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**ABSTRACT**

The transcript of the 1986 House of Representatives hearings on amendments to the Rehabilitation Act of 1973 contains verbatim testimony and committee questions, prepared statements, letters, and supplemental material. The Amendments require state plans to address rehabilitation engineering services, the development of mechanisms to provide technological devices to the disabled, restructuring of federal rehabilitation agencies, and provisions for increasing the state contribution from 20% to 25%. Organizations providing testimony or statements include: National Association of Rehabilitation Facilities; National Rehabilitation Association; Association of Retarded Citizens; Easter Seal Society; Matrix Institute; Council of State Administrators of Vocational Rehabilitation; Helen Keller National Center for Deaf-Blind Youths and Adults; American Cancer Society; National Council of Independent Living; National Federation of the Blind; National Council on the Handicapped; and American Rehabilitation Counseling Association.

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**THE REHABILITATION ACT AMENDMENTS OF 1986**

**HEARING**  
BEFORE THE  
**SUBCOMMITTEE ON SELECT EDUCATION**  
OF THE  
**COMMITTEE ON EDUCATION AND LABOR**  
**HOUSE OF REPRESENTATIVES**  
NINETY-NINTH CONGRESS  
SECOND SESSION

HEARING HELD IN WASHINGTON, DC, JANUARY 29, 1986

Serial No. 99-108

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## THE REHABILITATION ACT AMENDMENTS OF 1986

WEDNESDAY, JANUARY 29, 1986

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 2261, Rayburn House Office Building, Hon. Matthew Martinez (acting chairman) presiding.

Members present: Representatives Hayes, Martinez, Bartlett, and Jeffords.

Staff present: S. Gray Garwood, majority staff director; Robert Silverstein, majority counsel; Colleen Thompson, clerk; and David Esquith, minority legislative associate.

Mr. MARTINEZ. The Subcommittee on Select Education of the Committee on Education and Labor will come to order.

I would like to welcome you to this hearing on the Rehabilitation Act Amendments of 1986, introduced January 21, 1986. My colleague and the chairman of this subcommittee, Pat Williams, had to return to his district to attend a public hearing of extreme importance to his constituents. He asked me to express his regrets in his absence and assure you he will review your remarks upon his return.

We have held five hearings throughout the last several months. We have heard from disability groups and other consumers, Federal and State administrators, service providers, counselors, and others. The comments have been most helpful.

H.R. 4021 contains many of the ideas and suggestions we have heard. I won't mention them all, but I would like to mention some just to indicate the nature of the proposed changes.

Frequently witnesses highlighted the need for new technology and commented on the lack of access by persons with disabilities to existing technology. To address this need, H.R. 4021 requires that each State plan describe how rehabilitation engineering services will be used, or developed, to provide assistance to persons with severe disabilities.

Further, the Director of the National Institute for Handicapped Research is directed to present to Congress, within a year, recommendations for establishing an effective mechanism to ensure the development, cost-effective production, and efficient distribution of technological devices to persons with disabilities.

(1)

Witnesses also commented on issues related to leadership and management of rehabilitation programs. To address these concerns, H.R. 4021 requires that in the future, the Rehabilitation Services Commissioner and Director of the National Institute for Handicapped Research be appointed by the Secretary of Education. All three will continue to report to the Assistant Secretary of the Office of Special Education and Rehabilitative Services.

Other changes include restoration of language that will allow the Rehabilitation Services Administration to provide technical assistance to State agencies. Language is added to require evidence of due cause before an existing Client Assistance Program provider can be terminated.

Also, the Secretary is now required to transmit funds directly to the agency. H.R. 4021 makes changes in a State agency's review procedures to afford an individual the opportunity to submit additional information. In addition, the Director's final decision must be in writing and must specifically state reasons for the decision, and a copy must go to the individual affected.

One of the more significant changes is in the Federal-State match requirement, which for some time has been an 80-20 Federal-State match. Repeatedly, we have heard that the system is not serving anywhere near the number of persons eligible for services under the act.

It is also clear that investment in rehabilitation is a sound investment, the returns for which far outweigh the costs. Therefore, it is time that States assume a larger share of the financial responsibility for the services provided their citizens. H.R. 4021 changes the match to 75-25, while ensuring the State's contributions don't fall below their highest level.

Today we will hear from all parties affected by this reauthorization language. We share with you a genuine concern that our Nation's rehabilitation system has the capability to provide quality rehabilitation services for all eligible persons. We look forward to your constructive comments and recommendations for making this happen.

Mr. Bartlett, do you have a statement?

Mr. BARTLETT. Thank you, Mr. Chairman.

Mr. Chairman, today's hearing on H.R. 4021, the Rehabilitation Act Amendments of 1986, seems to me to be conducted in a significantly different economic and budgetary climate than in any previous year of the 60-plus years of this program. Because of our current budget deficit at the Federal level in the aggregate, a Congress that conducts business-as-usual in 1986 will inflict a great deal of hardship on millions of disabled persons.

This is the opening hearing on an extremely high priority Federal program, the Rehabilitation Act. It is a good time, it seems to me, to begin discussion of the broad budget context within which this reauthorization occurs.

First, let me say that I don't regard this as a partisan issue in any way, shape or form. With Gramm-Rudman in 1986, both sides of the aisle, both on this subcommittee and in the Congress as a whole, will have to and should discuss, grapple with, and help together to make those hard choices that will set the right priorities for the Federal budget.

I look forward to working with the members of this particular subcommittee to make that process work. Before I address that subject, let me say that H.R. 4021 I think represents a good beginning in the reauthorization of the Rehabilitation Act.

I particularly commend Chairman Williams and his staff for their work. I do support the reauthorization of the Rehabilitation Act as I did several years ago in the last reauthorization and I recognize it as one of the most vital Federal programs that serve persons with disabilities.

Its long and distinguished history of training disabled persons to work and to return to work is testimony to the devoted individuals who work within and advocate for the program. This is a cost-effective program which according to most calculations returns \$10 of income to the Government for every one Federal dollar that is spent.

Unfortunately, its continued growth and spending power is currently threatened by our current budget deficit. As we go through the reauthorization of the Rehabilitation Act itself, we will, of course, address all of the issues but I plan to, as I have in the past, focus on three areas: an emphasis on new technologies, employment as an outcome, and an emphasis on the service to the severely disabled.

Now, back to the budget deficit. The size of the budget deficit has compelled Congress, as we all know, to pass an act entitled Gramm-Rudman, which contains a sequestration process. That sequestration process is a matter of law and it contains a certain inevitability unless we on this subcommittee and in the Congress as a whole act to set priorities differently.

Sequestration is essentially an enforcement mechanism. It will be triggered only if Congress and each of us fail to meet our responsibility to reduce the deficit by the targetted amount specified in the process that was passed by the Congress and signed into law.

Now, while I believe there is an enormous negative impact of sequestration if it occurs on Rehabilitation and the Education of the Handicapped Programs, let me remind ourselves that, in fact, as bad as sequestration is, ultimately, even sequestration would be more desirable than leaving the budget deficit to grow unchecked.

Nevertheless, there is an opportunity within the budget process for priority budgeting that is far better than sequestration. Let me take this opportunity to go on record to say that I plan to work with the members of this subcommittee specifically to propose a plan which will spare the Rehabilitation Program and the Education of the Handicapped Programs from a sequestration order.

We cannot do that without making hard choices right here on this subcommittee and we cannot do that, unfortunately, by pointing to other committees and saying, "let some other committee make those choices". In order to accomplish that, I am advocating that a priority budget for the Select Education Subcommittee be devised with those two programs receiving the highest priority, as well they should.

For the fiscal year 1987 budget, I will propose that aggregate reductions for the subcommittee be drawn from those programs of lower priority until the target aggregate is met. This will mean that some programs will be placed on a funding moratorium. If this

occurs in the programs within the subcommittee's jurisdiction, in my judgment, Vocational Rehabilitation and Education of the Handicapped should be protected.

If Congress conducts business as usual and does not set those priorities, then the negative consequences to those two programs will be enormous. If Congress allows sequestration to occur, the cost of living increase provided within the Vocational Rehabilitation Program would be eliminated. By my calculation, that results in a loss of approximately \$52 million in fiscal year 1987 if we do nothing at all.

The impact of sequestration on the Education of the Handicapped Programs would be many times greater. Again, assuming a sequestration order of 25 percent for fiscal year 1987, the estimate is that Education of the Handicapped would incur in the first year a cut of approximately \$320 million. This figure represents only the impact of the sequestration order for 1987. If one assumes a sequestration order of 25 percent for each of the fiscal years through 1991, then the Education of the Handicapped appropriation for fiscal year 1991 will be 22 percent of its fiscal year 1986 appropriations or approximately \$320 million total.

The stakes are enormous, and it is up to this subcommittee and to the Congress as a whole to set a priority budget to cause that budgeting to occur within a rational way. To my mind, the major task before Congress this year is to determine a systematic, equally distributed, across-committee jurisdiction plan to avoid sequestration and spare programs such as Vocational Rehabilitation and Education of the Handicapped from across-the-board cuts.

If Congress defaults on its responsibility and allows sequestration to occur, then it is in effect saying that all programs are created equal, and I don't believe that is true. I don't believe that my colleagues on this subcommittee take that position either.

The solution to avoiding sequestration must involve a contribution by each Member of Congress and by each congressional committee and each subcommittee and cannot include an attitude that I know we don't have on this subcommittee that some other committee will take care of the problem.

The problem is all of us and the solution is for all of us to obtain. Mr. Chairman, thank you for the additional time.

Mr. MARTINEZ. Thank you, Mr. Bartlett.

Our first panel consists of two people, David Mentasti, director, Vermont Department of Services for the Blind and the Visually Handicapped, representing the Council of State Administrators of Vocational Rehabilitation, and Richard Switzer, deputy commissioner, New York State Office of Vocational Rehabilitation, representing the Council of State Administrators of Vocational Rehabilitation.



**STATEMENTS OF DAVID MENTASTI, DIRECTOR, VERMONT DEPARTMENT OF SERVICES FOR THE BLIND AND THE VISUALLY HANDICAPPED, REPRESENTING THE COUNCIL OF STATE ADMINISTRATORS OF VOCATIONAL REHABILITATION; AND RICHARD SWITZER, DEPUTY COMMISSIONER, NEW YORK STATE OFFICE OF VOCATIONAL REHABILITATION, REPRESENTING THE COUNCIL OF STATE ADMINISTRATORS OF VOCATIONAL REHABILITATION**

Mr. MENTASTI. Mr. Chairman, good morning.

Dick Switzer and I are here representing the Council of State Administrators of Vocational Rehabilitation. On behalf of the council, we appreciate this opportunity to present this testimony and we are pleased to be part of this testimony today. Before I begin our formal presentation, I would like to mention a sudden illness has regrettably prevented Susan Suter from being with us. Mrs. Suter is the director of the Illinois Department of Rehabilitation Services. They send her apologies and she has asked me to compliment the members of this subcommittee for the fine work you have done in this reauthorization process.

The Council of State Administrators of Vocational Rehabilitation is an association comprised of the chief administrators of the public rehabilitation agencies for persons with physical and mental disabilities in all the States, the District of Columbia, and our Nation's territories.

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 effectiveness 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.

The council appreciates this opportunity to provide the subcommittee with information on the rehabilitation program, and its views of H.R. 4021, the proposed Rehabilitation Act Amendments of 1986.

The core of America's rehabilitation 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 coordinates a wide range of services for eligible persons with disabilities.

These services are provided with the cooperation of, and through, private, nonprofit, community-based service providers and facilities.

The primary purpose of the provision of vocational rehabilitation services is to render employable eligible persons with mental and physical disabilities who, because of the severity of their handicapping condition, are unable to secure or hold employment.

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

In one act, provisions are included for: One, a comprehensive and individually tailored program of vocational rehabilitation services

to individuals with physical and mental disabilities; two, a training program; three, a research program; four, a program providing comprehensive services in independent living; five, a rehabilitation facilities program; six, a community services employment program; and seven, 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.

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, therefore, are extremely pleased with the measure introduced last week by Chairman Pat Williams, and several members of this subcommittee. The bill recognizes that the Rehabilitation Act is an extremely well-written and well-balanced statute which establishes the foundation for providing quality rehabilitation services to persons with mental and physical disabilities.

We are pleased that H.R. 4021 recommends the extension of the Rehabilitation Act for 5 years.

This extension is needed to ensure program stability in the State-Federal Rehabilitation Program and to ensure the continuation of the provision of quality services to the millions of disabled Americans who are in desperate need of rehabilitation.

This is important for it will give the States a clear indication of the future Federal commitment to the rehabilitation program and the persons eligible for services.

We are heartened by the authorization levels provided in the bill for section 110, rehabilitation service grants, for fiscal year 1987 and beyond.

Rehabilitation service grants 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 whose disability constitutes a substantial handicap to employment.

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.

In times of scarce resources, State agencies are required by the law to focus those resources on the provision of services to the most severely disabled persons, yet not stop providing services to other eligible groups of individuals.

Due to the increased costs of serving the more severely disabled, and the deterioration of the strength of the rehabilitation dollar, there has occurred since 1979 a marked decline in the number of persons served annually by State agencies, from a 1979 level of 1.1 million persons to under 935,000 persons in 1985.

Specific authorization levels are needed beyond fiscal year 1987 if the State-Federal Rehabilitation Program is expected to, at the least, equal its 1979 level of achievement.

It is now undisputed in the Congress and the administration that the authorizations for rehabilitation service grants constitute a legal capped entitlement.

We urge the subcommittee to build upon the fiscal year 1987 authorization level currently in H.R. 4021, as well as the strengthened entitlement feature, and provide specific authorization levels for fiscal year 1988 through 1991 at levels which will restore the purchasing power which has eroded since 1979.

There is no greater frustration to State rehabilitation administrators and advocates than the knowledge that adequate resources do not exist to provide services to eligible persons with disabilities.

The bill contains a recommendation to alter the Federal-State match ratio from the current 80-20 percent, to a proposed 75-25 percent.

To the extent that the subcommittee is seeking to discover ways to increase State as well as Federal resources for the provision of rehabilitation services, the council is enthused.

However, at this time it is not clear whether some States would face significant difficulties in meeting the requirements proposed in these provisions.

For any program to be successful, it 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 council is pleased that recommendations contained in H.R. 4021 recognize not only the wisdom of the Rehabilitation Act, and the need for additional resources, but also the need for more effective and coordinated leadership.

The bill recommends that the Commissioner of the RSA and the Director of the NIHR be appointed by the Secretary of Education, and contains certain requirements relative to the qualifications of the NIHR Director.

In addition, we believe the qualifications for the RSA Commissioner should be a requirement of the law, to assure that an individual with substantial experience in rehabilitation is appointed to this important position.

We believe that these recommendations could enhance the level of expertise and commitment of our Federal rehabilitation leaders, and also increase the level of cooperation and coordination between them. These are irreplaceable elements for any State-Federal program.

H.R. 4021 contains a number of provisions which we believe would improve the management of the State agencies, and enhance the quality of personnel working for State agencies.

During the hearings on the Rehabilitation Act held throughout the summer of 1985, this subcommittee heard from any number of

organizations and individuals about the quality and cost efficiency of technical assistance services once provided to State and private rehabilitation facilities.

The council welcomes the emphasis in the bill which is placed on restoring these important grants. It will enable rehabilitation facility managers to employ more cost-efficient management techniques and thus provide better services.

With respect to rehabilitation agency personnel, H.R. 4021 contains two important provisions.

By stressing the importance of qualified rehabilitation personnel, and especially by requiring recipients of Federal rehabilitation scholarships to serve a minimum tenure at a nonprofit or State rehabilitation agency, the bill would help to provide the public rehabilitation system with a significant number of professionally trained rehabilitation service providers.

H.R. 4021 contains two specific provisions relative to the scope of rehabilitation services—one on post employment services, and one on rehabilitation engineering.

The council is supportive of any effort which will enhance the provision of either time-limited, postemployment services or rehabilitation engineering services that might be needed to assist any eligible person with a disability in their effort to attain an employment goal.

As previously stated, the council firmly believes that the authorization level included in H.R. 4021 for section 110, rehabilitation service grants, for fiscal year 1987, will continue the efforts of the Congress to restore the purchasing power of the rehabilitation dollar to the levels achieved in 1979.

Again, the council suggests the need for specific authorization levels for fiscal years 1988 through 1991 for rehabilitation service grants at levels equal to a rise in the cost of living plus such sums.

With respect to other programs authorized by the act, the council would recommend that all authorizations be set at "such sums as may be necessary."

The council is encouraged by the cost-of-living adjustments included for most programs in H.R. 4021. However, some of these authorization levels—especially those for part A of title VII, comprehensive State independent living services—are too limited when viewed in relation to the needs and hopes of America's citizens with mental and physical disabilities.

The council stands ready to provide technical assistance, opinions, or suggestions to the subcommittee or any member thereof as the rehabilitation process continues.

The council compliments the subcommittee and its staff for their great concern for the rehabilitation program and for the people it serves.

Thank you.

[The prepared statement of David Mentasti follows:]

PREPARED STATEMENT OF DAVID MENTASTI, DIRECTOR, VERMONT DEPARTMENT OF SERVICES FOR THE BLIND AND VISUALLY IMPAIRED

Mr. Chairman, I appreciate the opportunity to present this testimony and I am pleased to be part of this effort today. I represent the State Agency in Vermont

which is responsible for the administration of the federal-state program of vocational rehabilitation for persons who are blind and visually impaired.

Basically, I can support the proposed changes to the Rehabilitation Act which are contained in the bill under consideration. I believe that these changes will improve and strengthen services to persons with disabilities. The bill recognizes and would maintain the balance and comprehensiveness which have made the Rehabilitation Act one of the most effective pieces of social legislation.

I was particularly pleased to see those provisions of the bill which would establish a rural research and training center and would restore the opportunity for technical assistance.

Vermont is a rural state, in fact, by some definitions it is the most rural state in the nation. As such, we face some special service delivery needs which are not shared, to the same extent, by our more urbanized and industrialized neighbors. Population distribution, resource clustering, transportation and employment opportunities are but some of the issues which challenge rehabilitation in a rural environment. A research and training center which focused on "rural issues" would be a much needed resource to begin to address some of these concerns.

Restoring the opportunity for the states to tap into a pool of technical assistance will enable us to improve our service delivery systems by extending our capabilities. As a past recipient of federally-sponsored technical assistance services, I can attest to their value and worth. The technical assistance helped to focus the particular issues involved and provided an expertise which would not have been available otherwise.

In fine-tuning the provisions of this bill, there are several concerns which I would like to bring to your attention. The bill would increase the states' participation to 25% in the Basic Support program, effective in FY 87. My concern is with the effective date of this change. In Vermont, we are required to submit a biennial budget and our budget for FY 87 is now before the state legislature. This budget was constructed assuming 80% federal participation in our vocational rehabilitation program. Since our legislature traditionally adjourns in April, the additional state matching requirement would create a difficult situation for our agency. Therefore, I would suggest that implementation of the increase be postponed until FY 88 in order to allow state agencies time to incorporate the change in their budget planning processes.

Another topic area I would like to mention involves the State Agency's review procedures. In Vermont there is a state law which establishes a fair hearing procedure for all clients of our parent agency. This review process seems even fairer to clients than the protections contained in current law. I would suggest that the states be offered an option in this area.

Lastly, I would like to comment on the authorization language for Title VII, Part C: Services to Older Blind Individuals. The bill calls for "such sums as may be necessary for each of the fiscal years . . .", however, I am not sure that this language will provide the continuity and stability for this new and long awaited program initiative. Authorization targets would give a clearer indication of Congressional intent with respect to this program and thus facilitate forward planning at the state level.

In closing, I would like to, once again, commend this Subcommittee for its outstanding work in this reauthorization process and to thank you for this opportunity to comment.

Mr. MARTINEZ. Thank you.

At this time the Chair would like to recognize Congressman Jeffords.

Mr. JEFFORDS. Thank you very much.

I am sorry I had to be delayed, but we were releasing a very important study on the work program. Being a major participant in that, especially on the conference committee this afternoon, I had to be present at the release of the results of that study.

I do appreciate your being here. It is good to have you. You made an excellent statement.

I am aware of the content of it and did hear the last part of it. I would like to ask you—that is a problem which is going to be occurring not only here, but in other programs, as to the impact of the shifting of more of the burden to the States on programs like this. I believe in your statement you indicated that Vermont has

just been able to meet the matching requirements under the present law.

Under this proposal there would be a further shift of another 5 percent to the State. Taking into consideration the ramifications of the Gramm-Rudman bill, Gramm-Rudman-Hollings, I will shorten it down even further to G-R because that probably expresses better how we feel about the bill, but I would ask you whether or not the States, especially Vermont, having had its problems with deficits and all, will be likely to meet the additional burden of additional match in the immediate future, taking into consideration that we may be dumping another somewhere between \$10 and \$20 million onto the State of Vermont for other programs?

Mr. MENTASTI. I guess my major concern with that change in the matching requirement is the effective date. The budget, the State budget, is before our State legislature and that budget was constructed assuming an 80-20 percent matching ratio. As you know, our legislature adjourns hopefully in April and it would be very difficult to then go and get those additional matching funds that would be required.

Again, my concern is the effective date. I would suggest that the subcommittee might consider postponing the effective date until fiscal year 1988 to give the States a chance to plug that into their budget planning processes.

But it would be close even if we had a sufficient information warning in terms of coming up with these additional matching requirements. If applied to the appropriations in 1986, that would have meant about another \$330,000 in State funds this year alone.

You know in Vermont that is a chunk.

Mr. JEFFORDS. Thank you. I appreciate that.

I would only comment that perhaps another solution would be for Congress to get out of here at the end of April and that would probably make all of us much happier.

Thank you very much.

Mr. MARTINEZ. Thank you, Mr. Jeffords.

Of course, I knew it was going to happen that now Gramm-Rudman will be the scapegoat for everything and, of course, we passed Gramm-Rudman. I should not say "we" because I voted against it, but some hard choices have to be made and people have to learn to live up to that responsibility without passing a bill like Gramm-Rudman and using it as a scapegoat for everything.

Before we recognize Mr. Switzer, I would like to remind the witnesses that your testimony as written is entered in the record in its entirety and, of course, we ask you to summarize your testimony.

Mr. Switzer.

Mr. SWITZER. I would like to ask Dave while Mr. Jeffords is still here, I would like Dave to complete his testimony on the State of Vermont. We were going to go into New York and back to Vermont, but let Dave finish his testimony on the State of Vermont.

Mr. MARTINEZ. Would you summarize, please?

Mr. MENTASTI. Sure. There are several provisions of the bill which I was particularly pleased to see.

One would be the establishment of a rural research and training center, and the other is the technical assistance. You know Vermont is a rural State. In fact, by some definitions, it is the most

rural State in the Nation. As such, we face some very special service delivery needs which are not shared by our more urbanized, more industrialized neighbors, population distribution, resource clustering, transportation, employment opportunities.

If there were a rural research center that focused on some of these issues, that addressed some of these issues, I believe it would be to our advantage in providing services to the disabled.

In terms of the technical assistance, as a past recipient of federally-sponsored technical assistance, I can personally attest to their worth and value. What happens is that it enables you to extend your capability. It helps focus some of the issues involved and, again, it brings an expertise to bear that would not be available otherwise.

Now, again, I think that the reauthorization is very well done, very well worded, but in the interest of fine-tuning again, there are several concerns that I would like to bring to your attention. One I have already mentioned, that being the effective date of the increase in the matching requirement.

I do believe Vermont would not be alone in terms of feeling the impact of such an increase. Another topic area I would like to mention involves the State agency review procedures. In Vermont, there is a State law which establishes a fair hearing procedure for all clients of our parent agency.

This review process seems even fairer to clients than the protections contained in current law. I would suggest that States be offered an option in this area. Lastly, I would like to comment on the authorization language for title VII, part C, services to older blind individuals.

The bill calls for such sums as may be necessary. However, I am not sure that this language will provide the continuity and stability for this new and long awaited program initiative. Authorization targets would give a clearer indication of congressional intent with respect to this program and would certainly facilitate planning at the State level.

Those are the major points.

Thank you, Mr. Chairman.

Mr. MARTINEZ. Thank you.

Before we ask any questions, we will hear from Mr. Switzer.

Mr. SWITZER. I am Dick Switzer, deputy commissioner of OVR, New York State. I just want to comment a little bit on the linkages with CSAVR and the Federal Government and States. I have to reminisce a little bit.

The late Mary Switzer, who was the great leader back in the fifties, sixties, and seventies, felt that it was extremely important to develop a council of State administrators to work very, very closely with RSA and the Federal Government to offer the technical assistance we can give committees like yourselves in improving the rehabilitation techniques and the rehabilitation program for the country.

That is why we are here. We are here primarily to help you and answer any questions you may have and give you the guidance that we feel is important in keeping this program going. If I was to summarize my formal statement, I would summarize it in this way. The vocational rehabilitation program is a partnership, a partner-

ship between the State, the Federal Government, but more important—and you are going to be hearing more of this, I think, this morning—the linkage and the partnership with the rehabilitation facilities, with the handicapped agencies, whether that be United Cerebral Palsy, whether that be HRC or any other parent organization.

It is a team approach, if you will. No matter what the appropriations are going to be, and it is very important that we get the appropriation, neither the State vocational rehabilitation agency nor RSA or OSERS can do the job alone. I am not sure if Congress is fully aware that when we offer the technical assistance to the rehabilitation facility we are only paying, in New York State anyway, approximately 50 to 75 percent of the total cost.

The difference is made up through fund raising and through hard work of the HRC's, United Cerebral Palsy, et cetera. We would not be able to do the job if it was not for our colleagues in this not-for-profit movement. We work as a team, as a partnership.

Going and reviewing my formal remarks which you have already received, last year New York State rehabilitated 10,000 individuals and placed them in competitive work. Of that 10,000, 60 percent were severely handicapped.

Over the last 30 years going back to when the Rehabilitation Act was first reauthorized, we rehabilitated well over 100,000 individuals. I bring that statistic to your attention when you think of the cost effectiveness of this type of program. Think in terms, if we were to do the charts, of the tax dollars saved and coming back to the Treasury due to the fact so many individuals were rehabilitated.

When I work closely with my legislature on the rehabilitation movement, they are proud of the partnership, if you will, between New York and the Federal Government because they know it pays off. It is probably the only human services program that does pay off. As far as the length of the reauthorization, I do support and agree with my colleagues in CSAVR that it should be a 5-year period, not 3, at least 5 years.

I would like to see it extended because of the stability it offers, the continuity. Every 5 years we have to be going through this and I would like to see that the Federal Government is taking their stand.

We need the Federal Government as the leader in this field. As far as the amendments affecting Indians and the Indian tribes, that is some of the major amendments and changes in the Rehabilitation Act, I am for that.

We do have a number of Indian reservations in upstate New York and in New York. But I am also concerned that you consider this Hispanic and the Asian population, as well. In New York City, we have a tremendous problem in dealing with the Hispanic disabled, not so much that we don't know how to rehabilitate them, but the training programs that have to take place with our counselors in working with the Hispanic, understanding the culture as well as solving their problem of disability.

I think it is extremely important built into the act which you have already done in the amendment is the thing to collect data. I think statistical data is extremely important. The taxpayer has a



right to know what they are getting for their tax dollars and the only way you can achieve this is selecting the statistical data, forwarding that to RSA and then in turn RSA giving it back to the Congress, if you will.

That is an extremely important part of the act. Rehabilitation engineering, that has already been commented on. With modern technology and the age of robots, we now can take a quadriplegic individual, we can take a retarded individual and through the touching of buttons they now can do competitive work.

A serious problem in most of the States related to this. Do we invest the \$10,000 necessary for a severely handicapped individual to buy those computers and those devices? I say yes. If we are investing dollars for artificial limbs and prosthetic devices, we should be investing dollars for that, but I am all in favor of that engineering part of the change in the Rehabilitation Act.

Postemployment, extremely important. If you look at our statistics on those that make it and fail in the rehabilitation movement, they fail because we get them the job and we don't follow through. So this will enable the counselor to do the followup of having that individual maintain the job, particularly when you are talking about the severely handicapped, particularly when you are talking about the retarded, particularly when you are talking about the head injury or learning disabled.

It is important that we give them the extra crutch that they will need to maintain the competitive employment. I agree with the authorization statements of the \$110. If you will, that is the base of the whole rehabilitation program and I agree we have already commented on the importance of the funding of both A and B of the independent living program.

Independent living, by the way, is one of the hot issues, at least in New York State, and in a sense, it is another example of the partnership of Federal and State. It is interesting that the Federal Government in a sense is supporting in New York State 8 of our independent living centers, however, we have 19.

The legislature saw fit to have more independent living centers throughout the State of New York and they, in a sense, should hear me now, don't mind appropriating the money for this sort of thing. They are beginning to understand the cost-effectiveness of vocational rehabilitation.

So that is why I do agree with the 75-25 match that you are proposing in the amendment. The reason for that, it kind of makes the State make a commitment to the movement. I am concerned that there are some States that won't be able to do this.

I am concerned, as my colleague pointed out, about the time frame on this when you are planning your budgets a year in advance so that the people can appropriate this. But it kind of makes the State committed to the movement.

Let me just touch training a little bit. Training dollars are extremely important. With new technology, with bioengineering, rehabilitation engineering, with the changes of disabilities, the counselor has to be trained. The individuals working with the handicapped, whether that be in a rehabilitation facility or whether that be with the State, local authority, have to be involved in this.

Training dollars are extremely important and should not be continued, in fact, increased, in my opinion.

Let me briefly talk about Projects With Industry, PWI. We have come a long way since 1973 in getting our colleagues in business and industry to accept and realize that the disabled individual can do a day's work for a day's pay. PWI is focusing on that problem. They are working closely with business and industry in all communities.

We have seven PWI projects in New York State. They compliment what the vocational rehabilitation counsellor is trying to do. It helps our placement program when we use PWI.

Finally, I think what I would like to say in closing is give you a little example and talk about the people that we are servicing. So often in a hearing like this we are talking about the budgeting and the statistical data and that is all important.

But let me just give you one example of what happens to a severely handicapped person in my closing remarks. You know in New York State in the aging out process, 10,000 disabled children as a result of Public Law 94-142 are aging out per year just in New York State.

The only hope we have for that disabled child who is now an adult and that parent who is faced with the problem of that severely disabled individual is vocational rehabilitation and we can take the seriously cerebral palsy person aging out of the school in his senior year, and in New York State we have an excellent linkage program between vocational education, OVR and special education, developing that IWRP, that vocational goal, early with that individual and then working with a rehab institution such as ICD or the Federation for the Handicapped in New York City, getting them trained for a specific job and then getting them placed in competitive work.

Gentlemen, that is what it is all about. That is the partnership and that is the teamwork that I am talking about. We have the Federal, the State and the local not-for-profit agency and the local school district working hand in hand to the overall goal of that disabled individual in getting employed or getting him into some sort of employment, whether that be sheltered or competitive.

I want to thank you for giving me this time to share my thoughts with you.

[The prepared statements of Richard M. Switzer and the Council of State Administrators of Vocational Rehabilitation follow:]

PREPARED STATEMENT OF RICHARD M. SWITZER, DEPUTY COMMISSIONER, NEW YORK STATE EDUCATION DEPARTMENT, OFFICE OF VOCATIONAL REHABILITATION

Chairman Williams, members of the Subcommittee on Select Education, I appreciate the opportunity to comment on the proposed amendments to the Rehabilitation Act of 1973 as previously amended. First of all I want to agree with my colleagues in the Council of State Administrators of Vocational Rehabilitation (CSAVR) that this particular bill was clearly and precisely written and it was done in such a way that few changes have to be made. It has survived since 1973 and since that year millions of people have been served by vocational rehabilitation.

However, today I would like to comment on some of the proposed changes. Before I do so, let me spend a few minutes on some of the innovative projects that New York State has implemented in serving the disabled. During the past year, New York State has rehabilitated approximately 10,000 disabled individuals, placing 60% of these people into competitive employment. Of those placed in competitive employ-

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ment, 60% were severely disabled individuals. In order to accomplish this, New York State has been a forerunner in the transition of disabled students from school to work and in the provision of transitional/supported employment opportunities. The pilot program that we initiated in Central New York over six years ago became the prototype for six additional pilot efforts in New York State, as well as for transition programs throughout the nation. In the area of transitional/support work, numerous small programs have been initiated throughout the state in cooperation with Private Industry Councils, the JTPA program and with private industry, the latter involving both large and small businesses. These are good examples of the overall effect of the Rehabilitation Act through the years in New York State. Since 1973, well over 100,000 disabled New York residents have become tax paying citizens, no longer living off SSI or welfare but taking their place in the community.

I totally agree with the change in the length of the reauthorization to a five year period. This is such an important program and one in which the return of tax dollars far exceed the cost. Having an authorization every three years creates an unnecessary uncertainty. I will hold my comments on the authorization levels until a later period.

I also agree that the Rehabilitation Services Administration (RSA) Commissioner and the Director of the National Institute of Handicapped Research (NIHR) should be appointed by the Secretary of Education. They should not be political appointments by the White House. The focus should be on the selection of professionals who are knowledgeable about their respective fields as it is in the case of the person heading Special Education. In addition, I concur with the use of the term "qualified" as it applies to personnel in vocational rehabilitation. The requirement that the state plan contain information about qualified personnel will insure the quality of individuals involved in the delivery of vocational rehabilitation services.

There are a number of proposed changes that focus on needs and the delivery of services to Native Americans. In New York State we have a number of Native Americans living both on tribal reservations as well as in the general community and are all currently being served under the Rehabilitation Act as it currently exists. Of course, we plan to continue to serve them as well as other disabled individuals who also have significant cultural differences.

I cannot emphasize too strongly the importance of collecting statistical data. It is only with comprehensive annual reporting systems that the Federal Government can gather the necessary data to make sure that states are accountable and measure the effectiveness of the program.

