontinue its financial commitment to the states. We are



at that point where we are seeing the first generation of special education students who have received the benefits and protection afforded by P.L. 94-142 making the transition into college or the working world. Ve are also seeing that along with this transition are the emergence of new problems relating to the lack of preparedness at the school level in planning for adult life. Now, more than ever, we need to continue federal support of research programs that can deal with these problems in creative ways.

We also urge the continued support of the Federal government of Part B of the Act. Without continued financial assistance we can only forsee the disintegration of education for our handicapped youth as well as a corresponding increase in the numbers of persons requiring lifelong subsidization or institutionalization. The reality of no federal financial support would be that many handicapped children unable to fit into available programs would be forced to sit idle in hallways and gyms.

In answer to your question relating to proposed changes to the provisions of the legislation, we would recommend the development of a mechanism for binding resolution of issues pertaining to purely educational matters. Our office houses the Special Parent Information Network (SPIN) which provides information and referral and more importantly, parental support to parents of special education children. By far, a large portion of the phone calls taken by our coordinator and parent volunteers deal with problems involving L.E.P.'s. Far too often these problems wind up in the courts even after a due process hearing is conducted and a decision is rendered. The time lapse involved in the judical resolution of these cases usually results in the child not receiving services for too long a time. Therefore we could welcome the addition of appropriate language that would address this area of concern.

We believe that several areas need to be clarified by Congress in the authorizing legislation of P.L. 94-142 rather than leaving interpretation to rules and regulations promulgated by the states or interpretations handed by the courts. In particular these include 1) the clarification of transportation as a related service which is critical to most children's special education program, 2) a requirement for mandated inter-agency agreements so that financial responsibility for programs does not fall solely on education departments, and 3) the ability of parents to receive attorneys' fee in cases in which they prevail.

In conclusion, we would again like to thank you for this opportunity to present comments.

[Whereupon, at 12:25 p.m., the subcommittee recessed to 1 p.m. of the same day.]

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