We in New York State also support a modification of the state plan to include a description of how rehabilitation engineering services will be used or developed to provide assistance for persons with severe disabilities. In this highly technical age, with advances in the field of communications and robotics there are almost infinite opportunities to reduce the limitations of disabled individuals, permitting a level of productivity that could not even be conceived of ten years ago. Such services are critical. Rehabilitation engineering is a relatively new field that holds tremendous promise for the disabled in the future. In many areas throughout the country disabled individuals have profited from the technological advances and it is critical that we find a way to both continue these advances in the field and to share the information on a national level.

At the present time many government agencies use the "last dollar" concept in the provision of their services. The existing language that requires that the rehabilitation dollar be the dollar of last resort definitely needs to be strengthened and we in New York State support this change in the Rehabilitation Act. We also support the strengthening focus on "post employment services". There is substantial documentation that, although vocational rehabilitation services enable disabled individuals to secure suitable employment, many of them require follow up services in order to maintain their job successfully. We have learned from the follow up programs provided to Social Security recipients that support services over a longer period of time after a disabled individual is placed on a job have a positive effect on job retention. The use of rehabilitation engineering services as one type of post employment support will in many cases not only help insure continued employment but is expected to provide disabled individuals with wider job opportunities.

I would like to see the research dollars of underserved populations have a twofold focus including populations with different cultural backgrounds as well as disabled populations who are significantly underserved such as the head injured and learning disabled.

Before moving on to the specific authorizations, I would like to comment about the level of professional staff of RSA. Over the past five years RSA personnel has diminished at least 25%. It is important for technical assistance that RSA be staffed

with professional staff members and that they receive the type of supports that permit them to meet regularly with the states in their regions. Travel is a critical factor in their effectiveness in serving as a resource to the states.

At this point I would like to comment on the authorization levels for Fiscal Year 1987. We are recommending that the full amount of \$1,349.4 million authorized for the Basic State Vocational Rehabilitation Program be appropriated. This is the foundation of the programs authorized in the Rehabilitation Act, as amended. This proven, direct service program has stood the test of time and has been well managed. According to the Rehabilitation Services Administration's latest report to Congress, the benefits/cost ratio exceeds \$10 to \$1.

More important are the benefits of this program to persons with disabilities. Behind the cost/benefit studies are individuals who have been provided opportunities to earn money and gain the self esteem that comes from a paycheck. To be working is to be part of mainstream America. This program helps persons with disabilities work and enter that mainstream.

This recommendation is based on the critical need to prevent a further decline in the number of persons served. Because of funding cuts and inflation, this effective program reaches only one in 20 eligible persons. We believe it is essential to stop the downward trend in the number of persons with disabilities provided rehabilitation services. Funding this program at the level recommended would help increase the level of services provided while, at the same time, increasing tax revenues.

We support the authorization of \$37 million for the Independent Living Rehabilitation Services Program, Parts A and B. The purpose of Part A is to provide services to individuals whose disabilities are so severe they do not presently have the potential for employment. However, this service may enable them to live and function more independently. We are recommending appropriations in the amount of \$13 million for this valued program. We believe the funding will allow persons with severe disabilities the opportunity to live and function independently and when possible, enter the vocational rehabilitation program. The services provided through Title VII of the Act not only enable persons with severe disabilities to live and function independently, but also reduce public costs associated with disability.

Part B funds 160 centers throughout the country. We urge that \$24 million be authorized to fund the program which establishes and operates center programs essential to over 30,000 persons with severe disabilities. Full funding is needed for personnel training, additional staff and program priorities.

In addition, we recommend authorization of \$46 million in rehabilitation research as administered by the National Institute of Handicapped Research. We are entering a new era in our nation, one that is exemplified by remarkable technological advances. These scientific and technical achievements can, and should, be brought to bear in the problems faced by our nation's persons with disabilities. Funding for rehabilitation research will pay direct dividends in future years as we discover more effective ways of meeting the needs of persons with disabilities and incorporate technological and scientific advances in our direct rehabilitation services programs. Full authorization will allow construction for the 50 research centers and expanding of multiple areas of interest and necessity for persons with disabilities.

We support authorization of \$29 million for rehabilitation training programs. The quality and success of any direct service program is directly related to quality training for service providers charged with turning rehabilitation goals into realities. We cannot allow documented shortages in many rehabilitation professions to continue without lowering the overall effectiveness and success of the nation's rehabilitation programs. In order to provide the highest quality of rehabilitation services for persons with disabilities to begin to repair the damage inflicted by funding cutbacks during 1977-1984, and to ensure that vocational and rehabilitation services are carried out in a cost-effective manner, it is imperative that Congress provide full support for the program.

The Client Assistance Program is needed to advocate for the rights of VR clients and to work cooperatively with the state vocational rehabilitation agency. We support authorizations of \$7 million for Fiscal Year 1987, \$7.3 million for Fiscal Year 1988 and \$7.7 million for Fiscal Years 1989, 1990 and 1991.

The successful placement of persons with disabilities as wage earners and taxpayers in the private sector is an essential part of rehabilitation. We support authorization in the amount of \$18 million to fund Projects With Industry (PWI) programs.

We support the authorization of \$22 million to fund the operating programs to meet the special needs of isolated handicapped individuals. In addition, we agree that the following amounts be authorized for special recreation programs: \$2.3 million for Fiscal Year 1987, \$2.4 million for Fiscal Year 1988, \$2.5 million for Fiscal Year 1989, \$2.6 million for Fiscal Year 1990 and \$2.7 million for Fiscal Year 1991.

Thank you once again for this opportunity to speak to you this morning and for your past consideration and attention to the vocational rehabilitation program.

PREPARED STATEMENT OF THE COUNCIL OF STATE ADMINISTRATORS OF VOCATIONAL REHABILITATION

The 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, which was recently reauthorized in February of 1984, by Public Law 98-221.

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 effectiveness 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.

The Council appreciates this opportunity to provide the Subcommittee with information on the Rehabilitation Program, and its views of H.R. 4021, the proposed "Rehabilitation Act Amendments of 1986."

THE REHABILITATION PROGRAM

The core of America's Rehabilitation 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 coordinates a wide range of services for eligible persons with disabilities.

These services are provided with the cooperation of, and through, private, non-profit, community-based service providers and facilities.

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

The Rehabilitation Act, as currently authorized, is the most complete and well-balanced 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 mental disabilities; (2) a training Program; (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.

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 program in the human services area, as well as one of the most cost-efficient.

We, therefore, are extremely pleased with the Measure introduced last week by Chairman Pat Williams, and several Members of this Subcommittee. The bill recognizes that the Rehabilitation Act is an extremely well-written and well-balanced statute which establishes the foundation for providing quality rehabilitation services to persons with mental and physical disabilities.

## FIVE-YEAR AUTHORIZATION

We are extremely pleased that H.R. 4021 recommends the extension of the Rehabilitation Act for five years.

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.

This is important for it will give the States a clear indication of the future Federal commitment to the Rehabilitation Program and the persons eligible for services.

We are heartened by the authorization levels provided in the Bill for Section 110, Rehabilitation Service Grants, for Fiscal Year 1987, and beyond.

Rehabilitation Service Grants 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 whose disability constitutes a substantial handicap to employment.

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."

In times of scarce resources, State Agencies are required by the law to focus those resources on the provision of services to the most severely disabled persons, yet not stop providing services to other eligible groups of individuals.

Due to the increased costs of serving the more severely disabled, and the deterioration of the strength of the "rehabilitation dollar," there has occurred since 1979, a marked decline in the number of persons served annually by State Agencies—from a 1979 level of 1.1 million persons to under 935,000 persons in FY 1985.

Specific authorization levels are needed beyond FY 1987 if the State-Federal Rehabilitation Program is expected to, at the least, equal its 1979 level of achievement.

It is now undisputed in the Congress and the Administration that the authorizations for Rehabilitation Service Grants constitute a legal "capped-entitlement".

We urge the Subcommittee to build upon the FY 1987 authorization level currently in H.R. 4021, as well as the strengthened "entitlement" feature, and provide specific authorization levels for Fiscal Years 1988 through 1991 at levels which will restore the purchasing power which has eroded since 1979.

There is no greater frustration to State Rehabilitation Administrators and Advocates than the knowledge that adequate resources do not exist to provide services to eligible persons with disabilities.

## FEDERAL-STATE MATCH RATIO

The bill contains a recommendation to alter the Federal-State Match ratio from the current 80-20 percent, to a proposed 75-25 percent.

To the extent that the Subcommittee is seeking to discover ways to increase State as well as Federal resources for the provision of rehabilitation services, the Council is enthused.

However, at this time, it is not clear whether some States would face significant difficulties in meeting the requirements proposed in these provisions.

For any Program to be successful, it 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 Council is pleased that recommendations contained in H.R. 4021 recognize not only the wisdom of the Rehabilitation Act, and the need for additional resources, but also the need for more effective and coordinated leadership.

The State-Federal Rehabilitation Program—in fact any Program—vitaly needs strong, committed, and knowledgeable National Leadership.

The bill recommends that the Commissioner of the RSA and the Director of the NIHR be appointed by the Secretary of Education, and contains certain requirements relative to the qualifications of the NIHR Director.

In addition, we believe that qualifications for the RSA Commissioner should be a requirement of the law, to assure that an individual with substantial experience in Rehabilitation is appointed to this important position.

We believe that these recommendations could enhance the level of expertise and commitment of our Federal Rehabilitation Leaders, and also increase the level of cooperation and coordination between them. These are irreplaceable elements for any State-Federal Program.

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H.R. 4021 contains number of provisions which we believe would improve the management of the State Agencies, and enhance the quality of personnel working for State Agencies.

During the Hearings on the Rehabilitation Act held throughout the Summer of 1985, this Subcommittee heard from any number of organizations and individuals about the quality and cost-efficiency of Technical Assistance services once provided to State and private Rehabilitation facilities.

The Council welcomes the emphasis in the Bill which is placed on restoring these important grants. It will enable Rehabilitation facility managers to employ more cost-efficient management techniques and thus provide better services.

With respect to Rehabilitation Agency personnel, H.R. 4021 contains two important provisions.

By stressing the importance of "qualified" rehabilitation personnel, and especially by requiring recipients of Federal Rehabilitation scholarships to serve a minimum tenure at a non-profit or State Rehabilitation Agency, H.R. 4021 would help to provide the Public Rehabilitation System with a significant number of professionally-trained Rehabilitation service providers.

H.R. 4021 contains two specific provisions relative to the scope of Rehabilitation Services—one on Post-Employment Services, and one on Rehabilitation Engineering.

The Council is supportive of any effort which will enhance the provision of either time-limited post-employment services or rehabilitation engineering services that might be needed to assist any eligible person with a disability in their effort to attain an employment goal.

As previously stated, the Council firmly believes that the authorization level included in H.R. 4021 for Section 110, Rehabilitation Service Grants, for FY 87, will continue the efforts of the Congress to restore the purchasing power of the Rehabilitation dollar to the levels achieved in 1979.

Again the Council suggests the need for specific authorization levels for Fiscal Years 1988 through 1991, for Rehabilitation Service Grants, at levels equal to a rise in the cost-of-living plus such sums.

With respect to other Programs authorized by the Act, the Council would recommend that all authorizations be set at "such sums as may be necessary."

The Council is encouraged by the cost-of-living adjustments included for most Programs in H.R. 4021. However, some of these authorization levels—especially those for Part A of Title VII, Comprehensive State Independent Living Services—are too limited when viewed in relation to the needs and hopes of America's citizens with mental and physical disabilities.

The Council stands ready to provide technical assistance, opinions, or suggestions to the Subcommittee or any Member thereof as the Reauthorization Process continues.

The Council compliments the Subcommittee and its Staff for their great concern for the Rehabilitation Program and for the people it serves.

Mr. MARTINEZ. Thank you, Mr. Switzer.

One of the major themes of the written testimony is that to amend or rescind portions of the Rehabilitation Act might unsettle the balance that makes this program one of the most, if not the most, balanced and effective program in the human services area, as well as maybe one of the most cost effective.

I would like you to expand on the notion of balance and provide us with examples of the kinds of amendments or rescissions that would upset this balance.

Mr. SWITZER. Let me just say the Rehabilitation Act as is, with no changes, has survived down through the years. The changes that you are recommending we have already addressed and we feel that they are appropriate.

You mentioned changes in the way the Commissioner and the Commissioner of National Institute of Handicapped Research is appointed. We feel that is a step in the right direction, to do it via the Secretary of Education as opposed to doing it maybe by an appointment by the White House because it adds continuity to the managerial part of it.

That is just one example. The fact that we need well-trained, qualified people in the field that you are addressing that issue is one of the weaknesses right now maybe in the Rehabilitation Act because in certain States anyone can go into the program with very little knowledge.

It is important that the Federal Government in RSA's and OSA's have the appropriate people with the background to do the leadership, if you will, in offering the technical assistance to the States. That is just two of the examples, all right?

Mr. MARTINEZ. Thank you.

The Rehabilitation Coalition is recommending that the Rehabilitation Act should be amended to clarify that the CAP agencies have jurisdiction in cases covering violations of section 504 and services in other agencies which are an integral part of the rehabilitation process. Would you support such a recommendation?

Mr. SWITZER. I would like to review that with my colleagues at CSAVR because I personally was not aware of that. Dave, do you want to comment on that?

Mr. MARTINEZ. Would you review that and submit to us in writing your comments on that?

Mr. SWITZER. Yes.

Mr. MENTASTI. Surely.

Mr. MARTINEZ. The Rehabilitation Coalition is recommending State plans be revised and to require all States to develop and justify an order of selection policy which represents the order in which persons with disabilities will qualify for vocational rehabilitation services. If all eligible persons who apply will not be served, do you support that recommendation?

Mr. SWITZER. Could you clarify that a little bit?

In other words, is the coalition for the order of selection? Is that what you are saying?

Could you just clarify that a little bit? I missed some of it.

Mr. MARTINEZ. Well, what they are asking for is the States to create a priority list of who will be served first.

Mr. MENTASTI. If there aren't enough resources available now, I think what you are saying is that should be part of the State plan submittal?

Mr. MARTINEZ. Right. That is what they are recommending.

Mr. MENTASTI. Again, personally speaking, I could support that, but again, I think we would have to go back to the council to give you a more definitive, broad-based opinion on this.

Mr. MARTINEZ. In order that you clearly understand what they are recommending, let me read from the statement.

State plans should further be revised to require all States to develop and justify an order of selection policy, which represents the order in which persons with disabilities will qualify for vocational rehabilitation services.

If you would submit a statement on that, the record will remain open for 5 or 10 days so anyone can submit additional written testimony. We thank you both very much for testifying before us. Your testimony is invaluable to us.

Thank you.

Our next panel consists of Dee Everitt, immediate past president and chairperson of the National Governmental Affairs Committee,



ARC-US, representing the Rehabilitation Coalition; William Sirak, president, Northern Rocky Mountain Easter Seal Society, representing the Rehabilitation Coalition, accompanied by Paul Marchand, cochairman of the Rehabilitation Coalition, and Irvin Rutman, executive director, Matrix Institute, representing the International Association of Psychosocial Rehabilitation Services.

**STATEMENTS OF DEE EVERITT, IMMEDIATE PAST PRESIDENT AND CHAIRPERSON OF THE NATIONAL GOVERNMENTAL AFFAIRS COMMITTEE, ARC-US; WILLIAM SIRAK, PRESIDENT, NORTHERN ROCKY MOUNTAIN EASTER SEAL SOCIETY, ACCOMPANIED BY PAUL MARCHAND, COCHAIRMAN OF THE REHABILITATION COALITION; AND IRVIN RUTMAN, EXECUTIVE DIRECTOR, MATRIX INSTITUTE**

Ms. EVERITT. Thank you, Mr. Chairman, members of the Subcommittee on Select Education.

I would like to, first of all, thank Congressman Bartlett for his opening comments on your efforts to protect the Rehabilitation Act from sequestration. We appreciate that. It is indeed an honor and pleasure to appear before you today along with Mr. Sirak and Mr. Marchand to testify on the reauthorization of the Rehabilitation Act on behalf of the Rehabilitation Coalition.

The coalition is made up of 26 national organizations representing provider, professional and advocacy groups who are all significantly involved in the Rehabilitation Act and its programs. For the past 2 years, I have served as national president of the Association for Retarded Citizens/U.S., and have spoken to hundreds of parents who, like myself, have grown children with handicaps who are greatly concerned about the services which are and which should be available under this act.

The Rehabilitation Coalition has spent considerable time over the past several months exploring ways to improve the Rehabilitation Act. Although its work is not yet complete, the coalition has come to unanimous agreement on certain provisions of the act it recommends be improved, and we hope to obtain your support for these recommendations. Mr. Sirak and I will discuss these briefly, but first I would like to convey to you the coalition's thoughts on H.R. 4021, the Rehabilitation Act Amendments of 1986, the bill many of you have sponsored to extend the Rehabilitation Act.

First, let me say on behalf of the coalition that we are pleased the bill has been introduced so soon in this Congress, and that you intend to consider this bill soon after this hearing. We applaud you for moving expeditiously to reauthorize the act. H.R. 4021 is an excellent framework for moving vocational rehabilitation forward and for modifying the act in several ways to improve services to persons with handicaps.

The coalition supports the technical amendments aimed at making the Rehabilitation Act gender free. We highly recommend you consider further amending the act by utilizing terminology concerning handicap and stability more in tune with current everyday usage. The revisions we seek would shift the focus of preference to persons with disabilities away from their handicapping conditions, emphasizing instead the unique individual.

The coalition stands ready to work with you and your staffs to substitute preferred terminology throughout the act, including changing the names of such entities as the National Institute of Handicapped Research and the National Council on the Handicapped. Speaking of the National Council, we support the provision in H.R. 4021 which would allow the council to share its annual report directly with the U.S. Congress without having it transmitted from the administration.

The coalition has given considerable thought to how the mandate and activities of the National Council could be improved. Our first conclusion is that if the council did perform its annual duties as specified under section 401 of the act, it would be undertaking and fulfilling a full-time job. In the near future, we would like to see the Council devote some of its time to framing research policy recommendations, in particular advice on research priorities for NIHR, identify and disseminate information on model programs of importance to the field of rehabilitation and consult more with consumers and providers of services to identify needs.

The coalition endorses the revision in H.R. 4021 in regards to client assistance programs designations. Governors should, as H.R. 4021 provides, redesignate CAP agencies only for good cause. We further suggest that language be added to the bill requiring any redesignation of "independent" CAP's only to other "independent" entities to follow the intent of the 1981 rehabilitation amendments.

We also strongly support payments from the Federal Government to the CAP agencies as provided in the bill. The coalition recommends three additional CAP modifications. First, the act should clarify that CAP agencies have jurisdiction in cases covering violations of title V of the act and cases involving programs and services in there agencies which are an integral part of the rehabilitation process.

Second, we suggest that the prohibition against class action should be removed. Often class action is the most effective and efficient method for problem solving. This important tool should be available to CAP agencies also. Lastly, we recommend that the minimum allotment for CAP's be increased from \$50,000 to \$75,000 per State.

The coalition also has several recommendations concerning the addition of recreation and leisure services in several components of the act. Last, in regards to H.R. 4021, we support the authorization level for fiscal year 1987 in the section 110 State grant program, but suggest such sums be authorized for the other programs within the act. Given the unknowns of Gramm-Rudman, we suggest authorizing such sums may prove to be a better strategy in the long and short run to maintain and expand necessary services through the act to citizens with disabilities.

As I mentioned previously, the work of the coalition is incomplete. I want to share with you the key provisions still under consideration by the coalition. They are working on the relationship between the individualized written rehabilitation plan and the denial of services interwoven in the IWRP process.

Also under consideration are modifications to the definition of "severe handicap" to assure that those individuals who are truly severely handicapped are included under the priority service provi-

sion. Postemployment service improvements are also being studied, as is the whole issue of supported work within the context of the Rehabilitation Act. Finally, strengthening provisions under the administrative or due process procedure and the protection and advocacy services under title VII are under review. Coalition recommendations in these six areas should be available to you very shortly. Thank you.

Mr. Sirak will now discuss other aspects of the Rehabilitation Act and coalition recommendations.

Mr. MARTINEZ. Let me remind you your entire testimony is in the record. Would you please summarize, Mr. Sirak?

Mr. SIRAK. Mr. Chairman, my name is Bill Sirak. It is a pleasure for me to join Ms. Everitt before the subcommittee today to present some of the Rehabilitation Coalition's views on H.R. 4021 and the reauthorization of the Rehabilitation Act.

I am the president of the Northern Rocky Mountain Easter Seal Society, which provides comprehensive rehabilitation services in Montana, Wyoming, and Idaho. Last year, our agency served more than 60,000 individuals, many of whom received services under Rehabilitation Act programs.

From a service provider's perspective, there are several revisions proposed in H.R. 4021 which would improve the delivery of appropriate and effective services under the Rehabilitation Act. Technical amendments to State plan requirements, the addition of needed rehabilitation engineering language, and provisions strengthening training and research activities are timely, well-targeted adjustments to the act.

The coalition supports the addition of the term "qualified" to State plan instructions regarding rehabilitation personnel. We recommend that State plan requirements also be amended to include a full needs assessment of persons with severe disabilities. At present, States do not systematically assess and provide data on the needs of persons in specific disability categories. Incorporation of this requirement would dramatically improve identification and awareness of these populations and enable States to more effectively carry out the priority to serve individuals with severe disabilities.

State plans should be further revised to require all States to develop and justify an order of selection policy, which represents an order in which persons with disabilities will qualify for vocational rehabilitation services, if all eligible persons who apply will not be served. The coalition believes that, given the widespread scarcity of resources, all States should be required to develop and justify an order of selection and document it in the State plan.

The policy would then be available for immediate implementation, if necessary, and would provide valuable client information for use by rehabilitation service providers, clients, client advocates, and others.

In the past, less than one-half of the clients with mental illness declared eligible for vocational rehabilitation services, were judged to be rehabilitated. The coalition urges that the definition provisions of H.R. 4021 be expanded so that the term "rehabilitation facility" is broadened to include service such as psychosocial rehabilitation services for individuals with chronic mental illness.

Psychosocial facilities are designed specifically to meet the rehabilitation needs of persons with chronic mental illness. We believe that greater utilization of these facilities would enhance the prospects for successful rehabilitation of individuals with mental illness.

The coalition strongly endorses the increased role for rehabilitation engineering described under H.R. 4021. Rehabilitation engineering services can dramatically improve the employment potential of people with disabilities. The coalition believes that rehabilitation engineering services should be appropriately incorporated into the full spectrum of rehabilitation services, including client evaluation for eligibility, rehabilitation, independent living, and employment. A substantial commitment on the part of the vocational rehabilitation system is needed to train rehabilitation personnel, provide expert advice and promote research in the benefits and application of rehabilitation engineering.

The rehabilitation program would not be the successful program that it is today were it not for the cadre of trained professionals who provide rehabilitation services. Further training and technical support for these professionals directly contributes to the ongoing effectiveness of the program. Restoration of a technical assistance program for State rehabilitation agencies and rehabilitation facilities is a sorely needed, cost-effective means of providing targeted information.

Facilities benefit substantially from on site consultation and the implementation of expert recommendations. I remember back in 1982 these services were sorely needed, and they are greatly missed.

The coalition is also pleased with the amendment requiring the repayment of funds from recipients of federally financed rehabilitation training who subsequently become employed at for-profit agencies. Many public and nonprofit rehabilitation agencies regularly experience shortages of qualified staff. This amendment provides an incentive for rehabilitation professionals trained at Federal expense to work in State agencies and not-for-profit settings.

Additionally, coalition members urge that training scholarship guidelines be modified to encourage the training of persons with disabilities. There is clearly a need for people with disabilities to serve in rehabilitation professions. Affirmative action in this area is overdue and would certainly have a positive impact on the delivery of rehabilitation services.

The coalition also recommends that preservice and in-service training for rehabilitation counselors emphasize services to people with severe disabilities. This training is needed to ensure that rehabilitation professionals are adequately equipped to implement the priority to serve individuals with severe disabilities. We propose an amendment which requires comprehensive instruction, including training on various conditions leading to severe disabilities, methods to properly evaluate functional limitations, and state-of-the-art methods to assess, prepare and place individuals with severe disabilities in employment.

Effective training for rehabilitation professionals is an important investment in the program which directly affects the quality of services available to persons with disabilities. Given limited re-

sources and a shortage qualified rehabilitation personnel, the allocation of Federal dollars for training must be carried out wisely. The coalition recommends that the act be amended to require the Commissioner of RSA to annually prepare and submit a report to the Congress which details areas of rehabilitation personnel shortages and accounts for the allocation of training funds.

Research in the field of rehabilitation also represents an investment in the long-term success of the program. The coalition supports revisions to the act which would establish a minimum grant amount of \$400,000 for rehabilitation research and training centers and amend peer review procedures to include a site visit and consideration of the applicants' past performance. The coalition also recommends revisions regarding field-initiated research, increased research training opportunities relative to the needs of people with disabilities and the need for balanced distribution of spinal cord injury services and research.

The ability to accomplish the goals envisioned under the Rehabilitation Act depends on the resources available to rehabilitation service providers and people with disabilities. The coalition strongly recommends that a technical amendment be included which assures the reallocation of basic State grant funds prior to the end of the fiscal year to insure that no such funds will lapse unused.

Every year, Federal dollars appropriated for the provision of vocational rehabilitation services are returned to the Treasury because a few States fail to release these funds for reallocation. In view of the many people with disabilities that go unserved due to a lack of resources, the loss of these dollars can no longer be tolerated.

The coalition will provide the subcommittee with additional recommendations, including proposed statutory language, for further consideration. We hope that these recommendations and our comments on H.R. 4021 are useful. On behalf of the rehabilitation coalition, I appreciate the opportunity appear before the subcommittee. Thank you.

Mr. MARTINEZ. Thank you.

Before we introduce Dr. Rutman, I would like to take this opportunity to introduce Mr. Charlie Hayes, another member of the committee.

Dr. Rutman.

Dr. RUTMAN. Thank you. I am Dr. Rutman, president of the Matrix Institute in Philadelphia, and I appreciate this opportunity to address the committee. I am here representing nine organizations, and since these are rather important ones, I will take the liberty of reading the names of them.

They are the American Psychiatric Association, the American Rehabilitation Counseling Association, the International Association of Psychosocial Rehabilitation Facilities, the Mental Health Law Project, the National Alliance for the Mentally Ill, which is a national organization of the families of seriously mentally ill persons; the National Association of Social Workers, the National Association of State Mental Health Program Directors; the National Mental Health Association, an advocacy organization; and the Rehabilitation Psychology Division of the American Psychological Association.

Our formal testimony has been submitted, I think, and I would like to use my time to summarize and underscore the high points of that testimony. Most of the members of the nine organizations that I describe have been meeting for approximately the past 2 months. As a working group, it convened in 1984 at the initiation of the Commissioner of the Rehabilitation Services Administration.

The Commissioner requested the group to provide him with a series of recommendations that might improve the vocational and community rehabilitation of the seriously mentally ill or the chronically mentally ill individuals in this country. The group has met faithfully and has prepared a series of recommendations that have been forwarded to the commissioners and others in RSA and are in large measure the substance of our recommendations to you.

Our position simply is that the mentally ill, as a group, have been long neglected in this country from the rehabilitation standpoint. They constitute in most States the largest single disability group receiving services. Their numbers currently—I am talking now of the chronically mentally ill—constitute an estimated 2 million persons, and that situation is getting worse apparently repeatedly, and among that group the data shows that there exists about an 80- to 85-percent unemployment rate.

Now, the bill under consideration, the amendments under consideration, although they continue in large measure the progress and activities of the RSA program, do not deal with the fact that there have been no substantial changes either in the scope or the success rate of rehabilitation services to this population over the past decade.

The data will further show upon an analysis that the chronically ill, the so called CMI population, are probably the most expensive to rehabilitate in terms of costs to the program, and that about, as I think has been noted, under 50 percent, about 45 percent of such individuals are successfully rehabilitated for a brief period, and that this 45-percent success rate is indeed some 20 percent lower than the overall success rate of rehabilitation outcomes among all disabled persons.

So our group who have been working at it and feel very strongly about it, really want attention drawn to the priority need of improved and expanded VR services to the chronically mentally ill. Let me briefly highlight six or seven specific points that are included in the formal testimony.

One, the chronically mentally ill are not adequately assessed for introduction and acceptance into the VR State Program under existing procedures. There is great emphasis placed on a diagnostic label type of assessment. The organizations representing the work group would very much urge that that be replaced by a functional assessment, not a diagnostic one.

Second, the rehabilitation field which has traditionally grown through its services of the physically disabled have utilized a series of particular rehabilitation practices and procedures. Many of these have been shown not to be effective with the chronically mentally ill. Different approaches, some of which have been mentioned by other speakers this morning, such as transitional employment, supported employment, and affirmative employment, need to be introduced, we think, into the armamentarium of the VR system.

So we think the bill should reflect that. Next, historically State VR agencies have placed time limits and sometimes arbitrary time limits on various types of vocational rehabilitation services provided to individuals. These time limits, so many weeks of this kind of service, so many months of that kind of service, very often are not meaningful, useful, or appropriate to CMI individuals.

Instead, we urge the adoption of an individualized plan of action for the chronologically mentally ill person and a loosening or reconsideration or an expansion of the de facto time limits that seem to operate in the operation of the system. Related to that is the definition of closure rehabilitation. That is a successful rehabilitation in the workings of the rehabilitation system, a point that was just addressed by the rehabilitation coalition.

We believe that the closure status needs also to be reexamined as it pertains specifically to the chronically mentally ill and that variations of existing closure definitions or expansions of those such as part-time employment or supported employment be regarded as separable closure status indications so that more individuals who are chronically mentally ill will be encouraged to be accepted and served by the system than is now the case.

Many people are not admitted into the system because their outlook for traditional, successful completion of the program is not favorable. Therefore, they simply will not be accepted. The point has been made about training for this population. Particularly, we feel more training is needed for counselors. More training is needed for rehabilitation psychiatrists. More training is needed to bring about the more effective collaboration of services between those in the vocational rehabilitation system and those in the mental health system, both public and private.

Although this training has been taking place in small measure in the last year or two, a considerable expansion of this is required. On the same note we urge that State programs, particularly, utilize more than they have the services of specialized counselors within their program who have received special training and have some standard of competence and quality in working with the CMI population.

Finally, to also underscore a point made by the Rehabilitation Commission, we recommend for your consideration that the utilization of psychosocial rehabilitation agencies and facilities across the country—there is a network of approximately 1,000 of these—be incorporated into the amendments as part of the services made available to the chronically mentally ill client. Thank you.

[The prepared statement of Irvin Rutman follows:]

PREPARED STATEMENT OF IRVIN RUTMAN ON BEHALF OF THE REHABILITATION COALITION

MEMBERS OF THE REHABILITATION COALITION

American Academy of Physical Medicine and Rehabilitation.  
 American Association for Counseling and Development.  
 American Association on Mental Deficiency.  
 American Congress of Rehabilitation Medicine.  
 American Foundation for the Blind.  
 American Rehabilitation Counselors Association.  
 Association for Children and Adults With Learning Disabilities.  
 Association for Retarded Citizens/U.S.

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Conference of Educational Administrators Serving the Deaf.  
 The Convention of American Instructors of the Deaf.  
 Council of State Administrators of Vocational Rehabilitation.  
 Epilepsy Foundation of America.  
 International Association of Psycho-Social Rehabilitation Services.  
 National Alliance for the Mentally Ill.  
 National Association of Counties.  
 National Association of Private Residential Facilities for the Mentally Retarded.  
 National Association of Protection and Advocacy Systems, Inc.  
 National Association of Rehabilitation Facilities.  
 National Association of State Mental Retardation Program Directors.  
 National Council on Rehabilitation Education.  
 National Easter Seal Society.  
 National Head Injury Foundation.  
 National Mental Health Association.  
 National Multiple Sclerosis Society.  
 National Recreation and Park Association.  
 National Rehabilitation Association.  
 National Cerebral Palsy Associations, Inc.

Mr. Chairman, Members of the Committee, my name is Irvin Rutman, I am President of Matrix Research Institute in Philadelphia, Past-President and Member of the Board of the International Association of Psychosocial Rehabilitation Services and I also serve as Chairman of the Rehabilitation Services Administration's Workgroup on the Chronically Mentally Ill. I am presenting this testimony today on behalf of a coalition of national organizations, listed on the cover page of my written statement, which are concerned about rehabilitation services for those with chronic mental illness.

My testimony will address problems with the current operation of the vocational rehabilitation program as it affects those with chronic mental illness. Additionally, I will comment briefly upon certain aspects of HR 4021, the Rehabilitation Act Amendments of 1986 introduced last week.

We have concerns about HR 4021. While the bill has a few provisions which may begin to improve services for chronically mentally ill persons, it is essentially an extension of current law with respect to services which would be available. It also provides only a modest 5% increase in funding. HR 4021 thus virtually assures continuation of the status quo, which for chronically mentally ill persons means continued lack of services, continued high failure rates and continued problems with the kinds of services offered. Our coalition most strongly urges that the Committee not take this approach in 1986. Not only for mentally ill persons, but for all severely handicapped persons (especially those with developmental disabilities), we call for substantial reforms to this program now.

We believe the provisions in the bill to improve the client assistance program, individualized written rehabilitation program and scope of post employment services are addressing areas of critical concern, but that far more substantial changes are needed.

We also urge higher authorizations for the Act, and particularly for Title VII, Part A; the independent living program state grants, which has only recently been funded at a modest rate and which we believe should be funded at a substantially higher level in the future.

Persons suffering from severe and chronic mental illness possess the capacity and potential for growth and development. Many of these individuals, despite their severe handicap, could benefit from rehabilitation services and, if appropriate services were provided, could engage in work. Work is an important part of normal life and the adult role. Vocational services are therefore an important part of community treatment of chronic mental illness. A normalized work environment should, to the fullest extent possible, be a vocational goal for clients with chronic mental illness. Chronically mentally ill individuals ought therefore to receive an equitable share of vocational rehabilitation services, and VR services should be integrated into a comprehensive system of treatment and support services.

Despite the requirement in the Rehabilitation Act that state agencies give priority to severely handicapped persons, individuals suffering from severe mental illness are clearly not a priority in the VR system. As a result, such individuals are either denied services or are accepted for service but then inappropriately and inadequately served. Individuals suffering from severe and chronic mental illness are suffering *de facto* discrimination in the program.

Individuals with psychotic illnesses have, as a group, the highest failure rate of any disabled population served by the VR system. In 1981, out of 29,367 chronically



mentally ill clients declared eligible for VR services, only 45.7% were judged to be rehabilitated. This rate is 20% lower than the rate for the overall disabled population. Of those who are counted as rehabilitated we know only that they stayed on the job for 60 days. Yet research also indicates that severely disabled mentally ill clients often exhibit serious problems in maintaining employment, which adds to the "revolving door" syndrome as it adversely affects the clients' own motivation and self-concept. This is not only poor policy, it is expensive. A typical cost of state hospital care is now \$128 per day. Rehabilitation services can prevent relapse, especially when coupled with a comprehensive mental health support system, thus saving the nation considerable mental health treatment costs as well as reducing welfare and disability payment expenditures.

Analysis of RSA statistics reports shows that neither the scope of services nor the rate of successful rehabilitations have increased proportionately over the past 10 years. Recent research also indicates that unemployment rates among those with chronic mental illness ranges at the remarkably high level of about 75-85%.

The problem of assessing and providing appropriate VR services for severely mentally ill individuals is one which has concerned the Rehabilitation Services Agency (RSA) for some time. In 1976, an Advisory Committee on the Rehabilitation of the Mentally Ill was established, and in 1978 an Interagency Agreement was developed between the Rehabilitation Services Administration and the National Institute of Mental Health to improve VR services for mentally ill people. In 1981, a National Conference was called to identify how to improve interagency collaboration between mental health and VR services. In 1984, RSA Commissioner George Conn appointed a Workgroup to provide policy guidance in this area.

The 1984 workgroup on Rehabilitation of Chronically Mentally Ill Individuals, which I chaired, was asked to build upon the recommendations from past studies and conferences, and to come up with a systematic approach to improving the grossly inadequate services now provided to severely mentally ill people under the VR system. The Workgroup's findings, consistent with recommendations of earlier studies, were that: chronically mentally ill persons frequently are inappropriately assessed for VR services—either being accepted for service when they are not ready or being denied services when they could be helped; traditional rehabilitation practices and intervention mechanisms, successful with persons with less severe and more stable disabilities, often are appropriate for persons with severe mental illness, yet state VR agencies continue to utilize them in working with this population; arbitrary and rigid limitations on length of time clients will be provided certain services are often applied by state agencies, which is inappropriate for this population; policies around successful closure often work against those severely mentally ill people who are unable to work on a full-time basis, even after rehabilitation; VR counselors are often not trained to work with this population; and lack of appropriate interaction between VR and mental health agency personnel working with these clients causes major problems.

The Workgroup developed specific policy recommendations, which must be implemented if severely handicapped persons suffering from chronic mental illness are to receive the appropriate VR services to which the law entitles them. While the law requires VR agencies to give priority to serving severely handicapped persons, the Workgroup found that those with mental illness are not benefitting from this priority because of systemic problems in the VR system and because of a lack of attention to the special problems and needs of this population.

To implement the Workgroup's recommendations, the federal mandate for giving priority to severely handicapped persons needs to be strengthened. Systematic changes are needed throughout the VR Act to accomplish this.

There has grown up in the VR system a body of informal and formal policies and practices, many of which against appropriate services for individuals with severe handicaps, including those with severe mental illness. To correct this requires federal action.

Our first recommendation is that a real priority be given to chronically mentally ill and other severely handicapped individuals in the rehabilitation system, as now called for in the law. The current definition of "severe handicap" must be altered to tighten it up so that in fact only those with really severe handicaps qualify under that priority. The definition should also be based on a measurement of the client's functioning as a means to assess the severity of the handicap. This change should be coupled with a requirement for states to conduct needs assessments for those with severe handicaps so as to identify the population, its service needs, gaps in the state system and so on. This data should be reported to Congress annually so that real measurements can be made of the needs of the severely handicapped population.

I want to stress though that tightening the definition will not accomplish the goal of improving services for persons with severe handicaps unless additional changes are made to the Act which address the structural problems of the VR program, as discussed below.

Traditional rehabilitation practices and intervention mechanisms often are not appropriate for persons suffering from a psychiatric disability. From its inception, the VR program focused primarily on persons with physical disabilities, most of which were stable in nature. In working with such populations, techniques and practices were developed which proved successful.

However, the program has attempted to transport these experiences and apply them to persons with severe psychiatric disabilities who exhibit quite different and more fluid functional limitations and rehabilitation needs, whose rehabilitation progress may be slow, incremental and at times characterized by set-backs and relapses. Statistics cited earlier on the failure rate for those with chronic mental illness indicate that this transference of rehabilitation approaches has not been successful. New ways of working with persons with psychiatric disabilities need to be utilized. We therefore recommend:

Changes should be made in definitions used by states for successful closures so as to include part time employment and Supported Work. State policies which require full time employment for successful closure preclude many persons from receiving any needed VR services because the closure criteria influence eligibility determinations. Such blanket policies are not conducive to working with persons with chronic mental illness. For some, part-time employment or supported work may be the most suitable form of employment (note that we include in our definition of supported work, transitional employment programs for mentally ill persons).

Individualized written rehabilitation plans should be based on functional assessments and a functional approach to service delivery. Services provided to an individual should be designed to achieve specific goals developed as a result of a realistic assessment of the individual's level of functioning.

New ways of working with persons with psychiatric disabilities need to be utilized. Two promising modalities are Transitional Employment Programs (TEP) and Supported Employment (SE). In addition to allowing supported employment and transitional employment programs to be successful closures for those who cannot engage in competitive employment, states should be encouraged to utilize TEP and SE for working with persons with chronic mental illness. Additionally, RSA should (1) provide technical assistance to state agencies on the conceptual and operational dimensions of TEP and SE with respect to persons with chronic mental illness, (2) identify TEP and SE for individuals with chronic mental illness as a priority area for applications submitted under Section 311(a) (1) and (2), and (3) to include TEP and SE for those with chronic mental illness as training areas in both in-service and long-term training.

State VR agencies should be required to identify psychosocial rehabilitation programs, and to utilize service contracts, establishment grants and technical assistance funds to support the enhancement and expansion of psychosocial rehabilitation program capabilities in serving those with chronic mental illness. Currently, states utilize traditional community-based rehabilitation facilities, particularly sheltered workshops, for provision of services to individuals with chronic mental illness, even though most of these facilities are geared to work with persons with mental deficiencies or physical disabilities. Psychosocial rehabilitation agencies are being developed to address a wide variety of needs of persons with chronic mental illness, including vocational needs. These agencies are potentially excellent resources for this population because they can provide not only VR training and counseling, but other supportive services as well, which will complement the VR services and enhance their effectiveness.

Section 102 of the Act should be strengthened to specify that "individualization" with respect to those with severe mental illness requires that state agencies not have policies which place arbitrary limitations on the length of time clients with chronic mental illness will be provided certain VR services. Some states now have policies which place arbitrary and rigid limitations on the length of time clients will be provided certain types of services, e.g., 10 weeks of Personal Adjustment Training. Such restrictive and blanket policies pose significant barriers to the rehabilitation of persons with chronic mental illness who frequently require incremental services over an extended period of time. Greater emphasis on the principle of individualization as articulated in Section 102 of the Act and interpreted by various court decisions is needed.

In addition to the above structural changes, we urge that RSA place greater emphasis on training in this area. A GAO study of five state VR agencies has docu-

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mented the need for preparation and continuing education of VR personnel who work with individuals with chronic mental illness. Rehabilitation personnel at all levels can benefit from such training. Administrators and managers could profit from information on service system design, program planning and evaluation and financial networking. Personnel at the service delivery level can improve practice through a better understanding of the dynamics of the disability, the individual diagnostic study, treatment planning, service provision and evaluation, and job development, placement and follow-through.

Such exposure to new ideas, knowledge, skills and attitudes should be provided through existing and potential training programs at the pre-service (undergraduate, graduate, and doctoral), in-service and continuing education levels. Joint in-service training for VR staff and mental health service delivery personnel is also essential to prepare mental health and VR staff to work together more effectively and efficiently for the benefit of their mutual clientele. Beginning in FY 1986, RSA should utilize all facets of the Training Grant Program to prepare personnel at all levels to work effectively with individuals with chronic mental illness. Specifically, we urge: At least six graduate programs in Rehabilitation Counseling be established within their curricula competencies for working with chronically mentally ill persons; at least one national program be established for the preparation of Rehabilitation Psychiatrists; Regional Rehabilitation Continuing Education Programs include appropriate training for serving this population; all state in-service training grant applications be required to target training to the chronically mentally ill population; and RSA continue its initiative for joint training programs of mental health and vocational rehabilitation personnel.

The law should also be amended to encourage training for specialized counsellors and the use of specialized counsellors for hard to serve population groups, such as those with chronic mental illness, should be encouraged. Specialized counsellors are quite often more successful with chronically mentally ill clients than counsellors who have little experience with this population.

The nature of severe mental illness is such that, uniformly, individuals with chronic mental illness require post-employment services to ensure successful rehabilitations. To provide rehabilitation services without providing essential post-employment services is short-sighted, as many mentally ill people may fail unnecessarily in this employment situation. States should be mandated to provide post-employment services to those with chronic mental illness for this reason. The law should therefore require post-employment services for all chronically mentally ill people who are rehabilitated for at least a six month period after placement.

In addition to the specific changes cited above, the serious lack of attention to the needs of individuals with chronic mental illness in all rehabilitation programs in RSA compels us also to suggest other amendments to the Act so as to refer specifically to this population. These amendments do not alter the purposes of the law, but simply specify that in carrying out certain sections of the existing Act, state and federal agencies must address the needs of those with chronic mental illness. Amendments should be made to the sections of the law authorizing demonstration projects, projects with industry, independent living, innovation and expansion grants and coordination, to specifically reference services for individuals with chronic mental illness.

It is our understanding that the population we are concerned about, those with serious and chronic mental illness, is not alone in having major difficulties with the VR Act. Other individuals, especially those with developmental disabilities, also find themselves excluded or inappropriately served by the VR system. We would welcome any legislative changes which address the needs, not only of those with serious mental illness, but of all severely disabled persons. Our objective is that HR 4021 ensure the appropriate rehabilitation of individuals with chronic mental illness who could work.

Mr. MARTINEZ. Thank you very much. One right off the bat, Dr. Rutman, I would like to get a definition of what a functional assessment procedure is and what is a functional assessment, and how does it differ from the current practices?

Dr. RUTMAN. The current practice usually relates to a diagnostic label of some clinical nature, schizophrenic so and so, manic depressive so and so, whatever—which is a very elaborate and formalized and not always accurate assessment of an individual's mental health condition. Functional assessment deals more with

what he is able to do, what his limitations as well as his capacity itself may be; what his strengths are, how he is able to function in terms of working, in terms of interrelating socially, in terms of meeting society's expectations over and above the diagnostic label.

Mr. MARTINEZ. The diagnostic label sounds like it is just a label attached to the person's illness, and then the other takes into consideration—

Dr. RUTMAN. The diagnostic label, if you trace it all the way back to its formation in a document developed by the American Psychiatric Association, has a lot of descriptions, so if a person is diagnosed as a particular type of, say, schizophrenic, that implies certain levels of ability. It is not simply a label, but it is used for the most part as a label. People using it are not usually aware of how it was derived.

Mr. MARTINEZ. How would this affect the rehabilitation cost itself?

Dr. RUTMAN. It really ties into the utilization, I think, of the psychosocial agencies about which you may not be too familiar. They work within many State rehabilitation programs, and they provide prevocational services and preparation for work types of services and social rehabilitation services on what is called an experience basis. That is, they don't see a person in their office for 1 hour a week or so, but may have the person in their program for 15, 20, or 30 hours a week practicing the skills of living.

That kind of functional assessment can be derived from the observations of the people working with those clients in psychosocial agencies and should not—need not change the costs. They can be part of the relationship—should be part of the individual's case record.

Mr. MARTINEZ. Along that line in your testimony, Mr. Sirak, you urge the definition of the professionals in the Rehabilitation Act be expanded so rehabilitation facilities are broadened to include those psychosocial rehabilitation facilities for individuals with a chronic mental illness.

Please expand on how that facility might differ from the services typically provided by a community mental health center.

Mr. SIRAK. We provided services through our sheltered workshop and work activity center both to people with developmental disabilities and people who have mental illnesses as well. Those services certainly can be expanded to specialize in—and specifically serve those individuals who are mentally ill. We currently provide such services.

It has been our experience that those individuals with severe mental illnesses are a very difficult population to serve, but the needs there are just really fantastic. That population needs further attention.

There is a real chronic need for rehabilitation.

Mr. MARTINEZ. You assert in your written testimony every year millions of Federal dollars are appropriated for this. Few States release these funds for reallocation. What is the extent of the problem, and how much money are we talking about?

Mr. SIRAK. I have to confer with the other members of the coalition. We can provide that figure for you. This relates more to some of the concerns about the current ratio, 80-20 versus 75-25. We

have a very timely issue in Montana right now. The Governor recently cut the State appropriations by 2 percent within the last 48 hours. We are going into special legislation—the State is going into special session in March.

Our chances of going back to the legislature and asking for additional appropriations for rehabilitation are going to be, I think, very very difficult, and we are very concerned about that.

Mr. MARTINEZ. Would Paul Marchand have that information?

Mr. MARCHAND. The data changes year to year depending on in many respects how State legislatures will behave in terms of matching. There is data. We will provide it to you, but it is not something that we can say it will be a million this year and a million next year. It is impossible to project. It has been substantial amounts, however, clearly worth moving to reallocate those dollars to those States that can in fact use those dollars.

Mr. MARTINEZ. We would appreciate your providing that information for us. Ms. Everitt, in Mr. Sirak's testimony, he touched on it, too, but I would like to find out from you the basis for your recommendation that the law should be amended to require all States to develop and justify an order of selection policy. Would you expand on that? What is the basis for that recommendation?

Ms. EVERITT. I can't speak for the coalition because I am not a member. Mr. Marchand is a staff person of ours, and he serves on the coalition. I can only speak on the issue of Nebraska, where I am from, and in Nebraska severely handicapped do not get served.

Mr. MARTINEZ. So the priority idea is to make sure those severely handicapped persons are served?

Ms. EVERITT. Yes. I am not sure, but I can't tell you why except I know they are a small funded State based on population. Of course my interest is in the area of mental retardation, and it is practically nil in the area of vocational rehabilitation.

Mr. MARTINEZ. Please expand on your recommendation that the Rehabilitation Act should be clarified to provide that CAP agencies have jurisdiction in cases covering violations of section 504 and cases involving programs and services in other agencies which are an integral part of the rehabilitation process, and I would like to know what you mean by other agencies that are an integral part of the rehabilitation process.

Ms. EVERITT. I am going to refer that question to Paul, please.

Mr. MARCHAND. Again, there are literally thousands of agencies in our country who provided rehabilitation services. Some of them provided a portion of their services exclusively funded throughout the Rehabilitation Act.

Others provide a large variety of services that are not funded by the Rehabilitation Act, however, they are serving individuals with handicaps, a variety of sorts in a variety of different contexts.

The idea there would be for those individuals to fall under protections. Just because you happen to be a client for whatever reason you are at this very moment being financed in your service delivery pattern by rehabilitation protects you.

The very next client sitting next to that individual may not for whatever reason be qualified and may be aggrieved similarly.

We would like agencies to protect the rights of those individuals as well, whether or not they are served via the rehab dollar. The

fact of the matter is the CAP agencies ought to be able to intervene on behalf of those handicapped individuals as well.

Mr. MARTINEZ. Thank you.

Mr. Bartlett.

Mr. BARTLETT. Thank you, Mr. Chairman.

I want to thank the panel for some quite specific and very helpful testimony. I look forward to reviewing each of the details that you have provided and this will take not a matter of a few hours at this hearing, but some days or weeks, I do appreciate your specificity.

Let me see if I have a couple of the concepts, and you may care to elaborate.

Ms. Everitt and others, it seems from what you are saying that there are two difficulties or two barriers to serving the severely handicapped in vocational rehabilitation. One is that the definition in some ways excludes the severely handicapped.

I am being careful in that obviously, it doesn't exclude severely handicapped in all ways, but in some ways it does. Second, the eligibility criteria—or that is to say, the requirement for outcome in other ways will tend to exclude severely handicapped persons.

Would you elaborate on that? First, will the coalition or others help to provide us with your recommendations in a timely way for a better definition? Second then—I am trying to understand, are you advocating two sets of standards between severely handicapped and nonseverely handicapped as far as an outcome standard or an eligibility criteria, or how would you work it out?

Would you keep one standard or make it two standards?

Ms. EVERITT. Many of the comments he made apply to persons with severe mental retardation. Because my experience has been most of the counselors are not—this is speaking personal experience—are not trained to deal with people with severe mental retardation that is a real barrier for them.

So, I would agree with him on the need for special training for counselors in his area, as well as ours. I am speaking strictly for myself now. I think closure is another very serious area, because the more severe the handicap, obviously the longer the period is going to take, and a lot of our sons and daughters can't make it in 18 months. They just can't.

Mr. BARTLETT. Dr. Rutman.

Dr. RUTMAN. Thank you. I think you restated essentially the point I was trying to make, and that is to be admitted into the program, there must be some reasonable expectation of vocational feasibility or likely outcome of the successful rehab program.

Mr. BARTLETT. As defined by full-time employment? Did I hear you say that?

Dr. RUTMAN. That is right. That is now, for the most part, full-time employment at the end of a certain time, which must persist for 60 days.

Our position, and I suspect this would hold for others as well, certainly the developmental disabilities field, is that that rigid closure requirement, that the only thing that works is going to be 60 days of full-time employment, be reconsidered, and that part-time employment or supportive employment or any other number of possibilities be introduced, and I don't think it is in the law.

I think this is in folk wisdom and sort of how the law gets operated. State by State. When we speak to RSA officials, but they say it is not in the law, but this is how the State directors have interpreted it, or passed on the message from on high.

So, that is an issue. There is a great deal of flexibility in fact from State to State about what is considered closure, but there has been no affirmation of the fact that part-time employment is perfectly permissible as a closure status.

Were that to happen then more severely disabled individuals, certainly CMI's, as well as developmentally disabled, might then be admitted for VR service. Now they are being precluded because it is felt they can't meet the traditional closure criteria.

Mr. BARTLETT. Let me switch over to attempting to find the funding, which it seems to me in the long run should come from the income that persons who are successfully obtaining either part-time, full-time, or supported employment obtained.

I would like your comment as to whether that is happening at all now, and how either a change in this law or other laws could affect it. One way would be to increase the contracting and provide for contracting between SSI and SSDI and vocational rehabilitation agencies, both private for-profit and not-for-profit.

Describe to us whether in the profit and not-for-profit categories, if that is happening at all. What could be changed to cause it to happen?

Dr. RUTMAN. Part of the answer to that is there are recent changes in SSDI regs concerning disincentives to work in the direction of saying to the person who is an SSDI beneficiary, if you choose to try to return to the work world—I am again speaking particularly from the standpoint of the psychiatrically disabled, and I think this holds true for all disabled—if you choose to return to the work world, and you didn't make it in the past, that would put you in a bad position.

You would have to lose your SSDI status, start all over, go through a long and tedious and difficult process to get reinstated as a beneficiary.

The changes have been in the direction of permitting a variety of staging steps over a period of a year or whatever so that the individual who is on SSDI doesn't automatically lose that status if he finds employment part time or full time; and if that employment, for whatever reason—and typically with the chronically mentally ill, there is a difficulty in retaining employment without strong post-employment services, but if he does lose, he doesn't start from square one again.

He has an easier road into reasserting his SSDI status. That change came about, I think, about 2 years ago, and it is spelled out in the regs in, I think, eight or nine different elements to those changes affecting the SSDI client.

But the fact that they exist is not well-known to most of the staff working with the SSDI clients, either on the VR side or on the social security side.

Mr. BARTLETT. Other comments?

Paul.

Mr. SIRAK. I can give you a good example of that. This issue of closure can cause serious problems. We had a young lady referred

to us by the vocational rehabilitation counselor to our facility as a regular employee, a receptionist, and we were very, very concerned that if somehow that would be deemed a successful closure in a relatively short period of time, and then we found out that it was not a successful placement, that this person would have to begin all over in getting qualified for the system, and she would really be out in the cold.

So, I think we do need some refinement on that definition of successful closure or placement. Otherwise, we really put a client at risk by placing them into what would appear to be a successful employment situation, only to find out several months later that they are out in the cold.

Mr. MARCHAND. To some extent, that is to the members of this committee and subcommittee and others in the field that disability programs escaped the huge cutbacks in the 1981 Omnibus Reconciliation Act generally, except for the rehabilitation program, which suffered a huge setback when \$100 million per year was cut out of the rehabilitation program, not through this act, not through the traditional rehabilitation program, but through a separate pot of funds that was available through Social Security trust funds, which were paid to rehabilitation agencies at the time prior to—in 1980 and prior, to provide specific rehabilitation services for individuals who were found to be eligible and recipients of supplemental security income and Social Security.

With the abolition of those funds, State rehabilitation agencies were forced to absorb \$100 million a year in cuts, absolutely impossible. Couldn't be done, wasn't done, isn't being done.

Those funds have not been replaced, despite the fact that the State rehabilitation program has grown somewhat in appropriations annually, it has in no way been able to barely keep up with inflation, let alone absorb the loss of those funds.

So, we have at the moment substantially less buying power in rehabilitation than we had back in the late seventies. In addition to that, the individuals that sort of got targeted for those cuts were individuals who were truly severely handicapped.

To be eligible for SSI, you have to be not able to earn substantial gainful activity, which is a very, very small amount of money per month. Anybody earning that amount is well below the poverty level.

So, we have in the field and rehabilitation specifically a real program in many of those individuals that might have gotten served through those funds are not now being serviced, which leads me to two points.

One, your bill, Mr. Bartlett, H.R. 2030, deals quite extensively with this issue of the relationship between SGA in the area of rehabilitation and the possibility of moving forward. Unfortunately, it falls significantly short—that is not a criticism of replacing that \$100 million a year, but it is clearly a very positive step in the right direction, and we commend you for that, and hope very much that bill will move either in this committee and in the other committee that it has to be dealt with.

Also, at the same time, we had this issue of justification. How does the State rehabilitation commissioners in the States make determinations over who is going to be served?



The rehabilitation program is not an entitlement as we would expect special education to be, for example. Every child has a right to special education, and must be served. Every handicapped adult does not have the right to rehabilitation.

So, since their moneys are limited, decisions have to be made. Who is going to be priority, who is not going to be priority, who is going to be on the waiting list, who is going to get rejected?

At the moment, the act calls for the States, when they know they don't have enough money to serve people, calls for the States to develop a list of who is going to be served, who is not going to be served.

That is a priority list, but they can do anything they want. They can put anybody in the top, they can put anybody on the bottom. That is all they have got to do is publish a list.

What we are suggesting is that they justify those decisions. Why would disability X be on top of the list and disability Y go on the bottom of the list. We want justification. We want the State agencies to tell us why they have picked these people, and they will get served, and why they would pick those people and they won't get served.

That is what we mean by justification of the priority list.

Mr. BARTLETT. Thank you very much.

Let me ask one additional question and ask each of you to comment on the proposal for increasing the State match. It seems that the correct way to look at the State match is not as punitive, but rather, how to increase funding for the rehabilitation of disabled persons.

Two questions: First, this is assuming that we direct, which we ought to, the transition to make sure it doesn't happen so suddenly that a State legislature doesn't have time to act. But first, do you support increasing the State match?

Second, do you think in light of the tremendous need that a 75-25 match is adequate, or should we phase in over a multiyear period of time a higher State match?

Ms. Everitt.

Ms. EVERITT. I can only speak for Nebraska's experience. We are an agricultural State, and our legislature had two special sessions last year where everybody got cut twice 2.5 percent. They are now in the process of meeting and doing the same thing, because we have had 12 banks go broke since January.

I don't think it would be very welcome by the State legislature to come up with an increase. They are already crying about what Gramm-Rudman is going to do to them in terms of highway funds, et cetera.

So, I can only speak from my State's perspective. I think it depends on the economy of the State. Nebraska would not be excited about coming up with an additional 5 percent. What was your other question, sir? I am sorry.

Mr. BARTLETT. I think that takes care of the other question, too.  
Dr. Rutman.

Dr. RUTMAN. I, too, can expertly speak for the nine groups I am representing, and I will fall back to what I think I know about the State of Pennsylvania, where our outgoing Governor has assembled a very sizable surplus in the State treasury, in the hundreds of mil-

lions, or possible billions of dollars on the one hand, and on the other hand, there has been a freeze on all State hiring for the last 2 or 3 years, and there have been cutbacks in VR, State agency VR services, particularly in a number of different respects, so that the VR program of the State, although trying valiantly, certainly is not flourishing, and is really declining in many ways.

So, we will have to await the new election and the posture of the new Governor to see if they will welcome or not welcome coughing up more money to match the Federal share.

If past experience is any barometer, I am not sure they would welcome it.

Mr. BARTLETT. Maybe I should rephrase my question, and you two may want to reanswer, or your answer may well stay the same. But the question is, Is there tremendous need for rehabilitating severely disabled persons?

With Gramm-Rudman at best we are going to have level funding, and we are going to have to work at that from the Federal level. Now, the question is, Are you then willing to accept level funding for the severely handicapped and other disabled persons as a result of that, or would you rather have a tradeoff of an increased State match?

It is OK if your answer is that you would rather accept level funding and an increase in State match, but it seems that is the question.

Dr. RUTMAN. Again, I will not try to answer for all of the groups involved. My own feeling on that is that level funding with the various changes that have been described and discussed here would go a long way toward improving the plight of the chronically mentally ill clients about whom we are most concerned.

I am not prepared to make a judgment about changing the match.

Mr. BARTLETT. I understand.

Mr. SIRAK. Speaking only on behalf of the provider of services in Montana, Wyoming and Idaho, in Montana we are confident with the new change in the funding formula we will lose \$1 million, is what we are looking at.

The shortfalls and State tax revenue, I think, are going to make it virtually impossible in that State, and I am afraid we have similar situations in Wyoming and Idaho. It is kind of ironic, my experience in this area has been that I have seen the development of special education services and the beautiful services and opportunities and facilities that we provide for school-age children.

It seems really almost a shame—I feel guilty sometimes in talking with parents who come through a beautiful special education facility, and magically, when they hit the age of 18 or 21, they just don't have that kind of support service.

The real tragedy is this is the one service—we deal with many, many funding sources—this is the one service where the taxpayer seems to me really gets a return on his investment, and I hate to see these funds diluted.

Mr. MARCHAND. Unfortunately, Mr. Bartlett, your question does not have a simple answer.

Mr. BARTLETT. The answer is yes and no.

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Mr. MARCHAND. The Rehabilitation Coalition basically has two functions. One is to provide the kind of oversight that we are trying to do today as it relates to the act, and how it affects individuals with disabilities.

The second function has been a more traditional function, has been to work hard within the Congress to secure additional funding for services and programs that we cherish for individuals who need them.

Over the course of the years, we have been working with you and the Appropriations Committee and others to see that happen. Some years, we have been successful. Other years, we have not for a variety of reasons.

We await, as you do, eagerly next week when the President's budget is released and Gramm-Rudman begins in earnest with the fiscal year 1987 decisions. Many of us are also part of a variety of other groups and coalitions who are working very, very carefully looking at disability economic policy as it relates to the entire budget.

I may be treading on thin ice here, but it appears to be relatively clear to me and many of my colleagues that are in the coalition that the Congress must take a very, very serious look at how Gramm-Rudman is going to impact on individual disabilities, and we reject outright pitting one human service group against the other, and decisions on how to make cuts.

There need to be other ways and there must be other ways that we can move toward a balanced budget in a way that it will not come on the backs of handicapped individuals, whether it is the individuals who might be being served under the Public Law 94-142 State grant program, or it might be individuals who are being served on the Head Start, or it might be a handicapped individual being served on the early childhood project.

What would be cut, the Head Start Program, or do we cut the projects? Our answer again is very complicated but real. Human services programs have been cut enough. No more cuts. We have had enough cuts since 1981.

Our field can't take it any more. Handicapped people, people with retardation will be out on the streets in the very near future, because the programs will not be there.

This Nation must look at increased taxation. It absolutely must look at increased taxation to begin to look toward other ways of balancing the budget. It must also look at the defense spending.

Beyond a doubt, real growth in defense has gotten to the point where the Pentagon doesn't know how to spend its money anymore. We have evidence now that there appears to be a \$40 billion-plus slush fund that the Pentagon is holding onto that will practically totally readily absorb the automatic budget cuts this year on the Gramm-Rudman, and possibly next year's budget cuts and hardly anything will be touched.

Taxation, defense spending and good domestic policy is the answer, but please let's not look at which of the handicapped programs we are going to cut. It is very important to prioritize State grants for special education, very important to prioritize State grants to rehabilitation, but let's not have other programs for disabled people suffer in the process, because all you are doing is play-

ing one handicapped person or one other vulnerable person against another, and that is something that we would like to avoid.

Mr. BARTLETT. Thank you.

Mr. MARTINEZ. Thank you, Mr. Bartlett.

Mr. Hayes.

Mr. HAYES. Thank you, Mr. Chairman.

The testimony I have heard has been very informative and quite interesting, by the way. I will read the written testimony of the witnesses to get further information on the respective positions.

I will limit my question to one. I am going through a rather traumatic situation myself, having just returned from a dentist engagement and the nerves which were put to sleep have awakened, hence I cannot talk very much.

Ms. Everitt, my one question is directed to you. You made mention of the fact of the unknowns under Gramm-Rudman. I wish you would elaborate just a little on that, because this is the order of the day, and I have some fears that the unknowns will readily become knowns.

I happen to be a part of a group that is working for the repeal of Gramm-Rudman, although I am not bubbling with optimism at this stage of the game, when it comes to success.

I would just like to know what you consider to be the unknowns of Gramm-Rudman.

Ms. EVERITT. It would be nice if I did. I only mentioned that in passing. It seems that suddenly the public is suddenly becoming aware of what has happened. When we were talking about it before it happened, it was hard to get their attention.

Now, you seem to have their attention.

Mr. HAYES. Not enough though, by the way.

Ms. EVERITT. I was remarking in the State I come from, they are now coming up with figures.

Mr. HAYES. It would be very helpful if that conservative State comes around.

Ms. EVERITT. Yes, that is the only reason I mentioned that. I think people in the human services field have been much more aware and much more concerned than the general public has. It scares the hell out of me, if you really want to know the truth, because I have a handicapped daughter, and I am not getting any younger, and I have to look out for her future, and as severely handicapped as she is, I have to look toward Government. We have to. We have no choice.

Mr. HAYES. Any other members care to comment?

Mr. SIRAK. I don't have a crystal ball.

Mr. HAYES. You will have one in a few weeks.

Mr. SIRAK. I can tell you at this point in time, our staff back in Montana, Wyoming, and Idaho are preparing alternate budgets, and they are going to reflect fewer services not only for this program, but many of the other services we provide.

The real problem is how far back can we cut? We may come to a point in time when we say there simply is not enough funds here to provide the kind of service that our organization wants to be affiliated with, and then it is going to be real tough, and that is what our real concerns are.

Mr. HAYES. Thank you, Mr. Chairman.

Mr. MARTINEZ. Going back to what Mr. Bartlett was asking about the prospects of the change of the format, 75-25, I think there are some people here that understand the premise that funding at the Federal level will stay the same with the percentage change and that you will have the advantage of that same amount of money leveraging that 25 percent into more money.

I have before me a table, and I just went through and, except for the State of Kansas, which only provided in matching funds 19.6, which is only four-tenths of 1 percentage point less than the 20 required now, all of the States provided more of a matching fund.

So that, except for the formal change now because of the 25 percent to them will be a greater amount of that Federal money, because there are some States, for example California, they in fact—in fact, Alaska provides 48, the other match, 48 percent, and in California just a slight percentage over, 21, but there are some States like Colorado that you wouldn't expect, 28 percent.

The only other areas that do not provide total matching funds are the Territories. So, I would follow the same thesis that I think Bartlett was alluding to, that according to those statistics, that that would probably mean, if the States carried through with the commitments they have made now, more money for the program.

Would anybody comment on that?

Mr. SIRAK. Again, I can only respond in terms of our particular State, and our State, as well as other States, fortunately do see the payback on this type of a program, and I think that is why legislatures, even in an era of severe cuts, are receptive to providing these funds.

Unfortunately, we are talking about a double whammy, not only Gramm-Rudman on the Federal level, we are talking similar kinds of cutbacks on the local level, because of particular things that are happening out west.

The mining industry, the lumber industry, the agriculture, we are experiencing very serious shortfalls in their tax revenues, and these decisions just become compounded when it is mandated, we have to come up with a bigger chunk of the pie.

Mr. MARTINEZ. Thank you.

One last question. This is to you, Ms. Everitt. In Mr. Mentasti's testimony, he described a State law which establishes a fair hearing procedure for all clients of the parent agency.

He also asserts this review process is even fairer to the clients than the protections contained in the current law. He then recommends that the States be offered this option.

Do you have a comment on that? Do you agree with that?

Ms. EVERITT. I don't know. It has been some years since my daughter went through rehab, which at the end of the closure, that was it. I can't comment intelligently whether that is working well or not. Sorry.

Mr. MARTINEZ. Dr. Rutman.

Dr. RUTMAN. No.

Mr. MARTINEZ. Mr. Marchand.

Mr. MARCHAND. One would assume it is conceivable a State or several States could in fact develop procedures that would be more strict, more stringent, better than the Federal standard. One would not want to dissuade States from doing that.

What we need is an effective, strong Federal bottom line that we feel will in fact protect the client. If a State wants to go beyond that, I don't think the law should prohibit it.

They should allow the State to proceed, but if there was an alternative type system in place, it should be left to the State to prove to the Federal Government that that system is in fact more stringent and not allow any sliding from the minimum Federal standard, which we are also working on to try to improve in the recommendations that we are going to bring to you, hopefully very, very shortly.

Mr. MARTINEZ. Thank you.

Mr. BARTLETT. Mr. Chairman.

Mr. MARTINEZ. Mr. Bartlett.

Mr. BARTLETT. This question relates the funding of rehabilitation of handicapped persons, to help them come back into the mainstream. That is what we are all here for.

It seems that we are faced in this Congress with a unique set of challenges, and limited options for how to accomplish that. In order to accomplish that and balance the Federal budget, there are alternatives.

One alternative would be a \$220 billion or 25-percent increase in total Federal taxes, which I don't advocate. All you would have to do to accomplish that is convince both Houses of Congress and the President, or two-thirds of both Houses of Congress, if you believe you can do that, then we can end this hearing and go on to other things. Another alternative is a doubling of the size of the cuts that are already projected for the defense budget, which are described by that committee chairman, who is not regarded as conservative, as being devastating already.

We can increase the match and go to States and say, "We think States ought to pick up a higher level of funding. We know that is difficult to do, but it is more feasible than having the Federal Government significantly increase its level of funding, because at least for the next 5 years, it doesn't look like that is going to happen.

We can make priority choices within other programs. It is true we should not pit one handicapped person against another. It is also true that some Federal programs, even within the jurisdiction of this subcommittee, have higher priorities than other Federal programs, and those are the kind of choices that we ought to face. We can try to do all of the above.

It seems that as we face this process that we should avoid drawing that line in the dirt and saying "No, we can't do this, this, this, or this."

Excluding all of the realistic alternatives then means a 32-percent—25-percent sequestration order in education of the handicapped and probably means, although it is exempted, but probably means a reduction in vocational rehabilitation. It certainly means level funding for the next 5 years, which probably would end up as a reduction.

I haven't described all of the alternatives, we can also, look at the 70 percent of the budget which was exempted from cuts under sequestration and see if there are priorities within that 70 percent that we can think about and talk about.

It is not my intention, and I know it is not yours, to draw that line in the dirt and say we can't do any of the alternatives because the result of that will be devastation for the lives of handicapped individuals.

I thank you, Mr. Chairman.

Mr. MARTINEZ. Thank you, Mr. Bartlett. I don't want to get into a debate about what the result of the problem is, but the one—and Mr. Bartlett admitted he didn't go into all the alternatives or solutions, but one that is most obvious to me is that, since this sequestration order would not be kicked in if we did not exceed that \$11 billion target, all we have to do is pick up half of the slush fund that the Pentagon has of that \$40 billion, \$20 billion.

We have that \$11 billion for that, and we have money to provide for these other programs, and that is the simplest, easiest thing, but sometimes we overlook the simplest and easiest solution to a problem, because we get diverted by the political notions, and what those political notions would mean to us, and other political considerations.

I say that the money is there. It is just deciding whether that priority is greater or this priority is greater, and that is the issue that we had before us before Gramm-Rudman that they were unable to make, so they chose to use Gramm-Rudman, and then they will justify to their cities and the programs that their constituents wanted, "It is not our fault. It is Gramm-Rudman's. It is in law. We have to do that." That is a copout. Mr. Hayes.

Mr. HAYES. There is one other option, I think, that we have to consider as the Government tries to reduce the huge deficit it is saddled with. That is the option of doing something about providing a mechanism for jobs for people who are out of work.

There are some 8 million people out of work, many of whom would like to pay taxes into the Government and could provide more money for the kind of programs we have been talking about, and others that are going to suffer.

I just want to mention that dimension, because I am particularly interested in that area, because I represent a district that is roughly 18 to 20 percent unemployed.

Mr. MARTINEZ. Thank you, Mr. Hayes, and I thank the panel. Your testimony was very informative, and we deeply appreciate it. Thank you.

We will start with Mr. Cohen.

**STATEMENTS OF MILTON COHEN, EXECUTIVE DIRECTOR, THE FEDERATION FOR THE HANDICAPPED IN NEW YORK CITY, REPRESENTING THE NATIONAL ASSOCIATION OF REHABILITATION FACILITIES; AND AMOS SALES, PRESIDENT, NATIONAL REHABILITATION ASSOCIATION, REPRESENTING THE NATIONAL REHABILITATION ASSOCIATION**

Mr. COHEN. Thank you, Mr. Martinez. I would like to present for the record my written testimony.

Mr. MARTINEZ. Mr. Cohen, could you hold it down a second?

Your testimony is in its entirety entered into the record.

Mr. COHEN. I would like to excerpt the highlights and make some comments on the written testimony. I am Milton Cohen, the execu-

tive director of an organization in New York City called the Federation for the Handicapped. I have been and currently am the executive director, and have been for 38 years.

It is a comprehensive vocational rehabilitation center providing services to some 1,500 severely disabled people daily. We have over 1,500 individuals on our payroll, so we are involved in what Mr. Hayes called some creative planning and training as some alternatives to funding problems.

I am here on behalf of the National Association for Rehabilitation Facilities. I was founding president of this organization 17 years ago. I am currently a member of the board and a member of the executive board. It is a membership organization composed of over 600 rehabilitation facilities and 21 affiliated State chapters.

Its purpose is to enhance the capacities of the facilities to provide quality services to the severely disabled persons. This is achieved through various activities, including technical legislation, publications, and administrative means.

The leadership of this committee in bringing this reauthorization bill up for early consideration, I assure you gentlemen is greatly appreciated. NARF was particularly gratified that technical assistance and postemployment services have been addressed in this bill.

Section 303 reestablishing technical assistance for State vocational rehab agencies and rehabilitation facilities now provides access to experts in a wide range of fields. It establishes again consultations, and we need them.

We need specialists in the job placement techniques, supported employment training, utilization of computer technology, innovative rehabilitation techniques, and others. This new, renewed technical assistance is most helpful to smaller facilities, particularly those in rural areas who do not have access to universities.

Section 104, emphasis on postemployment, is most welcome. Most severely disabled persons need post-placement services in order to insure long-term successful placements. This is particularly true for first-time placements.

Incidentally, this is not a new service under RSA. The Federal Government years ago provided a service that we call follow-along services. This now strengthens the follow-along services through postemployment service, and also supported employment is not new.

Some 20 years ago, many of us developed enclaves in industry, and this was developed throughout rehabilitation facilities. There is a new satellite-type of rehabilitation going on throughout the country.

We would like to identify it as workshops without walls. Let me tell you just one particular such technique. Federation of the Handicapped in New York City under the Javits-Wagner Act provides janitorial services to nine Federal buildings.

Two-thirds of the clients are mentally retarded, and most of them have multiple disabilities. But the gratifying payoff at the end of the workweek is that these individuals are averaging in excess of \$9 an hour.

These are the types of programs that probably we should alluded to if there are limited dollars going in the Rehab Act, how we can



provide creative, innovative techniques to create more training and more employment, et cetera.

Interestingly enough, the full cycle, Senator Javits, former Senator Javits, who lent his name to this very important act has been honored by having the largest Federal building outside of the Pentagon named after him.

That is 26 Federal Plaza, now known as the Jacob K. Javits Building, and full cycle is that Federation of the Handicapped is now negotiating with the deadline for September 1986 to take over this building, and provide janitorial and elevator services.

So, it is a high-water mark in our rehabilitation agency's history. The involvement of postemployment services would include counseling, retraining, relocating. Many of the individuals working in our buildings today, if they did not have ongoing supportive counseling, if we did not provide retraining, if we did not relocate them from one building to another, would lose many, many wonderful years of employment in the private sector.

So, ongoing postemployment services for the multiple handicapped, including the discussions held earlier with the psychosocial problem, because most of the severely disabled do have emotional problems.

That includes the mentally retarded as well, and we must provide many, many services. We would also like to suggest there should be a need for a statutory definition of supported work to be added to section 7 of the Rehabilitation Act.

As part of my testimony, there is a defined definition attached. The Rehabilitation Act should be extended for a reasonable amount of time. We know what it says in the act. We believe that the reauthorization should be for a period of 4 years.

This will allow sufficient time for new programs to be fully implemented and to be evaluated. H.R. 4021 also calls for an increase in basic State grant match. It is interesting, I think, most of the discussion or much of the discussion went around that, and it is understandable.

We are very concerned that some States would not be able to provide more than the current match. I have heard figures to the contrary. What I want to point out is there are States now providing costly services outside of the 80-20 match.

One in particular, New York State, has a program called Sheltered Employment Program. There are so many severely disabled people who will become institutionalized if we don't keep them in the community and the sheltered employment program is to provide through State and voluntary agency funding the long-term involvement of these severely disabled people in sheltered workshops, and oftentimes after you strip away the emotional problems, you see an individual who can become employed, who can become trained, and we have been successful in placing some 10 to 15 percent of these long term.

Now, the State of New York, the office of vocational rehabilitation provides starting this past October \$2,500 a year to the voluntary agencies, nonprofit voluntary agencies, to provide us and enable us to maintain these individuals in the community.

If they go into an institution, I don't have to tell you it is probably \$40,000 to \$50,000 a year to support them. We also have another program and this is matched, and most others.

There is a State Javits-Wagner-O'Day Act, where the State government and any subdivision of it purchases products and services from the voluntary agencies. This is through the office of general services. Again, they are State dollars, and I am seriously concerned that the higher match could very well jeopardize such gains that took years to implement.

Also, in terms of the match figures last year from CSAVR, rehabilitation can serve now only 1 in 20. I am sorry—Mr. Martinez, you made some questions, and I thought right now I made a comment on it, California took the leadership and provided a cap on administrative costs of State VR.

What happens is that the administrative costs come off the top salaries, any requirements of the State government come off the top. What is left then comes into basic services dollars, and there has been a shrinking, diminishing of State services dollars.

California took the leadership. I am not sure any other State, NARF attempted a few years back to explore that, and I believe we still are, but this is one of the ways we are trying to survive, because the match will create more problems, not less problems. More than that on this match.

We now are being referred from the office of vocational rehabilitation more and more severely disabled people who require more and more intensive services, not less.

Mr. Switzer, Commissioner Switzer, stated OVR pays only 50 to 75 percent. We believe it is closer to 60 percent of the State dollars required to rehabilitate severely disabled persons.

It is coming from us, from the voluntary sector. It is we who make up the differences. We are stretched to the point, and we are doing some creative planning to see that our programs grow, that the more severely disabled are placed in the private sector.

Perhaps this is not the best time to be an executive director, and perhaps this is not the best time to be a congressional person, but together with constructive planning, I think we can do something about that and cause the pain to be lessened and to create a greater environment for serving the severely disabled.

We urge that the RSA commissioner and the director of NIHR be a person of Presidential appointment.

We have worked for many years to upgrade the prestige of our field, and through this inclusion we would insure that through Senate confirmation there will be congressional oversights to examine the qualifications of the nominee. OSHA's report to Congress last year on training rehabilitation personnel, increasing emphasis on job development, placement supported work, and transitional programs, was also welcome.

NARF not only goes through in supporting these past few stated special facility personnel, but we want to go even further to include vocational evaluation and work adjustment areas. In-service training and short-term training needs to be emphasized because they are more easily addressed throughout the changing needs and can be done more quickly.

Several statutory changes in H.R. 4021 are very positive on administering the act; namely, requiring the report to be sent annually to the President and simultaneously to Congress. It describes how rehabilitation services can be utilized. For many years, Federal funding has improved. The prosthesis part of the Philadelphia arm, the mobility of the lower amputee, the improvement of the quadriplegic, this came through the engineering services.

Identification of State imposed requirements was spoken by earlier, and we agree about the priority rating and why and was it frivolous or was it a kind of list that just seemed the right thing to do. Interestingly enough, too, we are very strongly in favor of the pay-back requirement for persons trained with Federal dollars and who eventually go to work for proprietary firms.

Mentioned earlier, and NARF strongly supports projects with industry—nearly 20 years this has been going on as a demonstration under the Rehabilitation Act, placing disabled into industry. PWI requires the private sector to be a leading role model in cooperating with the rehab field. So we have a partnership with business, industry, and rehabilitation. But there is another facet to PWI that is overlooked in many ways.

It is also a marketing tool. It enables corporations and business to understand the value of severely disabled persons and therefore it is a job development tool. So, just as \$1 Federal brings back a minimum of \$10 or more through our Federal act, so does PWI with very modest dollars bring into the rehab fold a partnership with the private sector, and we need to lean on the private sector.

Mr. Martinez and other members of the committee, I would like to touch briefly on the role of the United States in international activities. I, for many years, have served as a consultant to the international division of RSA and that division is no longer part of our legislative act. It is a shame. For very modest dollars, the United States had a leadership role in international rehab, very modest dollars, and helped in setting up programs, in helping have this, whoever they are in different countries, come and learn some techniques to resolve, not the problems of the world, but to lessen the problems of the severely disabled.

We are not taking that strong stance to bring back the international division, but we need some vehicle to share the U.S. knowledge, to learn new trends from our partners overseas. We have to share with each other around the world. This is a partnership with the disabled that exists more closely through human services, I think, than any other field. So, it would be a great asset if this was to happen.

I hope that this subcommittee will address this issue in the Rehabilitation Act. This, gentlemen, concludes my statement, and I am sure you are ready for questions. If you are, I will attempt to offer an answer.

[The prepared statement of Milton Cohen follows:]

PREPARED STATEMENT OF MILTON COHEN, EXECUTIVE DIRECTOR, FEDERATION OF THE HANDICAPPED ON BEHALF OF THE NATIONAL ASSOCIATION OF REHABILITATION FACILITIES

Good morning, Mr. Chairman. My name is Milton Cohen. I am executive director of the Federation of the Handicapped in New York City. The Federation is a com-

prehensive vocational rehabilitation facility which serves over 1,000 persons with disabilities a day with vocational services and employment opportunities. I am here on behalf of the National Association of Rehabilitation Facilities. I was actively involved in NARF's formation seventeen years ago and I currently serve on NARF's Board of Directors. The National Association of Rehabilitation Facilities is a membership organization composed of over 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.

Your leadership, Mr. Chairman, in bringing this reauthorization bill up for early consideration is very much appreciated. The hearings you held in 1985 on the Rehabilitation Act were important in identifying the issues which needed to be dealt with in reauthorization of the Rehabilitation Act.

NARF was particularly gratified to see that technical assistance and post-employment services have been addressed in the bill you have introduced. The provision, Section 303, reestablishing a technical assistance program for state rehabilitation agencies and non-profit rehabilitation facilities will once again provide a means to give rehabilitation facilities and agencies access to expertise in a wide variety of fields which in turn will improve rehabilitation services and employment opportunities to persons with severe disabilities. This provision will allow the Rehabilitation Services Administration to reestablish consultation in areas such as job placement techniques, supported employment training, better measurement of disabled worker productivity, utilization of computer technology, innovative rehabilitation techniques and other subjects. As NARF noted in earlier testimony before you, this technical assistance program will be of most help to small rehabilitation facilities, especially in rural areas where access to university training programs is difficult at best.

Additional emphasis on post employment services as provided in Section 104 of the bill is also a welcomed addition to the state/federal rehabilitation program. Rehabilitation facilities have long realized that successful placement of persons with disabilities into jobs is often dependent on the level of service that can be provided to a person after the actual placement. Follow up services are needed to insure that the disabled person has been able to adapt to new environments and that the employer and co-workers have been able to adapt as well. These services are especially important as we continue to concentrate our efforts on more severely disabled persons. More and more often the persons served by vocational rehabilitation facilities have never worked before and long term post employment services are necessary to insure long term success.

Post employment services are also crucial to the success of new initiatives such as supported employment. It is these ongoing post employment services which allow severely disabled persons to work in competitive settings when they otherwise were assumed by the vocational rehabilitation system not to have vocational potential.

Many of the ideas on supported work being touted today as new concepts were innovative 20 years ago when they were originally developed in non-profit rehabilitation facilities. Enclaves in industry were developed over 20 years ago in rehabilitation facilities as workshops without walls and the most successful models of mobile work crews are operated by rehabilitation facilities providing services to federal agencies under the Javits-Wagner-O'Day Act. At the Federation of the Handicapped for instance, there are over 175 persons with severe disabilities working on nine different federal custodial contracts. Two-thirds of these workers are mentally retarded with many having multiple disabilities. The other workers have physical disabilities. The average wage for these workers is over \$9.00 per hour. Counseling and other supportive services are available to these workers on demand. Were it not for these support services these workers would not be able to work. This opportunity for severely disabled workers was begun at the Federation in 1977. Supported employment was begun in rehabilitation facility programs and the new emphasis on serving more severely disabled persons under this concept is a logical extension of these facility initiatives.

We were pleased that Congress recognized the importance of supported employment by appropriating \$9 million for fiscal year 1986 for these programs. The concept does however lack a statutory definition in the Rehabilitation Act. NARF is requesting that a definition of supported employment be added to Section 7 of the Rehabilitation Act which recognizes the appropriate role rehabilitation facilities can play in supported employment. Specific language is being submitted to your staff and for the record.

You have asked us to comment on provisions you have included in your bill. NARF agrees that the Rehabilitation Act should be extended for a reasonable

amount of time. We believe that four years would be a good length of time for reauthorization. It would allow sufficient time for any new requirements or programs under the Act to be fully implemented and evaluated.

H.R. 4021 also calls for an increase in the basic state grant match from 20 percent to 25 percent. While this would not result in any reduction in overall state grant funding initially, we are concerned that it could reduce the growth of these basic service dollars. We are aware that many, if not most, states are able to provide state funds in excess of the match requirement under the Rehabilitation Act. Some states are not able to provide more than the current match due primarily to state budget constraints or local economic conditions. The impact of Gramm-Rudman will only increase the burden on state government. The 80/20 ratio acts as a real incentive to states to match as much as possible, especially when there is a reallocation or an increase in funds due to increased Congressional appropriations. We would therefore recommend that the match remain at the 80/20 formula.

We can appreciate the management considerations in suggesting that the RSA Commissioner and the Director of NIHR be appointed by the Secretary of Education. On the other hand, we have worked hard for many years to improve the stature of RSA within the federal government. The Presidential appointment of the RSA Commissioner recognizes the importance of the rehabilitation programs and also insures that through Senate confirmation there will be Congressional oversight to examine the qualifications of the nominee.

NARF was pleased when OSERS sent its report on training needs to Congress earlier this year that new categories and new emphasis was being placed on training rehabilitation facility personnel. 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 maintain adequate services.

In service training and short term training need to be emphasized since under these two methods we can address changing training needs more quickly and they are more readily available to practitioners in the field. We also urge Congress to utilize the recommendations made by a major national Task Force on rehabilitation training needs. That report, dated March 21, 1984, has been given to your staff.

There are several statutory changes in H.R. 4021 that we feel will have a positive impact on administering the Act and in providing rehabilitation services to severely disabled persons. These include the requirement that the Annual Report be sent simultaneously to the President and to Congress, the requirement that state plans describe how rehabilitation engineering services will be utilized, the identification of state imposed requirements, and the payback requirement for persons trained with federal funds who work for proprietary firms. The last item is especially important. It is often difficult to retain qualified staff when they are lured away to for-profit agencies after they have been educated at public expense.

NARF is especially interested in Projects With Industry. This program is nearing twenty years as a demonstration program under the Rehabilitation Act. It has proven very successful as a program that places persons with disabilities into competitive jobs. PWI is unique in that it requires strong cooperation between business, industry and rehabilitation. A report evaluating PWI is due to Congress on February 1. The NARF staff would like to meet with your staff after that report has been sent to Congress by RSA to see if any statutory changes should be considered based on the findings and recommendations of that report.

Finally, Mr. Chairman, I would like to briefly touch on a subject that I doubt anyone else will address. That is the role of the United States in international activities. There is a need for the collaborative involvement of rehabilitation facilities, state directors of rehabilitation, rehabilitation professionals and researchers to learn of new trends in management and delivery of rehabilitation services from the world community. It is also important that we have the opportunity to share our knowledge and experience with others around the world. Especially in this time of fiscal constraint it is important to avoid reinventing the wheel and to share and to learn from our colleagues around the world. I hope that this Subcommittee will address this issue in the Rehabilitation Act.

Mr. Chairman, this concludes my statement. I would be glad to answer any questions you or other members of the Subcommittee might have.

#### DEFINITION OF SUPPORTED EMPLOYMENT

Proposed Amendment: Sec. 7(16) The term supported employment means paid work for persons who are severely disabled in a variety of integrated work settings, particularly work sites in which non-disabled persons work, irrespective of assumed

vocational potential, for whom competitive employment has not traditionally occurred, and, who, because of their disability need intensive, on-going post-employment support to perform in a competitive work setting. Supportive employment should take place in integrated community settings and can be provided by or administered by community based organizations, rehabilitation facilities, education agencies, or units of local government or governmental agencies. Modes of providing supported employment include but are not limited to Job Coach or Trainer Model in supported competitive employment, enclaves in industry, mobile work crews (including service contracts with the federal government under the Javits-Wagner-O'Day Act, P.L. 92-28), Projects With Industry, and competitive businesses.

Mr. MARTINEZ. Thank you, Mr. Cohen. Before we get into the questions, we will hear from Mr. Sales.

Mr. SALES. Mr. Chairman, members of the subcommittee, my name is Amos Sales, professor of Rehabilitation and director of the Rehabilitation Center, College of Education, University of Arizona in Tucson, AZ. I am currently, as you mentioned, Mr. Chairman, president of the National Rehabilitation Association, whose purpose since 1925 has been to promote and support rehabilitation efforts on behalf of individuals with disabilities.

The National Rehabilitation Association is the largest and oldest of the volunteer associations in rehabilitation. We currently have over 17,000 members within NRA, and in its seven divisions. As president of that association, I am pleased to be able to provide written testimony to you today. I will not attempt to read through and highlight each section of that testimony.

I will also try not to repeat some excellent testimony that has been provided today as well as excellent comments in terms of improvement of that legislation. I would like to highlight just a couple of comments from that document, however. The reauthorization language you propose provides for a very well-written and well-balanced piece of legislation as has been indicated in previous testimony.

It allows for a very creative process to occur in providing rehabilitation services to a wide range of individuals with disability. I think more importantly, though, that legislation signifies our society's recognition of its responsibility, if you would, to provide citizens with disability with an equal opportunity to access the benefits of this society.

The basic State Vocational Rehabilitation Program has a proven history of effectiveness. All studies, as has been mentioned before, indicate that that program is cost-effective. Work, as we all know, is of singular importance within our society. Who we are, where we live, what we do for fun all is related to what we do for work. To work in the United States is to be part of mainstream America. Yet yearly millions of individuals with disability are denied access to the societal and personal economic benefits of work simply because of a physical and/or mental disability.

Because of this, obviously the NRA endorses strongly the reauthorization of the Rehabilitation Act amendments that you propose. NRA views, though, as critically important the need to institute that funding levels truly meet the need within this society. Currently, this effective State service delivered program, because of funding limitations, is only able to serve 1 in 20 needing services.

Realizing the year ahead, the major budget deficits under which this Congress will be functioning, and as was well outlined by Mr.

Bartlett earlier, NRA's goal is that our society would eventually become enlightened to the need to develop a priority for funding for rehabilitation programs to adequately fund this program to insure that not 1 in 20, but all individuals requiring services can access them.

I assure you the National Rehabilitation Association is able and ready to provide you with consultant advice in terms of your deliberations in terms of reauthorization of the Rehabilitation Act. I thank you for this opportunity to have shared NRA's views and on behalf of NRA, thank you and your colleagues for your consistent and enlightened willingness to support legislative efforts in insuring that rehabilitation services are available to citizens with disabilities. I thank you.

[The prepared statement of Amos Sales follows:]

PREPARED STATEMENT OF AMOS SALES ON BEHALF OF THE NATIONAL REHABILITATION ASSOCIATION

Mr. Chairman, Members of the subcommittee: My name is Amos Sales, Professor of Rehabilitation and Director of the Rehabilitation Center, College of Education, University of Arizona. I am currently President of the National Rehabilitation Association, NRA an organization whose purpose, since 1925, is to promote and support rehabilitation for persons with disabilities and I am privileged to be here to present our position with regard to the reauthorization of The Rehabilitation Act of 1973, as amended.

I extend the sincere appreciation of the approximately 17,000 members of the National Rehabilitation Association and its seven divisions—the Job Placement Division, the National Association of Rehabilitation Instructors, the National Association of Rehabilitation Secretaries, the National Rehabilitation Administration Association, the National Association for Independent Living, the National Rehabilitation Counseling Association and the vocational evaluation and work adjustment association—to you for your consistent and enlightened willingness to support legislative efforts insuring that rehabilitation services are available to citizens with disability. Your past investments in these rehabilitation programs have returned significant dividends to our nation's taxpayers, and more importantly, to the persons with disabilities who receive rehabilitation services. No other program funded by the Federal government consistently returns so many benefits, both financial and personal, to all segments of our society. You have every reason to be proud of your widely-recognized leadership in assuring programmatic effectiveness and proper levels of investment in rehabilitation.

The Rehabilitation Act of 1973, as amended, and the reauthorization language you propose is a well-written, and well-balanced piece of legislation which allows for creative services to be provided to a wide range of persons with disability. In one Act, provisions are included for a comprehensive and individually-tailored program of rehabilitation services to eligible physically and mentally disabled persons; a training program to fully prepare rehabilitation personnel; a research program to develop new techniques in providing services; a special projects program to target services to specific populations; a comprehensive services program for independent living for persons too severely disabled to benefit from traditional vocational rehabilitation services; and other specially designed programs. The Rehabilitation Act and the programs it authorizes signifies our society's recognition of its responsibility to provide people with disabilities with an equal opportunity to access the benefits of this society.

As President of the National Rehabilitation Association, I am pleased to be able to provide you with the following comments on selected sections of the proposed legislation:

*Basic State Vocational Rehabilitation Services Program.*—This program serves as the foundation of the programs authorized in the Rehabilitation Act, as amended. This proven, finely tuned direct service program has stood the test of time and has been well managed. All studies indicate that this program is cost effective.

Of greater importance are the benefits of this program to persons with disabilities. Behind the cost/benefit studies are individuals who have been provided opportunities to earn money and gain the self esteem that comes from a paycheck. To be

working is to be part of mainstream America. This program helps persons with disabilities attain work and enter that mainstream.

Of basic concern is the critical need to maintain this basic service program and insure that funding truly matches the need within this society. Currently because of funding limitations, this effective program reaches only one in twenty (20) eligible persons. An NRA goal would be that our society would eventually become enlightened to the need to adequately fund this program to insure that not one in twenty (20) but all individuals with disability can access needed services.

#### TITLE I—SECTION 2—REHABILITATION SERVICES ADMINISTRATION

If, in changing the appointment of the Commission of the Rehabilitation Services Administration from the President to the Secretary level, the intent is to insure strong, effective and qualified leadership through the appointment in that position of an imminently competent, experienced rehabilitation professional, we would endorse this provision. However, we believe it important that language be developed to identify specific qualifications for this position and see precedent for such language within Section 202-C where qualifications are defined for the Director of the National Institute of Handicapped Research.

#### TITLE I—SECTION 3—DEFINITIONS

The National Rehabilitation Association supports any move that would enhance the amount of resources available to persons with disability. Any revenue enhancement proposals or guarantees of maintenance of effort are supported. We, additionally, would support any language or provisions that would control administrative costs for the rehabilitation programs administered within coordinated agencies. We would encourage that a ceiling on indirect costs be identified for the amount which coordinated agencies can charge to State Vocational Rehabilitation Agencies located within them. Direct costs should be allowed; however, indirect costs need review and control to insure that the maximum amount of resources allocated can be expended in direct support of clients. The National Rehabilitation Association recognizes that, as the reauthorization process of the Rehabilitation Act, the Congress is faced with major budgetting issues. We must point out that the appropriation levels identified are sorely lacking in terms of resources needed to meet the actual rehabilitation needs of all citizens with disability within this society. We would request that the language you develop related to appropriations would allow for more substantial initial funding commitments and for the potential to provide more substantial yearly increases as appropriate than those proposed.

#### TITLE I—SECTION 101

The National Rehabilitation Association endorses a five (5) year reauthorization commitment. Such would allow for the stability and continuity necessary to insure that our on-going programmatic commitment to citizens with disability can be met without disruption.

We further endorse efforts to insure that the requirement for "qualified personnel" be identified by the States. We ask rehabilitation personnel to perform very highly skilled tasks which require knowledge and competency in counseling, medical information, psychological information, evaluation and assessment, community resources and placement in order to develop individualized rehabilitation plans for services. Persons with disabilities deserve the right to have qualified personnel assisting them in the rehabilitation process. State agencies need to employ qualified staff and need to insure that they have the opportunity to keep abreast of new practices.

#### TITLE I—SECTION 104

The National Rehabilitation Association applauds the language in this section related to Rehabilitation Engineering and Technology as visionary in terms of the implications within these areas for future creative rehabilitation approaches.

We are entering a new era in our nation, one that is exemplified by remarkable rehabilitation engineering and technological advances. These scientific and technical achievement can, and should, be brought to bear on the problems faced by our nation's persons with disabilities. Funding for rehabilitation research will pay direct dividends in future years as we discover more effective ways of meeting the needs of persons with disabilities and incorporate technological and scientific advances in our direct rehabilitation service programs.



## TITLE 1—SECTION 303—TRAINING SCHOLARSHIP REQUIREMENT

NRA supports the concept that those receiving stipend awards should demonstrate commitment to the field rehabilitation through seeking employment therein after completion of degree requirements.

The quality of success of any direct service program is directly related to quality training for service providers charged with turning rehabilitation goals into realities.

We cannot allow documented shortages in many rehabilitation professions to continue without lowering the overall effectiveness and success of the nation's rehabilitation service delivery. We need to insure the highest quality of rehabilitation services for persons with disabilities through support of effective pre-service and in-service training efforts.

## TITLE 6—SECTION 601—COMPREHENSIVE SERVICES FOR INDEPENDENT LIVING

NRA strongly supports the thrust and funding for this section, which provides for services to individuals whose disabilities are so severe that they do not presently have the potential for employment. However, this opportunity to provide this service may enable them to live and function more independently and, when possible, enter eventually the Vocational Rehabilitation Program. We encourage continuation and financial support for Part A as the beginning steps to implement the Independent Living Service Program. Independent Living Services not only enable persons with severe disabilities to live and function independently but also reduce public costs associated with disability.

## TITLE 7—SECTION 701—GENDER NEUTRAL TERMINOLOGY

NRS applauds your sensitivity to the impact of language on attitudes within our society and commends the wording changes recommended. Given your sensitivity, I have attached to this testimony a copy of the National Rehabilitation Association's Glossary of Terms. This Glossary was adopted recently by the National Rehabilitation Association as a guide for terminology usage within all its publications. We believe the document to be an important first step in overcoming some terminology usage which has historically impacted negatively on individuals with disabilities and provide it to you in hopes that it will be value in your important deliberations on behalf of citizens with disabilities.

## SERVICE PROJECTS

The National Rehabilitation Association endorses the language developed to insure continuation of service projects—Indian Tribes Program, Helen Keller National Center, Architecture and Transportation Compliance Board, Client Assistance Program and Projects with Industry—developed to meet specialized service needs within rehabilitation. These programs are considered to be important and essential elements of support for and extension of the basic Vocational Rehabilitation Services program and provide for creative means of addressing unique problems by developing unique approaches to rehabilitation. As examples, the Client Assistance Program provides a programmatic commitment to insuring that client rights to services are not violated and the Projects With Industry program demonstrates a creative and effective strategy for linkage of business and industry with rehabilitation efforts for placement of persons with disabilities as wage earners and taxpayers in the private sector.

## SUMMARY

The National Rehabilitation Association commends the United States Congress for its long history of progressive legislation and funding of rehabilitation programs. That Congress has responded positively to the rights and needs of persons with disabilities is at least in part because of its recognition that rehabilitation programs are a part of a stronger United States. National legislation providing for rehabilitation services within this country reflects a social value commitment to insuring equal opportunity for all and provides for individuals with disability the avenue for full participation within our society. On behalf of the National Rehabilitation Association, I thank you and your colleagues for your enlightened and continued support of rehabilitation programs.

## NATIONAL REHABILITATION ASSOCIATION ON INDIVIDUALS WITH DISABILITIES

Words are your business, either printed or spoken. As professionals it is also your business and desire to be as accurate as possible in the use of those words.

The National Rehabilitation Association appreciates those efforts and the sensitivity that goes into your efforts. We offer a reminder of some areas of sensitivity that concern terminology on disabilities.

There are no laws governing the terminology any one organization or community might prefer. There are no hard and fast rules. There is a point of sensitivity.

The Research and Training and Independent Living Center at the University of Kansas has developed an excellent set of guidelines and a glossary of 16 commonly used terms or words for writing and reporting about persons with disabilities. The National Rehabilitation Association has adopted this report and hopes that you will do three things—read it, consider it in relation to your work, and keep its impact on a society in mind.

You know, better than most of the public, that it is not the correct words that are bothersome, but the incorrect and insensitive choices that we wish hadn't slipped by us.

We appreciate your time and consideration of this report.

For information, questions, input contact: National Rehabilitation Association, 633 South Washington Street, Alexandria, VA 22314 (703) 836-0850 (voice) or (703) 836-0852 (TDD). David Mills, Executive Director.

## ISSUES TO CONSIDER

The following points are issues to consider when portraying or writing about individuals with disabilities:

- a. Only make reference to a person's disability when it is important to the story.
- b. Avoid using adjectives as nouns as in: "the disabled, the deaf, the blind, a cripple, a retard/retardate, a victim, an arthritic, a spastic." It is more acceptable to say, "people who are deaf" or "person who has had polio," "persons with disabilities."
- c. Where possible, emphasize the importance of the individual rather than the disability by saying, "person" or "individual" before describing the disability. For example, say, "persons (those) with disabilities" or "people who are deaf" rather than "disabled persons" or "deal people."
- d. Avoid using descriptors such as unfortunate, pitiful, poor and other such value-laden words. When possible, use descriptors which emphasize a person's abilities such as: "uses a wheelchair/braces" rather than, "confined to a wheelchair" (a wheelchair enables mobility, without it, the person is confined to a bed).
- e. Do not sensationalize the onset or effects of a disability with phrases as: afflicted with . . . suffering from. It is more acceptable to say, "the person has (had), the person has experienced, a person with."
- f. Qualifying statements such as, "He uses a wheelchair but seems to be very bright" are demeaning and imply that the attribute is exceptional.
- g. Avoid implying sickness when discussing disabling conditions. To the general public, "disease" has connotations of being unsightly and contagious. A disability itself is not a disease nor is the person necessarily chronically ill.
- h. Avoid pejorative implications of disability-related words when used in commonly accepted metaphors (Wright, 1984). For example, alternatives for "blind faith" should be "unquestioning faith", "blind rage" should be "furious undirected rage."

## THE GLOSSARY

1. *Able-bodied*: is the preferred term for describing persons without disabilities. The word "normal" is often used as a synonym for able-bodies. However, this term should only be used to refer to statistical norms and averages.
2. *Blind*: is correctly used to describe a person with a total loss of vision. It is not considered appropriate for describing persons with partial vision. Such persons are more accurately described as partially sighted or with partial vision.
3. *Congenital disability*: is the correct term for describing a disability which has existed since birth. The often-used term "birth defect" is considered inappropriate when used to describe human beings.
4. *Deaf*: is correctly used to describe a person with a total hearing loss. It is not considered appropriate for describing a person with partial hearing. Such persons are more accurately described as having a (partial or severe) hearing loss or a hearing impairment (impaired).

5. *Developmental disability*: any mental and/or physical disability incurred before age 22 which is likely to continue indefinitely and results in substantial functional limitations in a combination of major life activities that will require individualized care and treatment of lifelong duration. This term includes individuals with mental retardation, cerebral palsy, autism, epilepsy, sensory impairments, birth injuries, traumatic accidents, or other disease processes which began prior to age 22.

6. *Disability, disabled, physical disability*: these terms are preferred over "handicap(ped)" to describe a permanent, physical condition that interferes with a person's ability to do something independently—walk, see, hear, talk, dress, learn, lift, work, etc. Terms such as cripple(d), deformed, victim, sufferer, invalid, and spastic, are considered negative and demeaning and should not be used.

7. *Down's syndrome*: is preferred over "mongolism(oid)" to describe a form of mental retardation involving improper chromosomal division at conception.

8. *Handicap(ped)*: this term is often used as a synonym for disability (disabled). However, except when citing laws or regulations, it is the less preferred term for describing a person's physical condition. It is better used to describe environmental conditions such as stairs, attitudes, or laws, etc., which inhibit a person's ability to function independently. For example, it would be correct to say, "The stairs are a handicap for her" but incorrect to say, "the handicapped child could not use the stairs."

9. *Mentally ill/mental disorder*: is correctly used to describe a person who has lost the social and/or vocational skills necessary to function independently. Negative, demeaning terms such as mentally deranged, deviant, maniac, crazy, lunatic, and mad are considered inappropriate and should be used only in direct quotations. Terms such as neurotic, psychotic, psychopathic, and schizophrenic (describing behavior but not for people) are not appropriate since these terms describe conditions people may have, not the people themselves. For example, use "an individual with schizophrenia" not "a schizophrenic" and use "a person with an alcohol dependence" not "an alcoholic."

10. *Mentally retarded*: is the preferred term for describing a person who, from birth, has developed at a rate significantly below average. Terms such as idiots, moron, mentally deficient/defective, imbecile, and feeble-minded are considered derogatory and should be used only in direct quotations when essential to the story.

11. *Person who cannot speak*: is the preferred term for describing a person who is unable to speak at all. Terms such as "deaf-mute" and "deaf and dumb" are considered degrading and imply that persons without speech are also deaf which may not necessarily be true.

12. *Seizure*: is correctly used to describe an involuntary muscular contraction symptomatic of the brain disorder, epilepsy. The term "convulsion" should be reserved for the more dramatic type of seizure involving contractions of the entire body. Although the term "fit" can be found in the dictionary and may be commonly used by the medical profession in other countries, it is considered inappropriate because it connotes mental derangement, willful emotional outbursts or loss of emotional control.

13. *Spastic*: is correctly used to describe a muscle with sudden abnormal involuntary spasms. It is not appropriate for describing a person with cerebral palsy—muscles are spastic, not people.

14. *Special*: incorrectly used to describe that which is different or uncommon about any person. However, except when citing laws or regulations, it is considered condescending to use this term to describe persons with disabilities in general.

15. *Specific learning disability (S.L.D.)*: is a disorder in the ability to learn effectively in respect to one's own potential when presented with an appropriate, regular instructional environment. This does not include persons with vision, hearing, or motor impairment, those with mental retardation or emotional disturbance, or persons who are environmentally, culturally, or economically disadvantaged. The term *specific learning disability* is preferred over the more general term, *learning disability* because it emphasizes that the disability effects only one or two areas of learning.

16. *Speech impaired*: is correctly used to describe persons with limited or different speech patterns.

Mr. MARTINEZ. Thank you, Mr. Sales. In your written testimony, you recommend that a ceiling on indirect costs be identified for the amounts which coordinated agencies can charge to State vocational rehabilitation agencies located within them. Would you expand on that and the reasoning behind that?

Mr. SALES. You will also notice in the documents NRA supports any efforts that would assure enhancement of funding would occur. Maintenance of State effort needs to be addressed, but additionally throughout the National Rehabilitation Association, we have become increasingly aware of very high indirect costs that have been charged to Federal-State vocational rehabilitation agencies within umbrella or consolidated types of social service agencies.

Obviously, direct costs need to be paid for, and as it relates to operation with a State-Federal cooperative program, but a free hand to build an unlimited amount, if you would, of indirect costs to the State-Federal program who are simply being housed within an umbrella social service agency needs close review and some determination of a ceiling.

Mr. MARTINEZ. What organizations are within that umbrella?

Mr. SALES. Within the National Rehabilitation Association? We have seven divisions. One of these is the job placement division. One is the National Association of Rehabilitation structures. Another is the National Association of Rehabilitation Secretaries. Another is the National Rehabilitation Administration Association. Another—

Mr. MARTINEZ. No. I mean the organizations that are charging those indirect costs that you are talking about.

Mr. SALES. My apologies. Umbrella social service agencies, for example, in my own State, Arizona, a department of economic security under which then are housed the State vocational rehabilitation agency, and a variety of other employment service programs, corrections, behavioral medicine, things like that in terms of specific kinds of agencies.

Mr. MARTINEZ. They incur costs that are really indirect to the program itself of the training and everything else that is involved?

Mr. SALES. Our impression is that they may be billing more to the State-Federal vocational rehabilitation housed within them than could be rightfully their due in terms of costs for simply being with those consolidated programs. Since about 1974, there is a significant increase in the number of States that have reorganized and developed the consolidated approach in terms of administering the various social service agency programs within the States and in the development of three consolidated programs.

What we have experienced and what we hear from our members is that there are in some cases inordinate amounts of indirect costs charged to State agencies, vocational rehabilitation agencies housed within some of these umbrella agencies.

Mr. MARTINEZ. Unfortunately it is just a drain on the funds that are available?

Mr. SALES. Very definitely. Very definitely.

Mr. MARTINEZ. Thank you. In your written testimony you make a recommendation for a proposed amendment that seems to be dealing with providing for people with severe handicaps the ability to work and be supported in that work with people that are not handicapped or less severely handicapped.

Would you expand on that?

Mr. COHEN. Are you talking about the definition, sir?

Mr. MARTINEZ. Yes.

Mr. COHEN. Yes. The concern we have in terms of supported work is that it does apply in the main. It is a general definition. It is an umbrella type definition, but we are mostly concerned with postemployment services involving not only private industry, but basically in private industry. We believe that it is more readily helpful to severely disabled people if we have these follow along services.

Let me give you one—a couple of quick examples. Three years ago, there was a need for drill press operators. We worked with this very large industrial manufacturing firm. We leased—he put in 10 drill presses. We trained 10 very severely disabled people on their work for which we were paid on a contract basis. Then we took one of our group leaders together with these 10 people.

We developed a minidepartment. We paid for the supervisor. The 10 drill press operators were paid the ongoing rate. These are the type of supported work, postemployment services that we have utilized for many, many years, and we encourage that in this, the new reauthorization act.

Mr. MARTINEZ. What I am really interested in is why you feel we need to make this part of the statute? Are there disincentives there for this to occur?

Mr. COHEN. No. We are concerned that tremendous investment in training severely disabled people and placing them in private industry; that we maintain their placement and supportive work, supportive ongoing, follow along services are extremely important in that endeavor.

Mr. MARTINEZ. John, would you like to answer the question?

Mr. DOYLE. With your permission, Mr. Chairman.

Mr. MARTINEZ. Would you identify yourself for the record?

Mr. DOYLE. John A. Doyle, executive director of the National Association of Rehabilitation Facilities—the Federal Government, as you know, has begun quite an initiative under the broad term, "supported work." There are some \$13 million, \$8 million in a special chunk and \$5 million outside of the discretionary projects under the Rehabilitation Act being devoted to supported work.

Yet, I dare say none of us in this room could come up with agreed upon definition of supported work that we as taxpayers, and you as Members of Congress have put up \$13 million for this year, which describes what it is we are doing with the money.

Now, contrast that with the, say, \$14 or \$15 million that goes for projects with industry grantees. We have a statutory definition of that program. We know what it is. We have an evaluation program underway that Congress is to receive within a month of how well it is doing, and you are to decide what future the program has. Contrast that with supported work where \$13 million is sitting there, and we don't even have a definition of where it is going.

I think the initiative is a good one. Mr. Cohen's testimony suggests we now should add the flesh to the skeleton and come up with a definition that tells us what sort of program we are indeed funding.

Mr. MARTINEZ. Very good. Thank you. I understand.

Mr. COHEN. One area following along John's statement, Mr. Martinez, that I would like to, in that definition, relate to, that is the section which says irrespective of assumed vocational potential,

those of us—I have been privileged to be involved in this wonderful field for 48 years—have seen the most severely disabled cast aside because we haven't looked underneath their severe disability.

We assumed that they were not vocationally or industrially placeable and by working with them, by providing them with the kind of support they need in the private sector, many have become very successful. So we have taken somebody off a future institutional role and have made them partially self-supporting, if not wholly self-supporting, so therefore this is a very important part of our definition irrespective of assumed vocational potential.

Mr. MARTINEZ. I see. Mr. Bartlett.

Mr. BARTLETT. Let me first clarify that. As I read the definition, it is in your testimony that if we adopt the definition that it should include only integrated worksites and exclude nonintegrated worksites.

Mr. COHEN. Not at all, sir, because if we do, again, we defy one of the most catastrophic group of individuals' vocational services, and that is the severely disabled homebound persons. I am sorry Mr. Jeffords is not here because the State of Vermont many, many years ago come out with what they called the Vermont plan, and that was to provide services to homebound.

My understanding is those trucks are still running up and down the State of Vermont, the hilly State of Vermont providing needed services to severely disabled. We have 200 severely disabled persons in our agency that we provided ongoing work at home. We train them in our agency. We transport them. We bring them back to their homes including word processors, telecommunications systems, very sophisticated innovative techniques.

But if we did not provide retraining, ongoing training, counseling in the home, ongoing supportive services in a nonintegrated setting, again, we would have a catastrophe of potentially retrained people not working.

Mr. BARTLETT. I understand. I would like to look at this definition and work it through with you as to the exact right words.

Mr. COHEN. It is a starting point, sir.

Mr. BARTLETT. If you were in our shoes and writing the bill, and you had a blank piece of paper, how in your judgment could we do a better job either through the private sector or otherwise, in increasing an emphasis on the use of technology, whether it is rehabilitation engineering or other kinds of technology? Are there ways that you would improve either the underlying law or the practices in technology?

Mr. COHEN. I think that is a very sound observation sir. I think, Mr. Bartlett, that the Government should and could take a tremendous leadership role in developing voluntary initiatives through the corporate and private sector.

There are, for instance, social lead programs, IBM, the giant. Notwithstanding the fact that our agency is a large organization in its own field, they loaned us a special list in the computer field for 1 year, cost this organization, this business corporation, in the neighborhood of \$150,000 in terms of salary, this person's salary, extra expenses, medical expenses.

I believe strongly that outside of Federal dollars, but with Federal leadership, we can involve the private sector. They want to

become involved. How many times I have heard executives say to me you were in the most fascinating field. We only make money. I try to show them we don't want them on our board to provide money.

We need their techniques. We need their know-how, their business judgments, comments, because more and more we are developing service industries within our agency. We are now involved in developing satellites with other vocational agencies and providing them with know-how in business so they can go out and market a product that is nationally developed.

We are doing that throughout the Javits-Wagner-O'Day Act. Minimal dollars on the Federal part, yet the combination of the blind and nonblind today have a deposit of \$300-odd million collectively in providing products and services to the Federal Government, minimum.

The Federal Government is buying it. Why not buy from us? There are safeguards so we don't hurt the private sector as well, but we are training disabled people. We are earning our own way, and we are providing a service to the Federal Government. There are many creative ideas, and we would like to sit down with you folks and together plot out some of these ideas.

Mr. BARTLETT. Mr. Sales, or Mr. Doyle, do you have any comments on emphasis on technology?

Mr. DOYLE. I would just say that the ongoing, Mr. Bartlett, the ongoing activities that the Federal Government does, funding needs to be even greater disseminated to the field, more greatly disseminated. There are very substantial enterprises underway. The National Institute of Handicapped Children, a modest institute by NIH standards, but nonetheless very significant by rehabilitation standards, and I think we would all wish to see the things that go on at NIHR disseminated even more widely to the rehabilitation field and to people like Mr. Cohen who are on the line every day training and rehabilitating disabled persons with these facilities.

Mr. SALES. Mr. Doyle has highlighted the kind of comment I would have shared in this issue. I might share with you in terms of current technology the use of computers in terms of cognitive retraining for brain-injured individuals has already reached some high level state of the art. A variety of uses of computerized learning programs for working with the severely mentally retarded have also proven to be very effective.

At issue, however, is dissemination of this kind of information to the practicing rehabilitation counselor and we need to, in terms of programmatic efforts insure that that communication gets to the primary service delivery person within the State and Federal program.

Mr. BARTLETT. Thank you. Thank you, Mr. Chairman.

Mr. MARTINEZ. Thank you, Mr. Bartlett, and thank you for staying with us to the end.

Thank you for coming and sharing with us your comments. We need those to put in order our thoughts as we progress with this bill. Thank you very much. We are adjourned.

[Whereupon, at 12:05 p.m., the committee was adjourned, subject to the call of the Chair.]

[Additional material submitted for the record follows:]

U.S. DEPARTMENT OF EDUCATION,  
January 29, 1986.

Hon. PAT WILLIAMS,  
Chairman, Subcommittee on Select Education, House of Representatives, Washing-  
ton, DC.

DEAR MR. WILLIAMS: I am pleased to provide the Department's views on your draft bill "To extend and improve the Rehabilitation Act of 1973." We welcome this opportunity to review and comment on your proposal in light of your own work on reauthorization legislation for this important area of Federal responsibility.

As you are aware, the Administration supports the reauthorization of those grant programs, authorized under the Rehabilitation Act of 1973 ("the Act"), which expire on September 30, 1986, and will propose, within the next few weeks, to extend these program authorities for one year to coincide with the expiration date for the basic State grant programs (title I of the Act). This legislative strategy would facilitate a more careful analysis of program evaluations now under review, particularly those evaluations mandated by the Rehabilitation Amendments of 1984 for submission to the Congress this February. For example, we are currently investigating ways to improve the training program (section 304 of the Act), Projects with Industry (section 621 of the Act), and the independent living program (title VII of the Act), and the independent living program (title VII of the Act). Therefore, the first of our two major concerns with your proposal is that it would reauthorize existing rehabilitation authorities for five years at a time when congressionally mandated evaluations and other studies, to be completed in the next few months, could provide a firmer basis for substantive improvements in the Act. We strongly urge to adopt a one-year extension so that the reauthorization process may have the benefit of this important information.

Our second major concern is that the proposed five-year funding levels are too high. In nearly every instance, the authorization of appropriations for 1987 substantially exceeds the 1986 appropriations level, and would increase each year. Of special concern is the definite authorization for the vocational rehabilitation State grant program, which is fully 20 percent (\$234 million) above the amount available for 1986. The proposal would authorize appropriations for currently unfunded authorities, such as the vocational training services program (section 302 of the Act) and comprehensive rehabilitation centers (section 305 of the Act), although the lack of current appropriations is indicative of low Federal priority. Further, the proposal would authorize appropriations for special recreational programs (section 316 of the Act) which we do not regard as an appropriate Federal activity. The Department strongly objects to such increased spending authority at a time when spending restraint is essential to reduce the deficit.

We support your proposal to increase the non-Federal share of funding of the basic State grant program from the current 20 percent to 25 percent. Greater proportional financial participation by the States is likely to increase State interest in operating high quality programs.

In addition to these major objections regarding the length of reauthorization and the level of authorized appropriations, we have several other concerns about the proposed legislation.

The first concern involves the proposed amendments affecting the appointments of the Director of the National Institute of Handicapped Research (NIHR) and the Commissioner of the Rehabilitation Services Administration. We support the proposed change of these two positions from Presidential to Secretarial appointments because we believe it is managerially appropriate for Presidentially-appointed assistant secretaries to have Secretarial appointees reporting to them. We do have some concerns, however, that the provisions inappropriately set these positions as Senior Executive Service (SES), compensated as GS-18. The SES level comprises steps ES-1 through ES-6. It is, therefore, inconsistent with SES rank to specify the GS-18 rate for an SES position, as proposed in the draft bill, and as such references should be deleted. Accordingly, the language in section 2(a) of the bill should be changed to read: "... The position of Commissioner shall be a Senior Executive Service position." Section 202(c) of the bill should be changed to read: "... The Director shall be a Senior Executive Service position." The bill should include conforming changes which give the Secretary the authority to, for example, make grant awards, issue reports to the President and the Congress, and receive guidance from the National Council on the Handicapped. In addition, while current law provides that the Director shall be guided by "general policies" of the National Council on the Handicapped, section 202(b) of the bill would require that the Director be "guided by the policies" of the National Council. The scope of this amendment is unclear. If the amendment is meant to circumscribe the Department's managerial authority, par-



ticularly in the area of funding decisions, we would have strong objections. To address this problem, we recommend that the current law be retained.

The Department strongly objects to section 202(c) of the bill requiring that the Director of NIHR establish a rural rehabilitation center. The Secretary should retain administrative flexibility to award research grants according to emerging needs and identified priorities on the basis of open competition. NIHR is currently studying the unique problems faced in providing rehabilitation services in rural areas.

Similarly, the amendment (section 107(a) of the bill) to limit a Governor's authority to change client assistance agencies is an inappropriate intrusion into internal State administration and an unnecessary limitation on a Governor's authority to make a decision regarding which agency he or she believes can best provide services under the Act.

There are two provisions relating to the rehabilitation of American Indians that are of particular concern. First, we object to section 109(c) of the bill, which would delete a provision of law preventing Indians on reservations served by title I, part D grants from being counted as part of the State population for purposes of allocating title I, part B Grants to States. We see no justification for allowing rehabilitation services for such Indians to be financed from two duplicative sources.

Second, we question the need for section 109(a) of the bill, which would allow the Commissioner to waive the 10 percent cost-sharing requirement for Indian tribes included in current law. The cost-sharing requirement for Indians is already only half the rate for States; we are not aware of any documented need for further special adjustment.

Finally, the Department objects to section 202(d) of the bill which calls for the submission of policy recommendations for the establishment of a new agency. Marketing and distribution of technological devices to assist disabled individuals is carried out under currently authorized activities. For example, one requirement usually applicable to NIHR grants is the dissemination of research findings, and NIHR already has rehabilitation engineering centers which focus on the technological aspects of rehabilitation services, including centers that are specifically concerned with the production, marketing, and distribution of technological devices. Since NIHR, through the Interagency Committee on Handicapped Research and in concert with the Veterans' Administration, the Department of Health and Human Services, the National Science Foundation, and the National Aeronautics and Space Administration, successfully provides for a coordinated program of production and distribution of technology, there is no need to establish a separate agency devoted to rehabilitation technology, nor for a special report to the Congress on this subject.

Although the Department has focused its efforts on a one-year extension of the Rehabilitation Act, we are developing a comprehensive proposal to reauthorize the Act beginning in fiscal year 1988. As noted above, we are reviewing several areas, particularly the training and independent living program authorities. We support in concept the proposal to require a term of employment in a public rehabilitation agency for each year of financial assistance received by individuals through the rehabilitation training program. We will consider the details of your proposal to require two years of service for every year of training support as we analyze the scope and effectiveness of the training program, and we expect to be able to recommend additional program improvements. Reforms are also needed in the independent living program; for example, we have serious concerns regarding the need for three separate independent living authorities. I look forward to working with you on reauthorizing these and other important rehabilitation programs and would be glad to answer any questions you may have.

The Office of Management and Budget has advised that there is no objection from the standpoint of the Administration's program to the submission of this report to the Congress.

Sincerely,

WILLIAM J. BENNETT, *Secretary.*

AMERICAN REHABILITATION COUNSELING ASSOCIATION,  
DIVISION OF AMERICAN ASSOCIATION FOR COUNSELING AND DEVELOPMENT,  
Alexandria, VA, January 21, 1986.

Hon. PAT WILLIAMS,  
Chairman, Subcommittee on Select Education, U.S. House of Representatives, House  
Annex No. 1, Washington, DC.

DEAR MR. WILLIAMS: On behalf of the American Rehabilitation Counseling Association, (ARCA), I am pleased with the opportunity to submit our recommendations

for the record as you prepare for the reauthorization of the Rehabilitation Act of 1973.

As we mentioned in our testimony before your committee in 1985, ARCA remains committed to quality rehabilitation counseling services for persons with disabilities. Our recommendations, which are attached, should serve to strengthen the rehabilitation service delivery system and to provide the highest quality service to persons with disabilities.

Again, our thanks to you for your interest and commitment to better rehabilitation services for American's with disabilities. Please feel free to call on us if we can be of any assistance.

Sincerely,

EDNA MORA SZYMANSKI,  
CRC, NCC, President.

#### ARCA RECOMMENDATIONS FOR EXTENSION AND IMPROVEMENT OF THE REHABILITATION ACT OF 1973

The American Rehabilitation Counseling Association (ARCA) is a division of the 47,000 member American Association for Counseling and Development. ARCA's primary mission is to help the profession of Rehabilitation Counseling to better serve persons with disabilities.

ARCA applauds the advances made by the 1973 Rehabilitation Act. However, much still needs to be accomplished in order to enable persons with severe disabilities to benefit more fully from the Rehabilitation system and to better actuate their potential as participating members of our society. Rehabilitation is a program which is consistent with the principles upon which our great nation was founded. It recognizes the inalienable worth and dignity of persons with disabilities and seeks to enable their full and productive participation in all aspects of society, especially employment.

The following recommendations are presented by ARCA with the goal of improving service to persons with disabilities:

*Change in Case Closure Concepts.*—The mandate for service to persons with severe disabilities introduced by the 1973 Rehabilitation Act has not yet been fully implemented. One impediment is the current case closure system which tends to emphasize quantity rather than quality. ARCA recommends a change in focus to emphasize quality of rehabilitation counseling service and de-emphasize quantity of closures. It is recommended that functional need reduction be considered as a major focus. That would result in consideration of competitive employment, supported employment, independent living and moves from institutional to community environments as positive outcomes of different magnitude depending on client need. It would also provide incentive for the delivery of quality rehabilitation services to persons with severe disabilities. In order to ensure that such a system remains consistent with consumer needs and rehabilitation counseling philosophy, recognized leaders in the consumer movement and the profession should be involved in its development.

*Least Restrictive Environment (LRE).*—A comprehensive LRE clause should be added to the Rehabilitation Legislation. Such a clause would require consideration and development of community integrated training and placement alternatives for persons with severe disabilities. It would not prohibit a "restrictive" placement but would allow it only when no other suitable alternative exists.

*Financial Incentives for Existing Rehabilitation Programs to Develop Supported and Transitional Employment Approaches.*—Given the current emphasis on Supported Employment, it is important that existing rehabilitation programs be afforded incentives and opportunities to develop community integrated employment and training approaches. Not to afford such an opportunity through financial incentives and training could result in the development of a costly duplicate service delivery system.

*Increase of Pre-service and In-service Training Funds for Rehabilitation Counseling*

*Pre-service Training* funds need to be increased in order to provide trained professional staff to meet the needs of persons with disabilities and carry out the spirit of the 1973 Rehabilitation Act. Consideration should be given to major funding increases to training programs desiring to modernize or broaden their curriculums in order to incorporate results of recent research and demonstration projects. Such incentives for major updating could provide substantial impetus for getting research into practice. The result would be significant improvement in service to persons with disabilities.

*In-service Training* funds need major increases in order to train rehabilitation counseling professionals in newly developed techniques and concepts. Research and demonstration projects continue to provide more effective ways of delivering rehabilitation service to persons with disabilities. Putting these methods into practice requires dissemination and training. An example is supported employment. Substantial training funds are needed in both pre-service and in-service categories in order to enable persons with severe disabilities to benefit fully from this new approach.

#### *Qualified Professionals*

*Direct Service.*—Agencies providing services authorized under the Rehabilitation Act should be required to hire individuals as rehabilitation counselors who possess the educational training for the position. This training is defined as a minimum of a Master's Degree from a CORE accredited program. Service to persons with disabilities should no longer be left to persons who are able to pass a civil service examination or fulfill other bureaucratic requirements but lack educational preparation. The service to persons with disabilities provided by rehabilitation counselors is a professional service requiring commitment and specific knowledge, skills, and abilities. It is not simply a bureaucratic function.

*Supervision and Management.*—Public and private agencies receiving funding through the Rehabilitation Act should be required to work towards the integration of rehabilitation philosophy and knowledge into all levels of management. It is suggested that by 1995, all such agencies be required to show that at least 80% of supervisory and management personnel involved with client services have education or experience in the provision of rehabilitation services. Such a concept would ensure a continued commitment to rehabilitation and an understanding of the complexities at all levels of agency management.

#### *Rehabilitation Services Administration (RSA)*

RSA has the potential to provide major leadership in service to persons with disabilities. To this end, federal leadership in RSA needs to include a significant percentage of persons with education and or experience in rehabilitation service delivery. This can promote both commitment to rehabilitation philosophy and an understanding of the complexities of service delivery.

Regional offices of RSA need to be revitalized. The role they provide in helping states to incorporate new methods and to better serve persons with disabilities cannot be underestimated. Yet, as the need for technical assistance and the complexity of the rehabilitation program has increased, this valuable resource has been eroded.

The American Rehabilitation Counseling Association (ARCA) is dedicated to continually improving the profession of rehabilitation counseling in its service to persons with disabilities. We are committed to work together with persons with disabilities towards the evolution of a society where they share equally in access to opportunities and benefits. ARCA, therefore, offers its assistance and support in efforts to improve Rehabilitation Services.

U.S. ARCHITECTURAL AND TRANSPORTATION  
BARRIERS COMPLIANCE BOARD,  
Washington, DC.

Hon. PAT WILLIAMS,  
Chairperson, Subcommittee on Select Education, House of Representatives, Washington, DC.

DEAR MR. WILLIAMS: As Chairman of the Architectural and Transportation Barriers Compliance Board, I am pleased to submit the following comments on your draft bill "To extend and improve the Rehabilitation Act of 1973." The comments address only the proposed amendments to section 502, which directly affect the Board.

The first proposed change<sup>1</sup> would restrict the office of the Board Chairperson to public members. Currently, Federal or public members may be elected Chairperson. Under the change, Federal agency members would not be eligible to be elected Chairperson. This change concerns us primarily because there has been no indication of any problem of Federal member domination on the Board. In fact, of the four

<sup>1</sup> For clarification, we note that in the proposed bill, the first change proposes to amend section (a)(1) by striking "The President . . ." The reference should be to section (a)(1)(B), following the listing of Federal agencies, since the phrase "The President . . ." appears earlier in section (a)(1) as well.

persons who have been elected Board Chairperson in the Board's history, only one was a Federal agency member. In addition, we note that the second change to section 502 in the proposed bill, which we do support, would put public members in a majority voting position on the Board, thus lessening the possibility of Federal agency domination in the future.

Given these considerations, the proposed change would be unnecessarily restrictive. Both types of members—public and Federal agency—each bring a unique perspective and potential for contributing to the Board. At any given time the Board should be free to choose its Chairperson based on the leadership qualities of the individuals under consideration.

The second proposed change would increase the number of public members by one, which would result in a majority of public members. This proposal, we believe, is consistent with the intent of the Congress in establishing the original composition of the Board. Prior to 1980 when the two successor agencies replaced the Department of Health, Education and Welfare, the public members of the Board held a one-seat majority.

The third proposed change would allow public members whose terms had expired to remain on the Board until a successor is appointed. This proposal results in a continuity of balance on the Board and a maintenance of the Congressionally prescribed balance. However, to clarify that this provision applies to interim appointments as well as to initial appointments to a full term, we suggest adding, at the end of proposed section 502(a)(2)(iii) the following: strike the period and insert "and until a successor is appointed."

I would be glad to answer any questions you may have. I can be reached through David Welch, my Executive Assistant, at (202) 245-1801.

Sincerely,

CHARLES R. HAUSER, *Chairperson.*

NATIONAL COUNCIL ON THE HANDICAPPED,  
Washington, DC, January 28, 1986.

HON. PAT WILLIAMS,  
*Chairman, Subcommittee on Select Education, Committee on Education and Labor,  
U.S. House of Representatives, House Office Building Annex No. 1, Washington,  
DC.*

DEAR CONGRESSMAN WILLIAMS: Thank you for your invitation of January 21, 1986 to provide written testimony for the reauthorization of the Rehabilitation Act of 1973. Recognizing the importance of the Rehabilitation Act, the National Council on the Handicapped has spent considerable time during the past several months developing a report of recommendations to improve the Act. I am pleased to submit a copy of this report for your review and incorporation into the Record.

Our views are based on comments from disabled consumers and rehabilitation professionals from across the country. Several of the recommendations are from our report, "Toward Independence," which is due to be presented to the President and the Congress this week. The recommendations are those of the Council and do not necessarily represent those of the Administration. This report has not been reviewed within the Executive Branch and has not been coordinated or cleared under the Office of Management and Budget's circular No. A-19 procedure.

We appreciate the opportunity to have our views on the Rehabilitation Act considered. If I can answer any questions or provide additional information to the Subcommittee, please do not hesitate to contact me.

Sincerely,

SANDRA S. PARRINO, *Chairperson.*

Enclosure.

NATIONAL COUNCIL ON THE HANDICAPPED—SUGGESTIONS FOR REAUTHORIZING THE  
REHABILITATION ACT OF 1973

#### OVERVIEW

As an independent Federal agency, the National Council on the Handicapped is charged with reviewing all laws, programs and policies of the Federal government affecting disabled persons and making recommendations to the President, the Congress and other Executive Branch officials. Whereas many government agencies deal with selected issues and programs affecting persons with disabilities, the Na-

tional Council on the Handicapped is the only Federal agency whose mission relates to all issues of public policy relating to persons with disabilities.

The Rehabilitation Act of 1973 (as amended by Public Law 98-221) stands as a landmark piece of legislation for Americans with disabilities. In the years since its enactment, much has been learned about the programs and activities made possible by the Act. A number of other significant changes also have taken place among rehabilitation service providers and the community of Americans with disabilities. Over the past year, these developments have been reviewed by Council members through public hearings and meetings with experts, including both consumers and rehabilitation professionals.

An analysis of the input from consumer and professional has resulted in some thirty (30) recommendations. The presentation of these views is consistent with the mandate of the Council. The recommendations are those of the Council and do not necessarily represent those of the Administration. This report has not been reviewed with the Executive Branch and has not been coordinated or cleared under the Office of Management and Budget's Circular No. A-19 procedure.

Briefly, the recommendations include: establishment of consumer advisory boards; coordination of services with special education; expansion of the dissemination and research utilization function of the National Institute of Handicapped Research; promotion of rehabilitation engineering training and enlarge reader and interpreter services; provision of management opportunities for disabled persons through the Projects with Industry program; and modifications for independent living services and centers. A new title, "Title VIII-Rehabilitation Technology," is proposed to address orphan technologies, guidelines for accessible office automation equipment and personal assistance technology.

The recommendations are organized by Title and Section within the Act, as can be seen in the Summary Chart following this overview. Each recommendation is constructed in the same way: after citation of the Section, a one-sentence summary of the proposed change is provided. This is followed by whatever level of detail is required (e.g., specific proposed wording changes in the Act) to indicate the Council's intent. A second part of each recommendation item is a rationale for the proposed change.

#### SUMMARY OF RECOMMENDED CHANGES IN REHABILITATION ACT

##### *Authorizations.*—1. Section 13. Report on RSA Goals and Activities.

##### TITLE I. VOCATIONAL REHABILITATION SERVICES

###### Part A. General Provisions.—

1. Section 100. Increase of appropriations.
2. Section 101. Create State Consumer Advisory Boards.
3. Section 101. Add payor of last resort language.
4. Section 102. Coordinate IEP's and IWRP's.
5. Section 102. Implement beyond a reasonable doubt criterion.

Part B. Basic Vocational Rehabilitation Services.—No recommendations for change.

Part C. Innovation and Expansion Grants.—No recommendations for change.

Part D. American Indian Vocational Rehabilitation Services.—

1. Section 130. Expand authority to serve American Indians.

##### TITLE II. RESEARCH

1. Section 200. Establish priority on dissemination and utilization.
2. Section 204. Promote enhancement of innovation grants.
3. Section 204. Promote rehabilitation engineering training.

##### TITLE III. SUPPLEMENTARY SERVICES AND FACILITIES

1. Section 304. Promote rehabilitation engineering training.
2. Sections 314 and 315. Enlarge reader and interpreter services.

##### TITLE IV. NATIONAL COUNCIL ON THE HANDICAPPED

1. Section 401. Retain current language, deleting one-time report requirement.

## TITLE V. MISCELLANEOUS

Recommendations regarding this title will be presented in the Council's February 1, 1986, report to the Congress.

## TITLE VI. EMPLOYMENT OPPORTUNITIES FOR HANDICAPPED INDIVIDUALS

Part A. Community Service Employment Programs for Handicapped Individuals.—No recommendations for change.

Part B. Projects With Industry and Business Opportunities for Handicapped Individuals.—

1. Section 621. Encourage continued funding of PWI Program.
2. Section 621. Provide management opportunities for disabled through PWI's.
3. Section 622. Encourage state use of authority for business opportunities.

## TITLE VII. COMPREHENSIVE SERVICES FOR INDEPENDENT LIVING

Part A. Comprehensive services.—

1. Section 703. Increase appropriations.
2. Section 705. Increase Part A funds to centers.

Part B. Independent Living Centers.—

1. Section 711. Facilitate meeting standards for centers.
2. Section 711. Moderate relationship of centers to state agencies.
3. Section 711. Enhance advocacy function of centers.
4. Section 741. Enable two-tiered fundings of centers.

Part C. Independent Living Services for Older Blind Individuals.—No recommendations for change.

Part D. General Provisions.—No recommendations for change.

## TITLE VIII. (PROPOSED) REHABILITATION TECHNOLOGY

Part A. Orphan Technology Act.

Part B. Guidelines for Office Automation Equipment.

Part C. Personal Care Assistance Technology.

Authorizations.—

## RECOMMENDATIONS

1. *Section 13.* The Council recommends that the RSA Commissioner be required to submit an annual report to the Congress summarizing the RSA's overall goals and annual progress on them.

*Rationale.* Currently the annual report of the RSA Commissioner emphasizes statistical information on the service delivery process. This is supplemented by statistical reports on training, by mandated (one-time) evaluation reports on programs such as Projects With Industry, and so forth. While such data are indeed valuable, an annually-prepared narrative analysis of RSA's overall program of funding support, technical assistance to state agencies, training, evaluation and other activities would permit better-informed Congressional review and decision-making.

## TITLE I. VOCATIONAL REHABILITATION SERVICES

Part A. General Provisions.—

1. *Section 100.* The Council recommends that authorization of appropriations be increased substantially. The Council does not, however, recommend a specific level of authorization, except that the funding should be well above that which would result from application of the PL 98-221 language on the consumer price index.

*Rationale.* Current funding levels for the Federal-State services program (Title I), for projects (Title II), for employment opportunities (Title VI), and for independent living (Title VII) in particular, all are well below the levels needed to provide quality services to eligible individuals.

In constant dollars, the Fiscal Year 1984 level of appropriations is just 75% of the Fiscal Year 1974 level. In other words, spending on rehabilitation has declined by one-quarter over the past decade, as measured in actual purchasing power.

The Rehabilitation Services Administration (RSA) reports that in Fiscal Year 1984 936,180 persons were served, the lowest number in years. Ten years earlier, 1,176,445 individuals were served.

RSA also reports just 225,772 closures in Fiscal year 1984. While slightly above the Fiscal Year 1983 level, the number rehabilitated remains sharply below the levels achieved in earlier years. In Fiscal Year 1974, for example, 360,138 persons

7015

were closed as rehabilitated. The Fiscal Year 1984 level is just 62% of that of ten years earlier.

Perhaps more critical, the Council believes, is the fact that Federal spending on all disability programs dwarfs that invested in rehabilitating disabled persons to independence and self-sufficiency. While \$52 billion was spent in Fiscal Year 1982 for SSDI (\$18 billion), SSI (\$9 billion), and Medicare/Medicaid for under-65 disabled persons and eligible dependents (\$25 billion), just \$1 billion was allocated for rehabilitation.

2. *Section 101.* The Council recommends that in subsection (a)(18) a requirement be added that a Consumer Advisory Board be established in each agency. This Board would have the authority to represent to the agency the views of individuals and groups which are recipients of service.

*Rationale.* Consumer involvement varies from state to state, and within states from agency to agency, such that in many states consumers lack meaningful access to and influence with state agency administrators. Where consumer advisory boards have been established, they generally have worked well.

3. *Section 101.* The Council recommends that the "similar benefits" subsection (a)(8) be strengthened to clarify which federal or state program is the payor of last resort when more than one program has such a clause in their legislation. Specifically, it is recommended that the VR program be designated the payor of last resort regardless of the provisions of any other program.

*Rationale.* "Payor of last resort" clauses may cause difficulties for disabled persons when VR clients are also recipients of Pell grants and other financial aid in post-secondary education programs, when VR clients also would be otherwise eligible for "uncompensated services" under the Hill-Burton Act or for Crippled Children's Services under federally-funded state programs, when Section 504 would seem to mandate interpreter services by colleges and universities attended by VR clients, and other situations.

4. *Section 102.* The Council recommends that cooperative development of Individualized Written Rehabilitation Plans and Individualized Educational Plans be mandated. This would involve amending subsection (b) by adding after the words "pursuant to section 112." the following: "In addition, for persons in secondary or postsecondary educational programs or eligible for such programs or for services under the Developmental Disabilities Act (PL 98-527), development of the individualized written rehabilitation program is to be undertaken in coordination with agencies and persons responsible for preparation of individual educational plans (IEPs) and individual program plans (IPPs) as appropriate."

*Rationale.* The cooperative development of IWRPs, IEPs, and IPPs promote effective coordination of services for persons with disabilities. In a few states, such cooperation already is in place, but only for some rehabilitation clients. Similar language to that being proposed here now applies to independent living services, under section 705(a)(4).

5. *Section 102.* The Council recommends that the standard "beyond a reasonable doubt" be specified as that which must be met before a claim brought under the Client Assistance Program may be judged as being without merit. The Council proposes amending subsection (c)(2) by adding, after the word "capable" and before the words "of achieving such a goal" the following: "beyond a reasonable doubt".

*Rationale.* Pursuit of legal, administrative and other remedies would be expedited by using a criterion well established in case history as more stringent than the standard now in use. The current standard unfairly limits clients and potential clients in their pursuit of remedies.

Part B. Basic Vocational Rehabilitation Services.—No recommendations for change.

Part C. Innovation and Expansion Grants.—No recommendations for change.

Part D. American Indian Vocational Rehabilitation Services.—

1. *Section 130.* The Council recommends that the authority for rehabilitation programs benefiting American Indians be increased so as to serve all tribes and reservations. The Council further recommends that the Congress hold hearings on implementation of the Part D program for American Indian Vocational Rehabilitation Services.

*Rationale.* The Council is concerned that too few tribes and too few reservations benefit from this vital service.

## TITLE II. RESEARCH

1. *Section 200.* The Council strongly recommends expanding considerably the responsibility of the National Institute of Handicap Research (NIHR) and of the

Interagency Committee on Handicapped Research for dissemination and utilization of research-based information.

The Council proposes amending section 200(2) by deleting the semicolon ending this subsection, replacing it with a period, and adding: "Dissemination and utilization of information and technologies useful to disabled persons, their families, and agencies serving them shall be a top priority for the National Institute of Handicapped Research and for the Interagency Committee on Handicapped Research."

*Rationale.* Pursuant to its authority to "establish general policies for, and review the operation of, the National Institute of Handicapped Research", the Council finds that research findings, rehabilitation engineering products, and other research-based information continues to be poorly disseminated and used by disabled persons, their families, and agencies and professionals serving disabled people.

2. *Section 204.* The Council recommends that the Director of NIHR appoint annually a special task force of experts in rehabilitation research and services (including also consumer representatives) to provide written guidelines for priority topics under the Innovations Grants program, and that subsection (13) be amended to this effect. These guidelines would be made available to potential applicants and to peer reviewers for the Innovations Grants program, and would be advisory rather than binding in nature.

*Rationale.* The NIHR Innovations Grants program represents an important opportunity for new ideas to be tested and further developed, and the program should be continued. However, without guidelines for both applicants and peer reviewers, and because of the relatively small amount of funding available, there has been an observed tendency for proposals to be submitted that are not in fact innovative, but are "retreads" of project ideas that have been turned down for funding elsewhere. Guidelines on important topic areas may serve to sharpen the competition, and also would provide guidance as to the areas of greatest current concern to NIHR, while not eliminating the possibility of funding in worthwhile areas that did not occur to the task force.

3. *Section 204.* The Council recommends that Rehabilitation Engineering Centers be encouraged to provide training for both professionals and consumers in the effective utilization of rehabilitation engineering services, especially with respect to enhancing vocational potential and independent living skills for severely disabled individuals. This would require an appropriate modification in the language of subsection (b)(2).

*Rationale.* The Rehabilitation Engineering Centers program has resulted in development of many worthwhile devices to aid disabled individuals. Services to adapt technology to given individuals' personal needs often are not fully utilized, however, because neither service professionals nor consumers fully understand how to access rehabilitation engineering services.

#### TITLE III. SUPPLEMENTARY SERVICES AND FACILITIES

1. *Section 304.* The Council recommends that rehabilitation engineering be added to the list of priority training areas cited in subsection (b).

*Rationale.* Wider utilization of rehabilitation engineering services would be made possible by increasing the number of professionals trained in this specialty field.

2. *Sections 314 and 315.* The Council recommends that the programs for grants for reader services for blind persons (section 314) and for interpreter services for deaf individuals (section 315) be activated and funded with such sums as may be necessary.

*Rationale.* For many blind or deaf individuals such services are vital for independent living, for employment, and for participation in the community as citizens. Existing services in almost all states limit assistance to current clients of rehabilitation agencies, employees of firms which are willing to provide such services, and to a very few "charity cases" of existing referral services. Even for state agencies and independent living programs and centers, provision of such services for clients is limited due to insufficient funding.

#### TITLE IV. NATIONAL COUNCIL ON THE HANDICAPPED

1. *Section 401.* The Council recommends that the present language be retained, deleting only subsection (b), referring to the one-time February 1986 report.

*Rationale.* The Council is functioning well under the authorization made in PL 98-221. In particular, the broad mandate and emphasis upon human rights provides the Council with the authority it needs to be effective. The one-time report will be completed before the Act is reauthorized.



## TITLE V. MISCELLANEOUS

Recommendations regarding this Title will be presented in the Council's February 1, 1986, report to the Congress.

## TITLE VI. EMPLOYMENT OPPORTUNITIES FOR HANDICAPPED INDIVIDUALS

Part A. Community Service Employment Programs for Handicapped Individuals.—No recommendations for change.

Part B. Projects With Industry and Business Opportunities for Handicapped Individuals.—

1. *Section 621.* The Council recommends that funding of the PWI program be continued.

*Rationale.* Current information indicates that the PWI program has had considerable beneficial impact on employment opportunities for disabled individuals. If these interpretations are confirmed by the external evaluation of the PWI program currently being completed for review by the Congress, options exist for continuing or even enhancing funding support for this seemingly worthwhile program.

2. *Section 621.* The Council recommends that PWI activities include attention to providing management-level employment opportunities for individuals with disabilities. This would involve modifying subsection (a)(1)(A) by adding, immediately after the words "in a realistic work setting," the following: "including management-level work."

*Rationale.* The Council is concerned that too many Projects With Industry (PWI) clients are placed into lower-level, nonmanagerial positions. The opportunity should be made available, for appropriate individuals to secure management-level jobs through PWI programs.

3. *Section 622.* The Council recommends that state agencies be encouraged to make more use of the authority this section provides to encourage entrepreneurial opportunities for individuals with disabilities. This would involve an appropriate modification in the language of this section, perhaps requiring discussion of decisions made in this area in the agency's annual plan.

*Rationale.* Few phenomena have so characterized the 1980's as has the explosive growth of entrepreneurial activity. Disabled persons should have the opportunity of participating in this activity, which has resulted in the creation of more than 600,000 new businesses in 1984 alone, if for no other reason than that as owners of their own enterprises, these persons would not face employment discrimination on the basis of disability.

## TITLE VII. COMPREHENSIVE SERVICES FOR INDEPENDENT LIVING

Part A. Comprehensive Services.—

1. *Section 703.* The Council strongly recommends that support for Part A programs be increased sharply over the current \$5 million appropriation level.

*Rationale.* Part A is a flexible, powerful tool for implementing independent living services which are vitally needed by the Nation's disabled individuals.

2. *Section 705.* The Council recommends that the amount of Part A funds available to independent living centers be increased. This would involve amending subsection (a)(8) by deleting "not less than 20 percent" and substituting "not less than 50 percent." The following should also be added to this subsection: "No more than ten percent of available funds should be used for administrative purposes. The remaining funds should be used at the discretion of the administering agency in any way that assists people with severe disabilities to achieve independence and productivity in their communities."

*Rationale.* The independent living centers have now demonstrated their ability to provide quality services to individuals with disabilities, including community advocacy services which appear to be best provided by a free-standing agency. Moreover, there is considerable feeling in the independent living community that the spirit and self-esteem of these programs would be enhanced by affording them greater independence—which is, after all, the overall goal of the entire program: to facilitate independence for disabled persons.

Part B. Independent Living Centers.—

1. *Section 711.* The Council recommends that core funding should be provided under Title VII, Part B for Independent Living Centers that meet the standards approved by the National Council on the Handicapped. This would involve adding a new item to subsection (c)(1): "Demonstrate that the proposed center meets the standards established for such centers, or in the case of proposed centers not yet

funded under the subtitle, demonstrate that the proposed center will meet the standards within six months of onset of the grant program."

*Rationale.* Now that standards for independent living centers are available, all existing Title VII-funded centers should meet these standards. Newly-funded centers should have a modest amount of time to reach compliance with the standards.

2. *Section 711.* The Council recommends that Part B funding be equally available to independent living centers directly and to state agencies. This would involve amending subsection (d) by deleting all words between "If, within six months" and "such an application," capitalizing "the" before "Commissioner" and adding, immediately after "from" the following: "designated State units."

*Rationale.* Because their activities often encompass individual and system advocacy as well as service delivery, independent living centers should be as independent as possible. The existing language grants preference to state rehabilitation agencies, which may not always be appropriate.

3. *Section 711.* The Council recommends that the advocacy functions of centers be expanded to make the statutory language consistent with the standards approved by the National Council on the Handicapped. This would involve amending subsection (c)(2)(C) to provide, after the words "counseling and" the following "individual and systems."

*Rationale.* The Council believes that the role of independent living centers encompasses advocacy not just on behalf of individuals acting singly but on behalf of groups of people collectively affected by service delivery and other systems.

4. *Section 741.* The Council recommends that a two-tiered approach be taken with respect to (b) authorizations for appropriations for centers for independent living such that centers currently funded by Title VII monies would continue to be funded if they demonstrated that they met the standards while additional funds would be designated for supporting centers not now receiving Title VII monies which demonstrated that they would meet the standards within six months.

*Rationale.* Providing sufficient funds to continue current centers while permitting new centers to receive funding would be in the best interest of disabled persons, in the Council's judgment.

Part C. Independent Living Services for Older Blind Individuals.—No recommendations for change.

Part D. General Provisions.—No recommendations for change.

#### TITLE VIII. REHABILITATION TECHNOLOGY (PROPOSED)

##### Part A. Orphan Technologies Act.—

1. The Council strongly recommends that an "Orphan Technologies Act" be placed into the Rehabilitation Act as Part A of a new Title VIII. This new Act would authorize funds for reimbursement to private industry for development, marketing, distribution, repair, and training services for technologies that, because of their limited market as special-needs devices appealing only to severely disabled persons, are in effect "orphans" that industry would not otherwise support sufficiently well so as to bring these technologies to the people who need them.

*Rationale.* Modeled after the orphan drugs legislation, this Act would serve to stimulate industry to research, manufacture, distribute and support special aids. The Council believes this new Act should be placed into the Rehabilitation Act so that the Council and NIHR could oversee its implementation.

##### Part B. Guidelines for Office Automation Equipment.—

1. The Council strongly recommends that Part B of the new Title VIII provide that, effective October 1, 1987, all office automation equipment purchased by the Federal Government be "accessible to and usable by, or at a minimum adaptable to meet the needs of, disabled persons."

*Rationale.* The Congress already has provided that public and publicly used private buildings, and that programs and activities benefiting from Federal contracts or Federal financial assistance be accessible to and usable by disabled people. It makes little sense not to provide, as the state of the art now allows us to do, that the equipment in these buildings and used in these programs and activities also be accessible to such individuals.

The Council recommends that persons and entities subject to sections 501, 503, and 504 be required to meet the same criteria effective October 1, 1988.

##### Part C. Personal Care Assistance Technology.—

1. The Council recommends that "Minimum Guidelines and Requirements for Accessible Design of Office and Educational Equipment" be developed by rehabilitation engineering centers authorized by Title II of the Act. Under the new Title VIII, these guidelines would be required to be developed prior to September 30, 1987. The

office of Special Education and Rehabilitative Services would be authorized to conduct public hearings on these guidelines while still in draft form, to seek input from consumers, manufacturers and rehabilitation professionals.

INTER-NATIONAL ASSOCIATION OF  
BUSINESS, INDUSTRY AND REHABILITATION,  
Rockville, MD, January 30, 1985.

Re Testimony supplementing that received during the hearing on the Reauthorization of the Rehabilitation Act held on January 29, 1986.

MR. CHAIRMAN AND MEMBERS OF THE SUBCOMMITTEE:

I-NABIR, the Inter-National Association of Business, Industry and Rehabilitation, representing the about 300 existing Partnerships With Industry and the more than 10,000 business organizations and labor unions which are joined with them, wishes to support the reauthorization of the Rehabilitation Act and to suggest specific additions/modifications to the existing act to facilitate and stimulate increased participation by the private business and labor sectors in the rehabilitation process.

We urgently request that you include language in the Reauthorization Act which will continue funding for the existing Projects With Industry (PWI) and provide for the expansion of this concept of operation into and throughout the remainder of the Rehabilitation Community. The basic PWI concept accepts the private sector employer, organized into Business Advisory Councils, as full partner in the vocational rehabilitation process. This acceptance has throughout the country mobilized many thousands of responsible business people in support of training and employment for the severely disabled. The private resources thus contributed in terms of time, in-kind contributions, and money far exceed the basic federal contribution to each project.

Recent budget submissions by the Department of Education quote estimates that there are 25-30 million disabled people in the United States of whom more than 10 million are characterized as severely disabled. The stated objective of the public program under Title I, however, limits the rehabilitation output to less than 300,000 persons. Under these conditions, there is absolutely no way the present rehabilitation program under Title I can realistically begin to address the existing training and employment needs of our disabled population without significantly increased guidance, assistance and support from the private sector.

It is our sincere belief that the PWI Program is by a wide margin the most successful placement activity within the rehabilitation process even though it has been operating at a very low level of support. PWI has placed in a network of business and industry over 100,000 disabled people whose earnings today are exceeding one billion dollars annually—not to mention the \$200 million they are paying to the government in taxes each year. In any consideration of legislative changes to the rehabilitation program, full recognition should be given to the existing several thousand private, nonprofit rehabilitation facilities in the United States and their potential for affiliation in Partnerships With Industry with the countless major and minor corporations, trade associations, and organized labor. We must involve and utilize the knowledge, skills and resources of all elements of the private sector if we are to adequately meet the needs of our disabled population for rehabilitation and employment. To accomplish this essential, high priority objective, a new federal initiative is urgently needed along with a strong national policy emphasizing the need for increased participation and contribution from these additional nonfederal resources.

A new emphasis at the national level should be placed on the highly successful Projects With Industry program. PWI has the potential to stimulate all of private industry in cooperation with facilities and foundations to assume a major role in the integration and placement of disabled people into private employment. PWI introduces the concepts and practice of competition, cost effectiveness, marketing, and use of the latest technology and training programs modified to meet the needs of the marketplace. Projects With Industry, combining the private, nonprofit effort with the capabilities of private industry and organized labor, offers the only practical way to accomplish the goal of rehabilitation and gainful employment of our disabled people.

Projects with Industry historically have been established to encourage and demonstrate new techniques and methods; they have therefore all been required administratively to compete for new funding at the end of each period in concert with any and all new proposals. With the establishment of extensive networks involving employers and other community resources, however, this mandated competition pro-

vides a major exposure to the forced abandonment of such highly successful networks and the consequent disillusionment of the involved community partners when project funding is terminated. Subjecting project funding to a series of stops and starts is inherently disruptive to the stability of the programs and deprives disabled people of real opportunities for placement in the private, competitive marketplace. Successful established projects should be converted to long-standing placement programs within their communities. Successful high-quality programs are best assured by the establishment and utilization of valid criteria for measurement and the continuance of those programs which meet the established high standards.

Enclosed for your consideration is a draft of possible changes for inclusion in the new Act. A Declaration of Purpose would establish the several elements of the system and a new Title would implement the Partnership With Industry program. Additional amendments are suggested to provide for continuing PWIs as suggested above, and to emphasize placement and the involvement of private industry in State Agency expansion grants, basic research, the R & T Centers, and the Rehabilitation Engineering program.

Your consideration of these vital matters is greatly appreciated. We shall be pleased to respond in detail to any questions or requests for further information.

Respectfully submitted,

NORMAN C. HAMMOND, *President.*

Enclosure—Draft Additions/Changes.

**INTER-NATIONAL ASSOCIATION OF BUSINESS, INDUSTRY AND REHABILITATION PROPOSED ADDITIONS AND CHANGES TO THE REHABILITATION ACT OF 1973 AS AMENDED IN 1984 FOR INCLUSION IN THE AMENDMENTS OF 1986**

Section 2. The purpose of this act is to:

(a) Develop and implement through research, training, services, and the guarantee of equal opportunity, comprehensive and coordinated programs of vocational rehabilitation and independent living.

(b) Authorize grants to assist States to meet the current and future needs of handicapped individuals, so that such individuals may prepare for and engage in gainful employment to the extent of their capabilities.

(c) Encourage the participation of the voluntary agencies and authorize grants to assist the development of the voluntary community in providing supplementary services.

(d) Assist in the establishment and improvement of rehabilitation facilities.

(e) Engage the talent and leadership of private industry as partners in the rehabilitation process.

A new TITLE VI is proposed to implement Section 2(e).

**TITLE VI—PARTNERSHIPS WITH INDUSTRY**

Section 601. The purpose of this Title is to promote opportunities for competitive employment of handicapped persons, to provide realistic placement resources for the public program, to engage the talent and leadership of private industry as partners in the rehabilitation process, to create practical settings for supportive work programs, and to secure the participation of private industry in identifying job opportunities and the necessary skills and training to qualify handicapped people for competitive employment.

**EMPLOYMENT OPPORTUNITIES FOR HANDICAPPED INDIVIDUALS**

Section 602. The Commissioner shall enter into agreements with individual employers and other entities to establish jointly financed cooperative arrangements which:

Shall create and expand job opportunities for handicapped individuals by providing for the establishment of appropriate job placement services;

Shall provide for Business Advisory Councils comprised of representatives of private industry/business and organized labor who will identify job availability within the community and the skills necessary to fill those jobs, prescribe training programs tailored to their need, and will serve as a policy decision making management arm of the partnership;

Shall provide for the development and modification of jobs where appropriate to accommodate the special needs of handicapped individuals;

Shall provide handicapped individuals with training and/or employment where appropriate in a realistic work setting in order to prepare them for employment in the competitive market;

Shall provide handicapped individuals with such supportive services as may be required to permit them to continue to engage in employment.

Section 603. Payments under this Section with respect to any project may not exceed ninety percent (90%) of the cost of the project.

Section 604. (1) The Commission may provide directly or by contract with experts or consultants, or groups thereof, technical assistance to (a) persons operating Partnerships With Industry—for the purpose of assisting such persons or entities in the improvement of projects or in the development of relationships with private industry or labor, and (b) entities considering the development of new Partnerships With Industry—with or without federal funding assistance.

(2) Any such expert or consultant, while serving pursuant to such contracts, shall be entitled to compensation and allowances in accordance with Section 506(2).

#### EVALUATION OF PWI

Section 605. (a) The Commissioner shall conduct an ongoing evaluation of the Partnerships With Industry program and submit each year at the time of the budget request a report to Congress utilizing a comprehensive information system based on evaluation standards. Existing programs shall be continued at no less than the current level unless a determination is made by the Commissioner that the program does not substantially meet the established standards. The Commissioner shall also conduct a comprehensive evaluation and submit a report on February 1, 1989 to Congress on the evaluation including recommendations for the improvement and continuation of each program and for the support of new Partnership With Industry recipients.

(b) The evaluation report shall describe the impact, the general effectiveness in relation to cost, control groups, and comparisons with other methods for the delivery of services under this Act.

(c) Evaluations shall be conducted by persons not immediately involved in the administration of the program or the project evaluated.

(d) In carrying out the evaluations, arrangements should be made for site visits to obtain the opinions of program participants about the strengths and weaknesses of the program, and the recommendations of private industry and organized labor.

(e) Funds appropriated under this Section are authorized for site visits of federal evaluation personnel to review projects under evaluation.

(f) No less than .0075 percent of the appropriations for this Title shall be used for evaluations under this Section.

#### AUTHORIZATION OF APPROPRIATIONS

Section 606. There are authorized to be appropriated to carry out the provisions of this Title \$50 million for Fiscal Year 1987, \$60 million for Fiscal Year 1988, \$70 million for Fiscal Year 1989, \$80 million for Fiscal Year 1990, and \$90 million for Fiscal Year 1991.

#### NATIONAL SCOPE PWI'S

Section 607. The Commissioner shall attempt to maintain at least one and preferably several PWIs with national scopes of interest involving major private business/industry and organized labor organizations with intent, in addition to the basic functions, of providing high visibility among such organizations of their involvement in vocational rehabilitation.

#### ADDITIONAL TECHNICAL AMENDMENTS NECESSARY TO INVOLVE PRIVATE INDUSTRY

Section 101(A)(21).—Delete the phrase "upon a determination by such agency that such profit making organizations are better qualified to provide such rehabilitation services than nonprofit agencies and organizations." It is not realistic to expect that a State Agency would determine that a profit making organization is better qualified to provide rehabilitation services.

Section 103.—Scope of Services—Job placement should be listed first since all other services are required only to assist in job placement.

Section 121(a) *Innovation and Expansion Grants*.—Add profit making to the public and nonprofit agencies eligible for expansion grants to encourage the participating of private industry under this Section.

Section 204(a).—Add "development and demonstration of methods of working with private industry to assure the placement of severely disabled persons into competitive employment."

Section 204(b)(1).—Add (D) "for providing research and training in working with private industry to assist rehabilitation practitioners to place severely disabled persons into employment."

Section 204(b)(2)(A).—Add "and to develop and implement the technology for work site modification and assistive devices that will enable handicapped individuals to secure employment."

PREPARED STATEMENT OF THE NATIONAL FEDERATION OF THE BLIND

Mr. Chairman, my name is James Gashel. My address is 1800 Johnson Street, Baltimore, Maryland 21230; telephone (301) 659-9314. I am Director of Governmental Affairs for the National Federation of the Blind. I appreciate your invitation to submit testimony for consideration by the Subcommittee in its review of vocational and other rehabilitation programs and the statutory provisions which authorize substantial federal assistance to make these programs possible.

During these hearings, Mr. Chairman, you will receive a substantial amount of testimony from professional rehabilitation workers and their associations. These are people who are employed to administer or deliver the services authorized by law. There is the provider perspective, not to be confused with the consumer perspective. I feel this distinction is too often not made in the rehabilitation field. Thus, the impression may be conveyed by some of the advocates for rehabilitation that the interests of everyone are generally the same—"doing the best for the handicapped or disabled." But the fact is that the interests of the providers and the interests of the consumers of rehabilitation services are not necessarily the same. We do not all speak with one voice, nor should we be forced to.

That said, Mr. Chairman, the National Federation of the Blind is a consumer voice for the blind in all matters of rehabilitation. The people we represent are on the receiving end of these programs. Our membership is broadly based and nationwide. So our collective experience with the rehabilitation system throughout the United States allows us to observe and report patterns of conduct. Just as there is a state vocational rehabilitation agency or state agency for the blind in each state and the District of Columbia, so too, we have an affiliate of the National Federation of the Blind in each state and the District of Columbia. We also have local chapters which blind people join in their home communities in most sizable population areas of the United States. Forty-six years ago, the National Federation of the Blind was formed as a vehicle for self expression by the blind. That is still our purpose and function today.

My focus in presenting this testimony will be on the Vocational Rehabilitation Provisions found in Title I of the Rehabilitation Act of 1973, as amended. From the client services end, this is the bread and butter portion of the statute. There is always a question of whether to sugarcoat a statement or to "tell it like it is." I am assuming that you want me to do the latter so members of this Subcommittee, and others in Congress, can make a thorough evaluation of how things are going.

For twenty years I have actively worked, in one respect or another, in and around the rehabilitation system. I have studied the law, the regulations, chapters of the Rehabilitation Services Manual, and many other written policies or interpretations of policy, all of which are collectively used as mandates or guidance for the administration of the program. I have also been a direct consumer of services, and I was "closed rehabilitated" more than once. For a few years, I helped to administer state programs for the blind in Iowa, so I also have direct knowledge of state agency operations from the inside. The following analysis and recommendations are based on my own experience and that of thousands of blind people with whom I have been in contact for over twelve years in my present position as Director of Governmental Affairs for the National Federation of the Blind.

At last summer's convention of the National Federation of the Blind (held during the week of the 4th of July in Louisville, Kentucky), a shocking fact emerged. It happened like this: Patricia Owens, Associate Commissioner for Disability at the Social Security Administration, was explaining how her agency is increasing the emphasis on successful beneficiary rehabilitation. She indicated that the Social Security Administration was less than enthused about the performance of the state vocational rehabilitation agencies. She said Social Security officials are actively seeking alternative rehabilitation programs which might be more successful. Several speakers from the floor voiced specific complaints about rehabilitation programs and their policies. The pattern which emerged in the discussion showed that this audience of nearly two thousand (either consumers or potential consumers of rehabilitation services) unanimously felt ill-served by current programs. In fact, not one

person spoke up to defend rehabilitation in its present form. So the policy position which emerged later in a resolution from the convention unanimously called for reform in rehabilitation.

That position (and especially the intensity of support for change) represents the culmination of a shift in our thinking about rehabilitation—something which has been evolving among the blind consumer population over the past several years. Remember that for purposes of priority for service, blind people are among the most severely disabled. Even so, rehabilitation agencies tended to be much more responsive to our needs twenty years ago than they are today. This, despite the more recent federal mandate to serve first persons with the most severe disabilities. Why? I believe there are at least three areas where the basic statute is being misinterpreted, misapplied, or is in need of correction today. Also, I believe there is a failure properly to coordinate the vocational rehabilitation and Social Security programs, resulting in frustrating policy conflicts.

#### ELIGIBILITY AND INELIGIBILITY

When a potential client approaches a rehabilitation agency for help, the first decision (which is central to the future relationship of the client and the agency) is the determination of eligibility or ineligibility. Put it this way: Is the welcome mat out, or does the sign read "No Vacancy." It all depends on the agency.

A "handicapped individual" under Section 7(7)(A) of the Act must have a disability which, for that individual, is a substantial handicap to employment. Further, there must be a determination that the provision of vocational rehabilitation services is reasonably expected to help the individual become employed. Surprisingly, it is not enough to have a severe handicap and to be unemployed. Rehabilitation counselors have wide discretion in deciding whether there is a substantial handicap to employment for the individual.

Consider the actual consequences of such a policy. Blindness, for example, is a severe handicap. That's what the law already says. But, take a person who is blind and unemployed. Is such a person eligible for vocational rehabilitation services, let us say even if the services would help the individual become employed? Not necessarily. The counselor may decide that the individual has worked before, and therefore does not have a substantial handicap to employment. Incredible, but true. Here we have a severely handicapped individual as defined in the Act who does not have a substantial handicap to employment, so says the counselor. Believe it or not, I know of an actual case where precisely that decision was made, and the Commissioner of the Rehabilitation Services Administration refused to ask that it be altered. He made it clear to me that the decision was a state decision, not a federal one.

Should everyone who has a severe handicap as defined in the Act be eligible for Vocational Rehabilitation Services? Probably not. Some persons may not be capable of achieving employment. But anyone who is capable and severely handicapped should be eligible, no counselor discretion involved.

The case I have in mind also shows another consequence which flows from giving counselors such wide discretion in deciding who is handicapped. If an individual receives Social Security Disability Insurance Benefits (this person did), there has already been a finding that the handicapped person is unable to perform "substantial gainful activity." More ironic, it is the same vocational rehabilitation agency that issues a finding of disability in connection with the Social Security programs. Yet the counselor for that agency is free to decide whether or not the handicap (which is substantial enough to qualify for Social Security) is a substantial handicap to employment. It makes no sense.

Also, something else makes no sense. You might call it the "merry-go-round" or "the revolving door of rehabilitation." If a person applies for and receives Social Security Disability Insurance benefits, one of the basic conditions is that there is a referral to the state vocational rehabilitation agency. Then the individual is required to accept rehabilitation services in order to become employed, if at all possible. The purpose is to encourage people to leave the Social Security rolls. That makes sense, but what does not make sense is that the rehabilitation counselor has the direction to turn the same individual away by saying, "There is no substantial handicap to employment." So, around in circles you go. Social Security refers you to rehab, and rehab turns you away. Yet Social Security requires you to accept rehabilitation services and to try to become employed.

How can you if rehab turns you away? So round and round you go.

Recommendations: (1) The Act should be amended to provide that anyone whose handicap is severe, as defined in the Act, shall be determined to have a substantial handicap to employment.

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(2) The Act should be amended to provide that anyone who is determined eligible for benefits under Title II or Title XVI of the Social Security Act shall be determined to have a substantial handicap to employment.

#### THE MEAN SPIRITED MEANS TEST

Economic need standards, or "means tests," are optional as determined by policies of each state agency. Up until about 1966, there was actually a federal requirement mandating a means test by every state agency in the program. Now, some states have them, others do not. Two abuses of the means test option have come to light in our analysis.

First, the idea of the means test is to determine whether the client of vocational rehabilitation services can afford to pay for any of the services which may be offered by the program. This is a determination which is made after the decision on eligibility or ineligibility. So, believe it or not, you may be eligible for vocational rehabilitation services which you are now required to pay for. What a bonus. That's why many refer to the needs standard as a "mean spirited means test."

A legitimate question is raised as to whether an eligible handicapped individual should be subject to a means test at all. At least 80% of the money for the program is federal, yet there is a virtual "hands off" federal policy on means tests. So the states are given wide discretion again. This leads to inequities among the states and a lack of uniformity in the program. But worse, than the federal hands off approach permits abuses that ought to be corrected by statute.

The first of these is the fact that eligible handicapped individuals are required to pay for services that are available in-house and provided directly by state rehabilitation agencies or obtained by contract with private agencies. Services from these agencies (which receive tax dollars specifically for the purpose of providing rehabilitation services) should be paid for by those tax dollars. The individual applying for services from rehabilitation agencies should not be taxed a second time to obtain the services that they provide directly or by contract with private agencies.

For example, if an agency for the blind provides in-house training for blind persons who want to become self-employed as licensed blind vendors under that agency's vending facilities program, training to enter that program should be a service provided without charge by that agency. Likewise, if the agency sends a client to a pre-vocational adjustment center where the techniques and attitudes concerning blindness are taught; that is a reasonable service to expect without charge from the agency. Requiring clients to pay for basic training and adjustment services which are directly available from state agencies or provided by contract with private rehabilitation agencies, makes one wonder where our tax dollars appropriated for vocational rehabilitation are actually going.

The second issue with respect to the means test has to do with the extent to which it actually serves as a disincentive in the rehabilitation of Social Security and Supplemental Security Income beneficiaries. Believe it or not, I have actually seen means tests which require these beneficiaries to pay for their own vocational rehabilitation services. Talk about meanspirited. Benefit levels for Social Security Disability Insurance and Supplemental Security Income are not that generous. In fact, most beneficiaries live at or near the poverty level. They can ill afford to pay for anything but keeping a roof over their heads and food on their tables. Now the rehabilitation agency comes along and says, "Here's a bill for the services we provided; pay up."

Restrictive requirements of this sort frustrate the goals of rehabilitation and, more particularly, the goals of the Beneficiary Rehabilitation Program, which is funded by the Social Security Administration and jointly administered with state vocational rehabilitation agencies. Remember once again that Social Security and SSI beneficiaries are required to accept vocational rehabilitation services, but where does it say in the Social Security Act that they are also required to pay for them. It does not. That is a discretionary requirement of some state agencies who administer means tests which they have established for vocational rehabilitation services. Again, this degree of discretion leads to abuse since Social Security and SSI beneficiaries are placed in an untenable position. If they do not cooperate with the rehabilitation agency and pay for their rehabilitation services, they may be reported to the Social Security Administration as declining rehabilitation. Then they will lose their benefits altogether. The net result is you either take essential living expense money to pay for rehabilitation, or lose the benefits altogether. Considering the fact that it is the Social Security Administration (not the vocational rehabilitation agency) who ultimately pays all of the cost for successful rehabilitation of beneficiaries, the means test, if there is going to be one, should be solely a matter of Social Security



policy, not rehabilitation. After all, there is not a penny of state or federal vocational rehabilitation money at stake.

**Recommendations:**

(3) The act should be amended to provide that in the administration of the state plan for vocational rehabilitation services, the designated state in it may not apply any standard of economic need for any services provided directly by the agency or paid for by contract with another agency primarily engaged in the rehabilitation of handicapped individuals.

(4) The Act should be amended to provide that in electing to establish any standard of economic need which requires handicapped individuals to share in meeting the costs of vocational rehabilitation services, the designated state unit shall exclude from consideration any income received by a handicapped individual pursuant to Titles II or XVI of the Social Security Act and shall further exclude such other income as may be reasonably necessary to meet all expenses of the household to extend that the handicapped individual is not required to become more dependent on funds provided others in the household to meet ordinary and reasonable living expenses and costs of vocational rehabilitation.

**SIMILAR BENEFITS**

The concept of similar benefits is intended to be used by vocational rehabilitation agencies in order to assure that handicapped individuals can also obtain the benefits of other programs to which they may be entitled. An example which seems obvious and reasonable is to utilize student financial assistance grants to the fullest (excluding loans) before applying vocational rehabilitation funds to pay for college tuition and other higher education expenses. But while that is reasonable, there are other practices that occur with respect to similar benefits that are not reasonable.

For example, students who receive scholarships from private organizations should not receive a corresponding refusal for services from vocational rehabilitation due to the receipt of a similar benefit. Yet, this is the most common result of the similar benefits provision. For example, the National Federation of the Blind awards scholarships annually amounting to almost \$100,000.00. Our largest scholarship is \$10,000.00. But the recipient may actually lose in the end or be no better off if the vocational rehabilitation agency determines that the similar benefit must then be used to exclude most or all vocational rehabilitation services that would otherwise be provided. For a private, non profit organization such as ours, it is rather discouraging to learn that individuals we intended to help are actually thrown into a turmoil with their vocational rehabilitation agencies. The recipients of our scholarships should not have to fight to receive some actual benefit from the scholarships we give them. A more appropriate approach would be to allow for the development of a plan under which such privately financed scholarships may be held and used in ways that would not jeopardize continuing vocational rehabilitation assistance.

The more extreme abuse of the similar benefits requirements occurs when state vocational rehabilitation agencies insist that all private sources for any vocational rehabilitation service must be tapped before funds will be authorized from the agency. For example, if equipment or aids of some type are to be purchased, there are agencies who require clients to sign releases which enable the agencies then to contact charitable associations in the community. This amounts to a solicitation of funds on behalf of rehabilitation clients in order to provide the services which tax dollars have been appropriated to pay for.

When I saw a recent example of this private fundraising behavior by a state vocational rehabilitation agency, I thought in the particular case involved it was more than just a little extreme. So as a policy matter, I brought the issue to the attention of federal officials in the region where the state agency was located and at the central office of the Rehabilitation Services Administration here in Washington. What do you suppose? Everyone said that the fundraising among charitable groups by rehab was an entirely appropriate enterprise, in fact required by the similar benefits concept. How interesting. I thought similar benefits meant that a client of vocational rehabilitation was required to explore and exhaust if possible all other benefits available from public programs for which the individual might also be eligible. That is quite a different requirement from fundraising as a matter of charity to obtain funds to buy services for clients of vocational rehabilitation. Yet this how the similar benefits requirements are being interpreted. Carried to its most logical extreme, there is almost nothing that vocational rehabilitation would ever have to pay for if the agency could find someone else to do it. And, that's exactly what rehabilitation is coming down to. Recommendations:

(5) The Act should be amended to provide that scholarship awards resulting from competition and based on merit, shall not be considered similar benefits where such scholarships are awarded by private, not-for-profit organizations.

(6) The Provisions Act should be amended to provide that a similar benefit is any service of the type described in section 103 of the Act, where such benefit is provided by a public agency or program and the handicapped individual meets the eligibility criteria for the specific service in question.

Taken as a whole, the six recommendations in this testimony are designed to make the vocational rehabilitation program more responsive to consumer demands for service. They address problems in eligibility, the beans test, and similar benefits. These areas are the cause of most blind consumer dissatisfaction. First, there is a question of eligibility. Then if eligible, there is a question of whether or not the individual will need to pay for the service in whole or in part. Finally, to round out the picture, if it is ultimately determined that the individual is, in fact, eligible and that the individual is further too poor to pay for the service, there is a third escape clause for rehabilitation by applying the similar benefits criteria. All of these provisions may be applied almost with a vengeance as I have described. As a result, there is strong evidence that rehabilitation agencies today are attempting to exclude, not include, potential clients. I think that is why so many individuals feel, and rightly so, that they just cannot get any service at all from rehab. If people are aware, as they inevitably are, that the vocational rehabilitation system nationwide has over \$140 billion in federal money alone to spend on vocational rehabilitation services this year, they wonder where the service actually is. In the days gone by, when funds were far less and annual increases more limited, we could expect to get some service from rehabilitation agencies, despite a few bumbles and stumbles along the way. Mostly, though, the agencies seemed to want to give service, and the money flowed to client needs. Now it does not. Counselors are more like gatekeepers at the purse strings of the agencies. So for the consumer, you can't get into the system, or if you do get in, you can't get anything out of it, or so it seems.

This sense of growing frustration with the current system of Vocational Rehabilitation has led many of us in the National Federation of the Blind to give thought to alternative systems of service rather than using the traditional vocational rehabilitation state agencies. One plan would be to install a free market system where clients could pick and choose among rehabilitation agencies who would, in a sense, be competing for their patronage. This would be a step beyond and outside of the institutionalized state vocational rehabilitation agency system. It would provide a rehabilitation benefit in the sense of portable funding available to a handicapped individual for use at any agency capable of providing the services. Maybe we are ahead of our time in proposing such a concept, or even thinking about it, but we think Congress should consider it. One way might be to adjust certain provisions of the Social Security Act in order to make the rehabilitation funding which now exists an actual component of the Social Security benefit for the handicapped individual who is eligible for Social Security Disability Insurance or Supplemental Security Income. To a certain degree, this would follow a concept similar to providing Medicare and Medicaid benefits as an attached service to eligibility for the cash benefit programs of Social Security.

There is a song we have in the National Federation of the Blind which shows, I suppose, the sense of frustration we share in dealing with the rehabilitation system and its characteristic limits that I have described. The problems and goals of other minorities have often been expressed in the songs they sing, and so it is with the blind:

"Today I am happy; today I am glad.  
I finished my five year course in rehab.  
I learned chair caning; I learned basketry.  
And now there's not a damn soul who wants to hire me.

Today I am happy; today I am glad.  
I finished my five year course in rehab.  
I learned chair caning; I learned basketry;  
And now there's not a damn soul who wants to hire me. Rehab, I'm glad rehab."

We call that the "Rehab Song." We sing it often and with great gusto, but it is not a song of joy. It expresses great frustration with what too many blind people regard as an absolutely worthless waste of time. Worse yet, there is the hassle that many described in just trying to get something out of what seems like a massive state rehabilitation bureaucracy. This is what has led us to begin thinking about an alternative free-market system where the client would take the money and buy the

service from the agency that was most responsive, based on individual preference and need.

Mr. Chairman, again I appreciate the opportunity to submit this testimony, and to have our views considered as you prepare the Subcommittee's proposals to amend and extend the Rehabilitation Act of 1973, as amended, I hope and believe that your deliberations will lead to constructive changes in the direction of better service for blind consumers. Toward that end, we have sought to present an honest appraisal of where we think rehabilitation is currently headed and how it can be improved. If the appraisal seems harsh, so be it. It would be worse for us to remain silent when we have facts that might actually help you improve upon existing programs. In any event, that is our goal. I thank you.

PREPARED STATEMENT OF MARTIN A. ADLER, MSW, ACSW, DIRECTOR, HELEN KELLER  
NATIONAL CENTER FOR DEAF-BLIND YOUTHS AND ADULTS

Mr. Chairman and Honorable Members of the Subcommittee, thank you for inviting me to testify before the Subcommittee in regard to our request for the reauthorization of the Helen Keller National Center for Deaf-Blind Youths and Adults. My name is Martin A. Adler and I am the Director of HKNC.

May we first offer a brief overview of the HKNC Service Delivery System, our needs assessment of programs for deaf-blind persons, funds necessary to meet some of these needs, and a general commentary as to the achievements of the HKNC Service Delivery System and its relationship to other severely handicapped groups. Following the overview, we will also offer a more detailed presentation of our Service Delivery System.

OVERVIEW

HKNC is operated by the Board of Trustees of what was formerly The Industrial Home for the Blind (IHB) and is now the Helen Keller Services for the Blind under an agreement signed in 1969 with the United States Department of Health, Education and Welfare. The authorization for our operation is now contained within Title II of the Rehabilitation Amendments of 1984. We operate under the general supervision of the Rehabilitation Services Administration. The Center is located on a 25-acre wooded site in Sands Point, New York. The training research and administration building, as well as the residence building, are specially designed and equipped to meet the accessibility and safety needs of clients served.

Though the Helen Keller National Center has been in operation since 1969, it became operational in its new Sands Point, N.Y. facility in 1976. For several years there was the process of managing the growth, development, provision of services to the deaf-blind, training of staff and developing a conceptual and operational framework of delivering services to deaf-blind persons, their families and agencies. A complete framework of a service delivery system had to be developed without precedent and/or based upon previous operating models. Now, a full national system is in place and has been providing comprehensive services to the estimated 40,000 target population, their families, and agencies. HKNC has developed a field service system that has provided over \$1.2 million to agencies, both public and private, enabling them to develop local service delivery programs for the deaf-blind. Training for hundreds of professionals in the field and at headquarters in modalities applicable to the deaf-blind has been accomplished as well as providing direct services to hundreds of deaf-blind individuals and their families through our ten regional offices.

The comprehensive evaluation and rehabilitation program at HKNC headquarters at Sands Point responds to a wide range of deaf-blind individuals including the very seriously multihandicapped who were victims of the 1963-65 rubella epidemic. Our outreach services in the field and expanded services at headquarters have resulted in an explosion of interest throughout the country, both on a public and a private level, to develop services for deaf-blind individuals. Thus, our purpose and one of our original mandates had been achieved, i.e. to demonstrate that rehabilitation can be successful with deaf-blind individuals.

We are now entering another stage of development within HKNC. As a result of a recent needs assessment response from 196 agencies, a total of 793 needs were identified, or an average of four per respondent. Analysis of the needs assessment data reflects the following priorities:

1. Technical assistance in Independent Living, including training, development of group homes, and community-based housing alternatives, was requested by 117 of the 196 agencies (60%).

2. Technical assistance in vocational services was requested by 110 of the 196 agencies (56%).

3. Technical assistance in rehabilitation models/methods/techniques was requested by 60 of the 196 agencies (37%).

In reviewing these priorities, HKNC wishes to expand the following areas:

At the present time, we have ten regional offices staffed by ten regional representatives and part-time secretaries. They are frequently requested to provide technical assistance, client contact, agency consultation and other forms of work activity related to serving deaf-blind persons. Using an analogy of the private business environment, the marketplace is asking for more services and we are unable to meet the full demand. The present level of salary funding for regional personnel is approximately \$427,000 per annum. There is a need to double the number of regional representatives available for service in the field. This would increase that category to approximately \$850,000.

There is a need to expand our vocational services at headquarters, particularly in relation to the increased numbers of low functioning multihandicapped rubella clients entering the rehabilitation system at Sands Point. Specific staff needed: Two additional behavior modification specialists, a prevocational specialist, and two daily living skills instructors. This increase would cost approximately \$147,000 per annum.

The need for training personnel in the field has also increased. Our three staffed National Training Teams should be doubled to a cost of approximately \$120,000 per annum.

Three other areas are also crucial to the service delivery system for deaf-blind persons. We are developing a quality assurance/evaluation program that should be finalized, tested and then exported to the field. This would aid in research and in developing further cost-effective and efficient systems. Approximately \$50,000 per annum is needed. A research and training center related to the deaf-blind is crucial. The cost for this would be approximately \$100,000.

The final third area has to do with the maintenance and capital improvement of our physical facility in Sands Point, which is approaching its tenth year of operation. Approximately \$8. million had been expended in 1976 for the construction of this facility. Many of the earlier construction and design problems are now making themselves felt in the maintenance of the building and the mechanical equipment. A preventive maintenance program must be instituted and this would cost approximately \$75,000.

The above needs would reflect an increase in Federal FY-87 of approximately \$1.242 million. The Federal FY-86 HKNC budget is \$4.3 million. We would need to begin meeting the above assessed needs with \$5.5 million for Federal FY-87.

We recognize, however, that this would be a rather sizable fiscal increase in an agency that has been receiving very limited funding for the past several years. In recognizing the needs of our country regarding deficit spending and yet comparing it to the very special needs of a very special population, we feel that a minimum of \$5 million or approximately a 16% increase for Federal FY-87 is warranted. We are also proposing that a 10% increase for Federal FY-88 be approved which would bring our budget to \$5.5 million. An approximately 12% increase, or \$6.2 million is also requested for Federal FY-89.

#### GENERAL ASSEMBLY

The methodologies developed within the HKNC Service Delivery System have positively impacted on the rehabilitative approaches and techniques of some other severely handicapped adult groups. Perhaps the most significant carry-over has been to stimulate agency administrators and staff to expect more positive results in their work with other severely handicapped individuals. It is not infrequent for staff participating in seminars or receiving technical assistance to transfer a helpful method in working with deaf-blind to their target population. Our technical assistance team has documented this carry-over relationship in almost all of their workshops. For example, the areas of carry-over have been related to our techniques in developing community based housing, funding, training of staff and community response. Another area has been the modalities utilized in preparing handicapped individuals for community living through Independent Living Centers. Our systems have supported and improved those institutional systems working with the severely mentally retarded and other developmentally disabled groups.

The recreation and leisure time craft techniques developed at HKNC have been implemented in numerous institutions where their population functions on levels similar to many of our clients. Home economics for the deaf-blind has been imple-

mented in other systems as well as training parents in "how to" methods of teaching their severely handicapped homebound children some additional cooking and self-care skills. As a result, some attitudinal changes have contributed to further deinstitutionalization programs, technical assistance, and appointing state coordinators for the deaf-blind.

Our Audiology department has found that pairing a vibrotactile stimulator and an auditory stimulus can successfully elicit a repeatable/reliable response to audiometric evaluation.

We have shared this approach with other Audiology facilities who service multiply handicapped groups, i.e. psychiatric centers and multiply handicapped children's centers, possibly affecting "positively" their evaluation/rehabilitation programs.

The HKNC VI-C program for deaf-blind children in the Mid-Atlantic and Caribbean area has also noted carry-over benefits to other handicapped children. Specific details are included in the main body of our testimony. There have been ongoing and increased sharing and utilization of: (a) curriculum materials for deaf-blind; (b) assessment procedures for deaf-blind; (c) methods and approaches for deaf-blind; and (d) usage of terminology; such as, (i) Transition, first used for the deaf-blind, (ii) Visual Tracking—also used for deaf-blind youngsters.

Several thousand deaf-blind children have benefited from the Title VI-C programs. They are now aging out from the educational systems and they and their parents are in need of further services, i.e. prevocational and vocational help and placement, preparation for community living and numerous other services supporting community living.

There has been carryover benefit in the vocational area. One case in point is from St. Francis Hospital. We introduced the concept of work experiences for our clients, and implemented a program that demonstrated success not only for deaf-blind persons but it has also developed a positive employer and co-worker acceptance of clients as productive workers. Because of this ongoing program, the hospital has expanded the program and now has approximately eight developmentally disabled persons from two other agencies. Compliments were given to our staff who "opened the doors" and gave ongoing support to hospital employees and clients.

Another similar example is a Hewlett-Packard plant that did have three deaf-blind employees on their staff. The plant made a videotape of their work abilities and displayed it to other employees. This enabled line supervisors to feel more accepting of handicapped workers and as a result, other handicapped workers were placed on jobs. Similar but less dramatic situations have occurred in other vocational areas.

The HKNC evaluation and rehabilitation program at the headquarters site continues to meet and fulfill the original congressional mandate. We have demonstrated that most deaf-blind persons can participate in the rehabilitative process and achieve notable improvement. About 43 percent of clients who received training at headquarters are currently in some form of remunerative employment. Most others have achieved a level of adjustment that enables them to reside outside of institutional care. Families have a greater feeling of hope that their deaf-blind son or daughter can now communicate more effectively, relate and care for many of their own basic needs. Our field services have stimulated many states (about 17) to develop programs and coordinating staff to work with the deaf-blind. Our National Training Team and Technical Assistance Team have provided training opportunities for hundreds of professionals. The HKNC Affiliation Network System has provided funds and direction for some 26 state and private agencies to start or expand programs for the deaf-blind.

We at HKNC feel we have accomplished what was necessary to demonstrate the benefits of a National Service Delivery System for the Deaf-Blind and we are ready for further programs to fulfill the needs of the deaf-blind population.

#### HISTORY AND GOALS OF THE HELEN KELLER NATIONAL CENTER

The Helen Keller National Center for Deaf-Blind Youths and Adults is operated by the Board of Trustees of the Helen Keller Services for the Blind (formerly IHB) under an agreement signed in 1969 with the United States Department of Health, Education and Welfare. The authorization for HKNC operation is contained in Title II, of the Rehabilitation Amendments of 1984, and funds for its operation are appropriated annually by Congress. It operates under the general supervision of the Rehabilitation Services Administration. The Center is located on a 25-acre wooded site in Sands Point, Long Island, New York. The training, research and administration building, as well as the residence building, are specially designed and equipped to meet the accessibility and safety needs of trainees served.

The Helen Keller National Center also operates ten regional offices to assist state and local agencies in serving deaf-blind persons in their home communities, and for referring them to the Center at Sands Point, N.Y.

The following goals were mandated by Congress when they established the Center:

*Regional office services*

To provide initial assessment of physical and psychosocial functioning to determine feasibility for admission to the Helen Keller National Center for comprehensive rehabilitation services or for referral to other agencies qualified to provide them with services appropriate to their individual needs and interests;

*Direct services*

To provide multidisciplinary evaluation to those deaf-blind individuals for whom rehabilitation seems feasible to determine their rehabilitation needs, interests and potentialities;

To provide individualized rehabilitation training, based on the findings of the evaluation, to achieve, as required in each case, (a) meaningful contact with the environment and effective means of communication, (b) constructive participation in the home and the community, (c) initial or enhanced employability, and (d) any other development important to the optimum rehabilitation of the deaf-blind individual;

To innovate and/or improve approaches and techniques of rehabilitation that will best contribute to the promotion of the personal adjustment, education, rehabilitation and social and economic effectiveness of the deaf-blind individual;

*Community education*

To provide community education designed to sensitize both the lay and professional communities to the special needs and normal aspirations of deaf-blind persons and to develop in the community an acceptance of and confidence in persons who are deaf-blind;

*National training team*

To provide training for new and prospective specialists in services for deaf-blind persons;

*Affiliation agency network*

To encourage and assist public and private agencies to develop services for deaf-blind persons in their local communities;

*Research*

To identify and locate youths and adults who are deaf-blind in order to develop a national register of these individuals which will provide information as to the composition and distribution of the deaf-blind population that will be helpful in the planning of services appropriate to the needs and interests of this population;

To encourage the initiation of and to cooperate in medical research into the causes of deaf-blindness and methods of reducing or eliminating these causes; To conduct research into the implications of deaf-blindness for the personal adjustment, education and rehabilitation of the deaf-blind individual; To conduct studies, including follow-up studies of clients, to evaluate the effectiveness and appropriateness of services offered by the Helen Keller National Center.

To design and/or improve sensory aids that will reduce the handicapping effects of deaf-blindness.

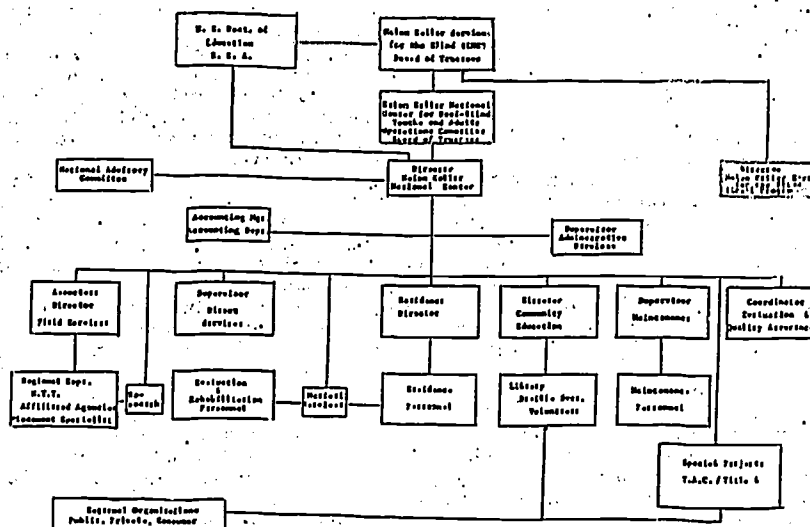
HELEN KELLER NATIONAL CENTER ADMINISTRATION

The organizational structure of HKNC is basically designed to permit flexibility within authorized structure. The Table of Organization recognizes the specialized functions of each department and/or unit of service and hence permits the development and implementation of specific objectives while administration maintains a span of control. This permits each department head who has line authority to exercise the authority within their department to accomplish goals and objectives. This also provides administration with accountability from department heads and at the same time enables each department head and its staff to have an ownership and motivational role in designing and implementing goals and objectives. Structured channels of communication with built-in flexibility also permits informal communications so necessary with a work-intensive professional staff.

Continuity of management is established by including the Associate Director in all major actions, and by his assuming duties and responsibilities of administration

in the Director's absence. The Director is directly responsible to the Chairman of the Board of Trustees of the Helen Keller Services for the Blind (formerly The Industrial Home for the Blind), and to the Operations Committee of the Board.

Table of Organization



#### DIRECT SERVICES AT HKNC

The Direct Services Component is divided into two sections and these are: (I) Instructional/Training Services, and, (II) Medical Services

##### I. Instructional/training services department

**Goal.**—To provide multidisciplinary evaluation to 87 deaf-blind individuals who meet specific admission criteria of HKNC.

Based on the results of these evaluations, provide individualized rehabilitation training for each client, to achieve: (a) a meaningful contact with the environment and effective means of communication; (b) constructive participation in the home and the community; (c) initial or enhanced employability; and (d) any other development important to optimum rehabilitation of the deaf-blind individual.

**Objectives.**—The objectives under the Direct Services Component may be grouped under nine major areas of training activities and services, as described below:

These services will be provided according to an individualized rehabilitation training program plan, developed, as a result of comprehensive evaluation completed on each deaf-blind client.

The nine major areas of services to be provided are:

1. Arts and Crafts and Horticulture (Leisure Time and Recreational as well as vocational in nature).
2. Audiologic Services: (a) Audiologic Evaluations and Training, and (b) Hearing Aid Evaluations and Training.
3. Communications Learning Center: (a) Communication Skills Development, and (b) Communication Devices/Aids.
4. Daily Living Skills Training: (a) Personal Management; (b) Wardrobe Management; and (c) Leisure Time Activities.
5. Home Management Services: (a) Independent Living Experience Program, and (b) Alternate Morning Program.
6. Industrial Arts Department: (a) Competitive Work Training; (b) Sheltered Work Training; and (c) Work Activity Center Training.
7. A. Orientation and Mobility Skills Training.

- B. (i) Low Vision Training; and (ii) Low Vision and Aids and Devices.
- 8. A. Rehabilitation Counseling: (i) Prevocational Training/Work Adjustment Program; and (ii) Work Experience Program.
- 9. Social Services: (a) Coordination of Intake Process; (b) Group/Individual Counseling; and (c) Behavior Management Activities.

*Abstract of approach*

The direct services component of HKNC consists of approximately 50 personnel, well-trained in various areas of services provided under the well-qualified and experienced supervisor of each of the nine direct services programs. During the clients' initial stay at the Center, they receive comprehensive evaluation which includes physical and emotional health, hearing and sight, skills in communication, mobility, skills of daily living, educational, social, and vocational achievements, and all other characteristics that can be further developed in order to enable them to become more independent and self-fulfilling. Once the evaluation is completed, the clients then undergo an individualized rehabilitation training which may involve months and even years of in-residence training within the HKNC headquarters.

Crucial to the attainment of the Direct Services Goal is the provision of an on-campus residential program. In addition to the expected activities of a residential program, the direct services program and the residential program integrate program concepts and staff throughout the deaf-blind individual's waking period. The daily living skills' staff work with the lower functioning clients at 7:00 A.M., waking them, teaching and practicing their morning personal hygiene skills, clothing selection, and eating skills. Communication learning staff and mobility interact with clients during lunch, teaching and practicing communication methods and mobility. Home management will work with another client, preparing for shopping or preparing an evening dinner and social gathering in the Independent Living Experience apartment in the residence. The program is cost effective in that it expands the client's training program from 7:00 A.M. to 9:00 P.M. All of the major training programs developed standardized evaluation systems (curriculum models) that set short- and long-range program objectives and define and quantitatively measure client progress and achievement in specific program areas. The results of these evaluations are then shared with the clients and their sponsoring agencies, for follow-up service plans to be carried out by individual sponsoring agencies.

*Statistical Breakdown of the 185 Clients who are Currently Employed in Remunerative Employment June 1969 to June 1985*

*Employment*

Remunerative employment includes four categories: competitive employment, sheltered workshop, work activities center employment, family enterprise/homebound employment.

*Employment information as of June 30, 1985*

Competitive employment.....	52
Sheltered workshop employment.....	97
Work activities center employment.....	31
Family enterprise/homebound employment.....	5
<b>Total.....</b>	<b>185</b>

Percentages based on the 185 former trainees in remunerative employment. Of that 43.7% of all former trainees are in remunerative employment.

	<i>Percent</i>
Competitive employment.....	21.1
Sheltered workshops.....	52.4
Work activities center employment.....	16.8
Family enterprise/homebound employment.....	2.7

**COMPETITIVE STATISTICS FROM FEBRUARY 28, 1981 TO JUNE 30, 1985**

[In percent]

	Feb. 28, 1981 *	June 30, 1982	June 30, 1983	June 30, 1984	June 30, 1985
Categories:					
Competitive employment.....	24.1	24.8	23.0	23.9	28.1
Sheltered workshop.....	64.8	59.6	51.2	58.7	52.4

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## COMPETITIVE STATISTICS FROM FEBRUARY 28, 1981 TO JUNE 30, 1985—Continued

(In percent)

	Feb. 28, 1981 <sup>1</sup>	June 30, 1982	June 30, 1983	June 30, 1984	June 30, 1985
Work activities center employment.....	8.3	11.0	13.7	13.6	16.8
Family enterprise/homebound employment.....	2.3	4.6	2.1	3.9	2.7

<sup>1</sup> Variation of lengths of report periods should be noted.*Statistical Report of Direct Services July 1, 1984 to June 30, 1985*

1,267 clients received services during the period covered by this section of the report. 207 were served by headquarters' staff and 1,253 were served by ten regional representatives, including 193 clients who were served by both headquarters' personnel and regional representatives:

Carried over from the previous period.....	501
Opened for active service during the period.....	517
Reactivated for active service during the period.....	234
Served only by headquarters.....	14
Removed from active service status during the period (including 424 who received no service during the period and 4 who were determined not deaf-blind, and 20 who died).....	448
Remained in active service status at the end of the period.....	819
87 clients (43 women and 44 men from 35 states) were enrolled at the Helen Keller National Center headquarters for rehabilitation evaluation and/or training during this section of the report.	
Enrolled at the beginning of the period.....	40
Admitted during the period (including 1 who was trained at the Helen Keller National Center prior to this report and returned during this period for further training).....	40
Left during this period (including 2 who were trained at HKNC prior to this report and received further training during this period).....	45
Placed in competitive employment.....	7
Placed in sheltered workshops.....	5
Placed in work activity centers.....	4
Retired.....	2
At home, receiving services from local agencies.....	6
Receiving training in another facility.....	1
Able to assume responsibilities as homemakers.....	4
Students.....	6
At home, awaiting employment.....	4
Placed in a custodial institution.....	3
Died.....	1
Others are receiving mental health services; and staying home not receiving services.....	2
Enrolled at the end of the period (1 reentered training from a past period).....	40

There were 42 applications for rehabilitation activities being processed at the end of this period (6/30/85) for enrollment at the Helen Keller National Center. This number includes 16 clients who had received admission dates.

## COMMUNITY EDUCATION DEPARTMENT

Community Education has, as its primary goal, the task to sensitize the lay and professional communities to the special needs and normal aspirations of deaf-blind persons.

This primary goal has been operational since 1969 and several objectives have been developed to reflect the goal:

1. To increase the awareness of the abilities of deaf-blind persons by state and local governments, potential employers, and the general public.
2. Increased utilization of public media.
3. To offer consultation and service to communities in order to provide deaf-blind persons opportunities in community activities.

4. To increase the use of the service delivery system of HKNC as a resource for dissemination of information about deaf-blind services.

5. To provide a corps of trained, responsible volunteers.

These objectives are generally achieved in an assertive and outreaching manner toward deaf-blind individuals throughout the country, their families, the professionals that deliver services, toward employers, and the at-large community. The dissemination process utilizes all methods of communication. This includes radio, TV coverage, press releases, distribution of printed materials, a library on deaf-blindness, advocacy, speaking engagements, films and exhibits. The development of a second National Helen Keller Deaf-Blind Awareness Week was achieved by Congressional resolution, signed by the President, and supported by many governors throughout the country.

#### FIELD SERVICES

Field Services, an integral part of the HKNC National Service Delivery System, is directly supervised by the Associate Director, who reports directly to the agency Director. Field Services comprise the ten regional offices, each staffed by a full-time, highly skilled Regional Representative, with half-time clerical support services. The Affiliation Agency Network Program, the National Training Team, and the Placement Specialist, are within the HKNC Field Services Department.

Each unit of service has a mission goal, related to the original congressional mandate. In order to reach the mandated goal, several objectives have been developed on the basis of need expressed by the field. Each of the programs within Field Services will be described in terms of goals and objectives in subsequent pages of this report.

*Regional Representatives—Goal, Regional Office Services.*—To provide initial assessment of physical and psychosocial functioning to determine feasibility for admission to the Helen Keller National Center for comprehensive rehabilitation services or for referral to other agencies qualified to provide them with with services appropriate to their individual needs and interests.

#### Objectives

1. Work closely with state vocational rehabilitation agencies and other interested public and private agencies offering consultation and technical assistance to develop or expand services to the deaf-blind.

2. Locate, assist, and refer deaf-blind individuals to the most appropriate program for comprehensive services.

3. Prepare individual assessments and assist in formalizing and implementing the most appropriate plan of service for each client referred.

4. Work cooperatively with sponsoring agencies and clients to facilitate the process of resettlement and transition.

5. Maintain continual interest and periodic monitoring of all clients to determine if further services or assistance are needed.

6. Encourage deaf-blind youths to remain involved with educational programs as long as possible and to register with local VR agencies at the earliest age at which applications for services are accepted to facilitate long-range planning by individual states.

7. Locate and identify deaf-blind youths and adults for inclusion in a national register maintained by the HKNC. This confidential, computerized data provides statistical information regarding the composition and distribution of the deaf-blind population and the nature of the handicap. General statistics are available to public agencies for planning further services.

8. Provide support and consultation to agencies affiliated with the HKNC for the development of services in local communities.

9. Coordinate and/or participate in workshops, seminars, and conferences.

10. Provide free lectures to schools, service clubs, parent and professional organizations, and other community groups.

11. Utilize and participate in newly developed projects and grants, i.e. TAC and TASH in providing transitional support systems to state and private agencies.

#### HKNC REGIONAL OFFICES

I. New England Region, 89 State Street, Suite 1130, Boston, Massachusetts 02109, (617) 523-7015 (TTY and voice) Connecticut, Maine, Massachusetts, New Hampshire, Rhode Island, Vermont. \*Mary Ellen Barbiasz (\*Regional Representative).

II. Mid-Atlantic Region, 111 Middle Neck Road, Sands Point, New York 11050, (516) 944-8900 (TTY and voice), New Jersey, New York, Puerto Rico, Virgin Island. \*Barbara Martin (\*Regional Representative).

III. East Central Region, P.O. Box 9056, Philadelphia, Pa. 19113, (215) 521-1370 (TTY and voice), Delaware, District of Columbia, Maryland, Pennsylvania, Virginia, West Virginia. \*Elizabeth Bixler (\*Regional Representative).

IV. Southeastern Region, 1001 Virginia Ave., Suite 320, Atlanta, Georgia 30354, (404) 766-9625 (TTY and voice), Alabama, Florida, Georgia, Kentucky, Mississippi, North Carolina, South Carolina, Tennessee. \*Ronald A. Cyphers (\*Regional Representative).

V. North central region, 35 E. Wacker Drive, Suite 1268, Chicago, Illinois 60601, (312) 726-2090 (TTY and voice), Illinois, Indiana, Ohio, Michigan, Minnesota, Wisconsin. \*William Goodman (\*Regional Representative).

VI. South central region, 1111 W. Mockingbird Lane, Suite 1330, Dallas, Texas 75247, (214) 630-4936 (TTY and voice), Arkansas, Louisiana, New Mexico, Oklahoma, Texas. \*C.C. Davis (\*Regional Representative).

VII. Great Plains region, 324 E. 11th St., Suite 2310, Kansas City, Missouri 64106, (816) 474-8299 (TTY and voice), Iowa, Kansas, Missouri, Nebraska. \*David L. Bennett (\*Regional Representative).

VIII. Rocky Mountain region, 12075 E. 45th Ave., Suite 222, Denver, Colorado 80239, (303) 373-1204 (TTY and voice), Colorado, Montana, North Dakota, South Dakota, Utah, Wyoming. \*Susan Olson (\*Regional Representative).

IX. Southwestern region, 870 Market Street, Suite 853, San Francisco, California 94102, (415) 956-4562, (TTY and voice), Arizona, California, Guam, Samoa and the Trust Territories, Hawaii, Nevada. \*Constance Miles (\*Regional Representative).

X. Northwestern region, 649 Strander Blvd., Suite C, Seattle, Washington 98188, (206) 575-1491 (TTY and voice), Alaska, Idaho, Oregon, Washington. \*Louis D. Anderson (\*Regional Representative).

PROJECT DATA—TOTALS OF REGIONS

Region	Active cases	Agency contacts (programs)	Number of		Diagnostic	Service category		Advocacy	Agency contact re: client
			Personal client	Contacts family		Technical assistance counseling	Employment, vocational assistance		
I. New England.....	141	60	106	37	64	100	40	117	153
II. Mid-Atlantic.....	434	18	74	16	68	9	2	341	34
III. East Central.....	282	28	141	79	11	241	40	90	322
IV. Southeastern.....	162	124	26	22	31	159	54	87	198
V. North Central.....	274	94	56	36	120	276	43	113	323
VI. South Central.....	336	542	112	21	174	152	83	436	246
VII. Great Plains.....	149	201	94	45	95	87	36	22	218
VIII. Rocky-Mountain.....	248	72	86	72	362	101	44	93	449
IX. Southwestern.....	206	159	145	33	38	171	94	70	317
X. Northwestern.....	282	136	114	56	117	252	15	15	396
All regions.....	2,514	1,434	954	417	1,080	1,548	451	1,384	2,658

Note.—In the preceding 1984 HKMC Annual Report, the nine regional representatives served 949 clients. The 1985 number of 1,253 clients is a 32% increase. This increase is a continuing process in meeting the primary goal of the regional services. In addition, this had added more impetus to agencies requesting T.A. which in turn improves effectiveness of services.

## NATIONAL TRAINING TEAM

The National Training Team, initiated in May 1981, was developed due to the great number of requests made to the Helen Keller National Center for seminars on deaf-blindness. These seminars will familiarize professional people to deaf-blindness, develop a positive attitude toward deaf-blind people, and provide opportunities to gain enough skill to increase or improve their services. Seminars of this type help to introduce and/or improve communication skills among many of the workers who are apprehensive and fearful when informed that they will have to work with deaf-blind people.

As specific needs of agencies differ, and can change from time to time, the NTT will be in a position to be flexible enough to meet these needs. Knowledge of community resources and utilizing local skilled personnel will be a way the NTT will work together with requesting agencies. Special aids and electronic instrumentation used by deaf-blind individuals will be brought and shared with the community, as well as curriculum and methodology.

It is hoped that through this expanded and ever-increasing program that these efforts will help prepare the country to meet the needs of the four thousand rubella children who are now in their late teens. In addition to this, the increased awareness of Usher's Syndrome. We do not request an honorarium for services delivered but we do ask that transportation and lodging be provided.

The NTT consists of a Communications Instructor (coordinator), Home Management Instructor and an Orientation and Mobility Instructor. In addition, other appropriate HKNC staff are available for seminars.

**Goal.**—To provide training for new prospective specialists in services for deaf-blind persons.

**Objectives (field activities)**

1. To develop a sensitivity to the special needs and problems of deaf-blind persons.
2. To heighten the awareness of the potential of deaf-blind persons.
3. To affirm the abilities and skills of our listeners so they will accept deaf-blind persons as clients, peers, friends.

**Project approach**

Communication is the exchange of ideas and the meeting of minds. Whenever this happens, the educational process is begun, better questions are verbalized, solutions are agreed upon, and progress is made.

The first objective has been addressed generally in all the activities of NTT but more specifically this year in the seminars for State Directors. This level of administrators formulate policy and allocate the budget for programs and services. Their knowledge and on-site experience have made an impact across the country.

There is evidence that the second objective is in process by the acceptance of deaf-blind persons in Group Homes, Centers for Independent Living, Rehabilitative Centers for the Blind, new job opportunities and interpreters seeking training so they can serve deaf-blind persons. Our strongest opposition at NTT conferences has been fear. In most situations this has been dispelled.

The third objective has been addressed specifically by rehabilitation workers of the blind who hesitate to accept the deaf-blind when manual communication is the primary mode—also rehabilitation workers of the deaf who rely on a visual mode. The deaf-blind person needs the support, skills and strengths from both these disciplines. We have brought them together in New England, Texas, New York, Utah, etc. and the results were amazing.

The problems are being clarified and the relevancy of the questions is being refined. The solution is PROGRESS and that is on-going. As we continue to dream dreams larger than our lives, we shall continue to remain on the cutting edge of progress.

**Project achievements**

State Directors' seminars began on the west coast and systematically moved across the country. This has impacted on all levels of state programs. Interpreter Training Programs are now serving the deaf-blind population. State hospitals and developmental centers are seeking training and alternate placement for their higher functioning clients (top 10%). Junior and senior high students enroll in schools for the deaf. Transitional population which unites Special Education and Adult Rehabilitation Services facilitates interaction and communication with each other.

Development of a series of video tapes, overhead transparencies, and handouts enhance the ever-updated presentations of the team members.

A revision of the curriculum for the Western Maryland College program has occurred.

*Project data*

*Completed Conferences, Seminars, Workshops*

- 27 Intensive In-service conferences in the field.
- 7 Week-long seminars at HKNC for professionals.
- 160 Professional visitors requesting a tour of the facility, information re: specific topics, observation, and hands-on experience in specific departments.
- 12 One-day in-service to local schools and agencies.
- 1 Week—International Congress for deaf-blind personnel in New York City.
- 10 Days consultation to the Nordic Deaf-Blind Program. On-going consultation with Western Maryland College Program.
- 22 Days professional training for international professional visitors at HKNC.
- 2 Weeks participation with Regional Representatives.
- 1 Week participation with Affiliates.
- 1 Day consultation with Eastern Correctional Facility.

*Objective (seminar and in-service training)*

To provide week-long, in residence, hands-on training to 10 to 12 individuals. General training and orientation to the evaluation, rehabilitation, and other program activities of HKNC 10 to 12 times per year.

*Project approach and data*

Sixty-five participants from 28 states, American Samoa, Guam, Northern Mariana Islands, Mali Mali, and District of Columbia completed the one week training program of Intensive Training in Service to Deaf-Blind Youths and Adults offered in seven sessions of this program during the period covered by this report. These 65 bring the total number who have completed the program at the Helen Keller National Center to 770.

The 770 participants were drawn from all the 50 states, the District of Columbia, Puerto Rico, the Virgin Island, American Samoa, Guam, Northern Mariana Islands, Mali Mali, and seven foreign countries. Five hundred and eighty-six came from public agencies and 184 came from voluntary agencies.

They included 33 deaf-blind specialists, 85 rehabilitation counselors, 19 social workers, 107 rehabilitation instructors, 42 mobility specialists, 15 placement specialists, 153 administrative personnel, 38 special education teachers, 14 psychological services, 14 evaluators, 14 vocational specialists, 10 medical personnel, 12 outpatient therapists, 16 interpreters, 57 interpreters students, 17 speech and hearing personnel, 42 aides, 6 recreation specialists, 22 graduate students, 8 volunteers, 21 parents of deaf-blind children, 13 residential personnel and 2 low vision specialists.

Two hundred and sixty-three of them are employed in the field of work for the blind, 111 are employed in the field of work for the deaf, 124 in the field of work for the deaf-blind, 65 in the field of work for the multihandicapped, 59 in the field of the mentally retarded, 2 in the field of speech education, 39 employed at psychiatric hospitals, 86 are from general agencies, and 21 are parents.

**AFFILIATION AGENCY NETWORK**

*Goal*

To encourage and assist public and private agencies to develop services for deaf-blind persons in their local communities.

*Objective*

The basic objective is to establish service delivery systems for the deaf-blind in almost every state, or a center serving two or three states whose incidence of deaf-blindness is low.

*Project approach*

There are approximately 40,000 deaf-blind individuals in the United States. HKNC headquarters generally evaluates and trains about 90 individuals per year. It is then obvious there is a need to develop, train, support and expand a delivery system that provides multi-services in numerous throughout the country. State funds for services to the deaf-blind are generally not a high priority and services are expensive. The availability of trained personnel is scarce. It is necessary to then offer agencies, both public and private, funds to initiate and provide services, train per-

sonnel and offer ongoing support through a network of similar service delivery systems. During the period of April 1974 through June 30, 1985, the Center has provided temporary financial assistance, as well as other supportive services, to twenty-six different agencies in its Affiliation Network. The purpose has been to enhance a nationwide development of services to deaf-blind persons by assisting agencies in providing services on the local level. At the same time, we have been able to increase the amount and quality of communication and cooperation among all agencies serving the deaf-blind. The Center's financial assistance is on a five-year, de-escalating model, which allows the affiliate agency to gradually absorb a greater amount of the cost of the project with each successive year.

The Center's portion of the direct cost of the project is reimbursed to the affiliate agency on a quarterly basis upon receipt of a quarterly invoice and a brief progress report.

Since there is a limited amount of money available for new products, we are quite concerned with the prospective affiliate's ability to provide the services needed by the deaf-blind in its state or community. With this in mind, a substantial number of factors are considered before an application for funding is approved. These factors are listed in all applications.

A major benefit of the affiliate program has been the networking of affiliated agencies, which has led to improved programs and services for deaf-blind persons. This has been accomplished primarily through our annual affiliates' meeting held at HKNC New York. At these week-long meetings, which include the HKNC regional representatives and the Center's direct service staff, a number of experts in the field are brought in to speak on current issues and concerns. During the week, the affiliates report on their individual programs and are able to learn what is taking place throughout the country.

Another means of improved networking has been the Affiliate Network News, which is published quarterly and contains up-to-date information on what is happening in the field of deaf-blindness. Articles, many of which are submitted by affiliate specialists, cover such topics as federal and state legislation affecting the deaf-blind, new programs being developed throughout the country, critical issues confronting the deaf-blind, and job openings.

#### *Project data*

Based on HKNC Affiliate Services Profiles submitted by each agency, from progress reports submitted by the Affiliates, and through clarification obtained from Affiliate Agency Specialists, there was an unduplicated total of 1151 deaf-blind persons served by the Affiliated Agencies during the twelve month period ending June 30, 1985. This number reflects an increase of 16% over figures presented last year.

Of the 1151 deaf-blind persons served last year, 299, or 26% were newly opened cases.

During the twelve month period, a total of 389 persons completed, or otherwise terminated, services of the Affiliated Agencies. A breakdown of the outcome of services for those individuals is as follows: 39 were placed in competitive employment; 52 were placed in employment in sheltered workshops; 25 are working in work activity centers; 7 are unpaid workers in a family business or enterprise; 40 are homemakers; 37 are awaiting employment; 22 are enrolled in higher education programs; 37 are at home, 45 are residing in a mental health/mental retardation facility; 6 are deceased; 79 fall in other categories (some are being served in education programs with supportive services of the Affiliates).

These statistics reflecting a 16% increase of deaf-blind clients served and an increase of 26% of new cases certainly coincides with our primary goal of assisting facilities to increase services to this population. With the addition of two new affiliates (Rhode Island Services for the Blind and Visually Impaired, and the Research and Training Center on Blindness at Mississippi State University), the objective of establishing deaf-blind services centers in almost every state continues to progress. In addition, funding has enabled the R & T Center at Mississippi State to hire a staff specialist whose activities will focus on the development and participation in research projects of the RTC/B-LV which address the career development needs of deaf-blind youths and adults.

#### *Project constraints*

From April 1974 to June 1981, sixteen agencies were funded to develop services for deaf-blind persons. At that time, there were, perhaps, two or three agencies applying for financial assistance under our affiliation program. In July of 1981, we developed the network affiliation program. Since July 1981, we have increased the number of active affiliated agencies to twenty-six. Five additional agencies discontinued their programs and our funding between 1974 and the present. At this time

we have a waiting list of ten to twelve agencies applying for affiliation within this program. Our inability to provide affiliation status is based upon limited funds and is a major project constraint. During this report period, we expended a total of \$123,942 for the affiliation program with a total of \$121,778 provided directly to agencies. This is 2.8% of the total HKNC budget. From 1974 to the present, \$1,063,748 was provided directly to agencies.

#### PLACEMENT SPECIALIST

##### *Goal*

To coordinate vocational placement for clients who are recommended for competitive employment, sheltered workshop programs, work activity center programs. To fulfill administrative responsibilities.

##### *Secondary goals*

To assist with residential placement, to provide consultation, to compile information on employment of deaf-blind persons.

##### *Project data*

1. Competitive Placement.....	11
2. Sheltered and Work Activity Center Placement.....	14
3. Active Caseload.....	24
4. Consultation.....	20
5. Group Counseling Caseload.....	18

The information on Page 11 lists clients working as of June 30, 1985. The Placement Department statistics are those placed between 7/1/84 and 6/30/85. This means that some clients that were placed during the reporting year did not continue working until June 30, 1985. Those clients listed as competitive/sheltered workshop/activity center placed were not all on an active caseload, but information from the field noting placement has resulted in inclusion in those statistics. Twelve of the clients listed above in No. 1 and 2 are included in active caseload.

##### *Project approach*

The Placement Specialist is involved in developing and effectuating vocational placements for those clients where vocational placement has been recommended by the HKNC staff. Goals for the clients vary, thus placements are sought in competitive employment, sheltered workshops, work activity centers, day programs, and vocational training programs. Because some clients who have vocational goals also have housing needs, the Placement Specialist participates in location, assessment, and advocacy to assure a residential placement.

Job development commences in advance of client's return to his home community. Initially, the Helen Keller Regional Representative and the client's State Rehabilitation Counselor are consulted to discuss the client's goals and gather information about employment opportunities in the preferred resettlement area. The Helen Keller National Center's Placement Specialist then utilizes community information in conjunction with independent job development to create placement choices for a client. Each job-ready person is involved in his job search to the best of his ability. Once potential work sites or residences are located, the Placement Specialist requests meetings and onsite visits to conduct the following activities: establish a relationship with the employer, perform task analyses, environmental assessment, advocate for the client explaining his skills for the selected position or program, educate the employer about techniques, i.e., communication and mobility that the client is adept with, and explain placement and follow-up services. The goal is to match up the client's goals with the most appropriate employer. If a work site is decided upon prior to completion of training, specifics of the job, employment requirements and residential routines are given to HKNC staff so that training for the transition can begin.

The Placement Specialist arranges for support services at the commencement of the job, can accompany clients on interviews, and is able to assist with initial adjustment to the work site. If problems arise during employment, the Placement Specialist is available for consultation or an on-site visit. An important component that assists in a successful vocational placement is a well-rounded social life and ability to occupy leisure time. The Placement Specialist is also engaged in locating community resources to help reintegrate the client to his or her community.

Pre-placement activity at the Center includes planning and conducting a counseling group called the Career Awareness Program (CAP). The curriculum focuses on job readiness, with goals of information dissemination and client interaction. This



group is conducted for 12-15 weeks, 2 hours per week and contains 6-7 clients per group.

Placement services has developed a Job Bank Questionnaire to obtain nationwide information on the types of jobs that deaf-blind persons are performing or have performed.

#### *Project constraints/modifications*

One Placement Specialist has been able to place 25 deaf-blind individuals in some form of employment. Due to budget restraints, a second position for placement specialist has been "frozen."

#### *Commentary*

We anticipate continuing to place 7 to 10 clients in competitive employment in the next reporting period. Placement of clients in sheltered and work activity programs will remain at approximately the same level. With the possibility of an additional placement specialist, it is probable that the work placement of our clients could be nearly doubled.

#### IMPACT OF VI-C DEAF-BLIND PROGRAMS ON OTHER SEVERELY HANDICAPPED GROUPS

The HKNC is the Sponsoring Agency of the Mid-Atlantic and Caribbean Regional (MACR) Deaf-Blind Center, which served the states of Delaware, New Jersey, Rhode Island, the Commonwealth of Puerto Rico and the U.S. Virgin Islands, during the FY 1984-85.

A total of 330 children were registered as deaf-blind of which 79 were under the category of non-Part B (ie. between the ages of birth through five years of age), except in Delaware, as shown on the table below:

State	Nonpart B 0-5	Part B children		Total 0-21
		4/6-17	18-21	
Delaware.....	(0-21) 39	(30)	(9)	39
New Jersey.....	(0-3) 16	114	65	195
Rhode Island.....	(0-3) 6	9	8	23
Puerto Rico.....	(0-5) 16	30	14	60
Virgin Islands.....	(0-5) 2	4	7	13
Total.....	79	157	94	330

The deaf-blind population of 330 in the Center Region ran a whole gamut of handicapping conditions as well as functioning levels—from (a) maximum assistance and supervision to (b) independent in self care, mobility, communication, and, potential for competitive placement vocationally. However, a large percentage (from 85 to 90+) are severely handicapped enough requiring varying degrees of assistance and supervision.

Since a majority of programs are located in and part of larger programs serving either, the deaf, blind, mentally retarded, orthopedically handicapped, or other severely handicapped, as well as, normally sighted children, there have been ongoing "spin off" of benefits derived by other (special) education personnel working with various types of handicapped children, especially, the severely handicapped individuals.

Following is a brief overview of impact/benefits of VI-C Deaf-Blind programs in the Center Region.

#### *Technical assistance*

Since technical assistance (TA) is one of the priorities of the Regional Center Services, and were provided to the State Education Agencies, as well as, to those personnel who work directly with the deaf-blind children and youth, through the regional center, and through the purchase of consultant services, almost, in all cases, inservices—consultation and workshops, conducted for the d-b project personnel, were made available, at the requests of the SEA officials, invariably from each state and territory, to other special education staff, since the methods and materials developed for the deaf-blind, could easily and effectively be applied with other Severely Handicapped (SH) students, and that, in most cases, the deaf-blind programs were located in and part of the larger programs serving other types of handicapped pupils.

Especially, in the Commonwealth of Puerto Rico and the U.S. Virgin Islands, where, there is a general dearth of expertise in the field of Special Education, the Directors of Special Education from both places, made special requests, that other Special Education professionals be allowed to attend, each and every, TA sessions, conducted for the deaf-blind project personnel.

During the FY 1984-85, the Regional Center conducted, in cooperation with the SEA, "State-wide Planning Meetings" in each state and the territory, towards the sharing of information on the existing services for the deaf-blind, and, planning and developing a "continuum of services" for deaf-blind. In each "State Planning Meeting" efforts were made, not only, to share and exchange information on various types of services for deaf-blind, among the various State, Local, and Private agencies, serving the handicapped, but also, to begin to develop "linkages" between various agencies, so that, sharing of information may be increased, as well as, access to services available, for each other, may be facilitated. The increase in desire to know more about the programs for the deaf-blind—curriculum materials, methods, etc.—resulted in the dissemination of over 500 pieces of print and video materials during the FY 1984-85.

### *(2) Programmatic impact*

As mentioned earlier, the majority of the deaf-blind programs, except in Puerto Rico, where the program is self-contained and located in a facility provided by the Department of Health, are located in either schools for the deaf, the blind, the retarded, the orthopedically handicapped, as well as, in regular public school settings. Because of this arrangement, there has been carry-over for teachers of severely handicapped students. Deaf-blind methods and materials could be effectively used with other severely handicapped students.

There has been ongoing exposure, and sharing of information, methods and materials, either through "team teaching", resource room, where some staff members work with both the deaf-blind and other severely handicapped students. Because of the small size of the deaf-blind program, these programs have been considered as "prototypes" for other larger programs for the severely handicapped. Here also, any or all types of technical assistance sessions, provided through VI-C funding, were made available to all other Special Education personnel, who utilized the methods and materials, in working with the severely handicapped pupils—especially in the areas of: (a) Assessment, (b) Communication Skills, (c) Visual Training—"Visual tracking" was first used with the deaf-blind children, (d) Daily Living Skills development.

### *Technical assistance center (TAC)*

A review of TAC activities and progress indicate that each of the stated objectives have been addressed. TAC has used two approaches in providing technical assistance: (1) reactive: response to requests from agencies/organizations for assistance; and (2) proactive: initiation of Regional Training Workshops based on perceived and expressed needs. The technical assistance has taken a variety of forms: on-site consultation; state-wide, multi-state or regional conferences and workshops; information and referral services; service providers' attendance at week-long seminars at HKNC. Technical assistance has been provided to a range of state and local rehabilitation and education agencies, regional centers for deaf-blind children, parent organizations, and other social service agencies providing services for deaf-blind youth. Evaluation data have been collected and preliminary review of the data indicates positive response as well as the need for further technical assistance and training. Based on TAC experiences of this past year, feedback from the field, and federal directions and trends, the following program priorities have been defined and will provide the framework for TAC activities in the 2nd year.

Technical assistance will assist agencies, organizations, or programs to facilitate the transition of deaf-blind youth from education to age-appropriate, community-based work and residential options in the least restrictive environment. Technical assistance will lead to increased and improved community-based housing for deaf-blind youth; e.g., develop or replicate new settings, or identify existing services into which deaf-blind can be integrated. Technical assistance will lead to increased or improved community-based work opportunities, in the least restrictive environment.

Technical assistance will increase or improve programs preparing deaf-blind youth for transition to community-based work and living options, e.g., in-service training of staff.

Technical assistance will identify or develop the necessary support services, explore and/or develop innovative approaches to increase/enhance the independent living skills of deaf-blind youth.

Technical assistance will foster increased inter-agency cooperation in providing comprehensive services for deaf-blind youth. Technical assistance will strengthen the involvement of parents and families in the transition process.

PREPARED STATEMENT OF BARBARA HOFFMAN, ESQUIRE, FOUNDATION FOR DIGNITY,  
CANCER PATIENTS EMPLOYMENT RIGHTS PROJECT

I received a death sentence twice: once when the doctor told me I had cancer; and then when my employer of ten years fired me because of it."<sup>1</sup>

I. INTRODUCTION

This testimony is on behalf of the more than five million Americans who have a cancer history, many of whom are denied equal opportunities in the workplace solely because of their cancer history. Discrimination against qualified employees costs society billions of dollars in lost wages, lost productivity and needless disability payments, and cruelly isolates those who have battled against an awesome disease. First, this testimony describes the scope of employment discrimination against people with a cancer history and discusses employers' underlying reasons for such discrimination. It examines common myths about cancer in light of modern medical achievements, and profiles several cancer survivors who have faced employment discrimination.

Second, this testimony surveys state and federal laws governing employment discrimination based on health. It examines the Rehabilitation Act of 1973,<sup>2</sup> state laws, and federal employee regulations in light of their applicability to discrimination based on cancer history.

In conclusion, the testimony proposes minor changes to the Rehabilitation Act of 1973 to expand the scope of the Act to cover individuals with a cancer history.

I. EMPLOYMENT DISCRIMINATION BASED ON CANCER HISTORY

*Summary of professional research*

Cancer is no longer a secret disease that kills all of its victims. More than five million Americans have a history of cancer.<sup>3</sup> Of this number, more than three million are considered cured and enjoy a normal life expectancy.<sup>4</sup> One-half of all Americans diagnosed with cancer today will recover and each year the percentage of those who survive increases. Because thirty percent of all Americans alive today—twenty million people—will contract some form of cancer, the ranks of the survivors will continue to swell.<sup>5</sup>

Unfortunately, winning the battle against cancer is often only the first step towards returning to a normal life. Many people who have cancer, or who have recovered from it, are faced with job discrimination based solely on their health history.<sup>6</sup> Common types of discrimination include: (1) exclusion from health insurance and other benefits; (2) demotions and denial of promotions; (3) refusals to hire; (4) undesirable transfers; (5) hostility in the workplace; and (6) requirement of medical exams which are unrelated to job performance.<sup>7</sup> Instead of being treated according to their ability to perform their jobs, several hundred thousand people are being treated by their employers and fellow employees because of their medical histo-

ry. A number of recent studies have examined employment discrimination against people with cancer histories. A five-year study of cancer-related employment discrimination against white and blue collar workers and young people indicates that more than one-half of the participants in each group had experienced work prob-

<sup>1</sup> Feldman, In Support of the Cancer Patients Employment Rights Act of 1985 (H.R. 1294): Hearing on Education and Labor, Subcomm. on Employment Opportunities (June 6, 1985) (summarizing research findings set forth in *Work and Cancer Health Histories*, infra, n. 11) [hereinafter cited as Feldman Testimony]. The June 6, 1985 hearing will hereafter be cited as "House Hearings on H.R. 1294."

<sup>2</sup> Rehabilitation Act of 1973, Pub. L. 93-112, sections 2-504, 87 Stat 357-944 (codified as amended at 29 U.S.C. sections 701-796i (1982)).

<sup>3</sup> American Cancer Society, 1985 Cancer Facts and Figures, 3 [hereinafter cited as "Cancer Facts and Figures"].

<sup>4</sup> *Id.*  
<sup>5</sup> *Id.*  
<sup>6</sup> *Id.*  
<sup>7</sup> *Id.*

lems due to their cancer histories. All of the participants experienced anxiety over potential reactions by employers and fellow employees to their histories, and about one-quarter were fired from their old jobs, or rejected from new jobs, because of their histories.<sup>8</sup>

A study by the California Division of the American Cancer Society found that most California corporations and governmental agencies discriminate against job applicants with a history of cancer for a period of three to ten years after treatment.<sup>9</sup> A draft of a soon to be published Stanford University study of 403 Hodgkin's disease survivors found that forty-three percent of the survivors experienced difficulties at work that they attributed to their cancer histories.<sup>10</sup>

Both public and private employers discriminate against employees with a cancer history without considering the individual's ability to perform the job. Corporate and professional studies, as well as thousands of case histories, have shown that people with a cancer history are as productive in the workplace as people without a cancer history.<sup>11</sup> Such discrimination, rooted in erroneous stereotypes about cancer and poor business practices, costs society billions of dollars annually and withholds income from the often financially burdened cancer survivor.<sup>12</sup>

### B. Cancer myths

Discrimination by both employers and fellow workers against people with a cancer history usually centers on three misconceptions: (1) The cancer victim is going to die; (2) Cancer is contagious; and (3) the cancer victim is an unproductive drain on the employer.<sup>13</sup>

The fear that the cancer victims is going to die is often unfounded:<sup>14</sup> one-half of the people diagnosed with cancer this year—nearly 500,000 Americans—will be cured. Each year, the percentage of survivors increases and researchers make new gains in diagnosis and treatment of cancer. Moreover, the survival rates for most

<sup>8</sup> For an excellent discussion of underlying reasons for such discrimination and its effects. See *House Hearings on H.R. 1294, supra* note 1, at 15-21 (prepared statement of Robert J. McKenna, M.D., President, American Cancer Society) (individual misconceptions and various social attitudes impact on employer and employee as result of cancer).

Dr. McKenna notes that three classifications of work-related discrimination exist: (1) dismissal, demotion, and reduction or elimination of work-related benefits; (2) problems arising from co-workers' attitudes; and (3) problems relating to the cancer patients' attitudes about how they should be perceived by co-workers resulting in alienation and avoidance by others. *Id.* at 15 (citing F. Feldman, *Employment Issues, Concerns and Alternatives for Cancer Patients* 15-19 (1982)).

<sup>9</sup> See F. Feldman, *Work and Cancer Health Histories*, (summarized in Proceedings of Western States Conference on Cancer Rehabilitation, San Francisco, 1982) (five year study of the work experiences of 344 white collar workers, blue collar workers and youths with cancer histories). Dr. Feldman's studies were sponsored by the California Division of the American Cancer Society in response to alleged incidents of discrimination. See also, Feldman Testimony, 15-17. See also Bureau of Labor Standards, U.S. Dept. of Labor, Bull. No. 234, *Workmen's compensation and the Physically Handicapped Worker* 12-13, (1961), (reasons given by employers for refusal to hire disabled workers include safety factors, fear of higher insurance costs, and resistance by fellow workers).

<sup>10</sup> See Feldman, Testimony, *supra* noted 1, at 1. Feldman found that 54% of white-collar respondents described work problems that they attributed to cancer; 84% of the blue-collar respondents identified such work problems, and 51% of the youth reported discrimination at work or school. *Id.* at 7.

<sup>11</sup> *Id.*

<sup>12</sup> Presentation by Robert J. McKenna, M.D., National Conference on Advances in Cancer Management Part I, Treatment and Rehabilitation (Nov. 25-27, 1974).

<sup>13</sup> P. Fobair, R. Hoppe, I. Bloom, R. Cox, A. Varghese & D. Spiegel, *Psychological Problems Among Survivors of Hodgkin's Disease*, 9 (Aug. 30, 1985) (unpublished manuscript submitted to *Journal of Clinical Oncology*) [hereinafter cited as Fobair].

<sup>14</sup> For example, a 1960's survey by the Bell Telephone System of more than 900,000 Bell employees found that 1.67 employees per thousand each year had seven or more days of illness related to malignancy. Of those employed at the time of their cancer diagnosis, 81.2% returned to work. Only 4.1% were permanently disabled while 14.7% died of cancer before returning to work. Cancer survival rates have increased considerably in the two decades following the Bell survey. See Fobair, *supra* note 13, at 1-2, for a brief discussion of the Bell survey.

A year study by the Metropolitan Life Insurance Company, conducted between 1959 and 1972, concluded that the work performance of people who were treated for cancer differs little from that of others hired at the same age for similar assignments. When compared with other employees of the same age, the turnover, absence, and work performance of cancer patients were satisfactory. In addition there were no deaths among employees hired after treatment for cancer during the observation period. *Metropolitan Life Insurance, Co., Statistical Bulletin*, 5-6 (1973).

types of cancer have increased, often at dramatic rates, over the past twenty years, and will continue to increase over the next twenty.<sup>15</sup>

Despite decades of international research that proves that cancer is not contagious,<sup>16</sup> many people still fear contact with cancer victims. Cancer is not one disease. It is general name given to a variety of conditions characterized by cell metastasis.<sup>17</sup> Medical researchers have discovered a number of known and unknown causes and they have formulated varying theories on how best to prevent the disease. Nevertheless, one fact is accepted by the medical profession: cancer is not contagious.<sup>18</sup>

Cancer evokes such intense fear that even highly educated and seemingly rational people avoid cancer patients with paranoiac conviction. At a top Ivy League university in the late 1970's, a student found himself ostracized when the school's medical director disclosed the student's medical records to his roommate's father without the student's permission.<sup>19</sup> When the student told his roommate that he had recently recovered from Hodgkin's disease, the roommate's father called the medical director after reading a study that erroneously suggested that Hodgkin's disease may be contagious. The medical director then insisted that the student spend his freshman year in the infirmary. When the student refused, the medical director told the student that he could not have a roommate unless he disclosed his medical history and warned the roommate that Hodgkin's may be contagious.<sup>20</sup>

<sup>15</sup> For a discussion of the economic costs of cancer, see T. Hodgson, *The Economic Burden of Cancer* 148 (manuscript present at the Fourth Annual Conference on Human Values and Cancer) (1984).

<sup>16</sup> *House Hearings on H.R. 1294 supra* note 1, at 16 (McKenna Testimony). Until present myths about cancer are dispelled, discrimination based on cancer history will be inherent in society. Author Susan Sontag comments that cancer has become the tuberculosis of today.

<sup>17</sup> "As long as a particular disease is treated as an evil, invincible predator, not just a disease, most people with cancer will indeed be demoralized by learning what disease they have. The solution is hardly to stop telling cancer patients the truth, but to rectify the conception of the disease, to de-mythify it.

<sup>18</sup> "When, not so many decades ago, learning that one had TB was tantamount to hearing a sentence of death—as today, in the popular imagination, cancer equals death—it was common to conceal the identity of their disease from tuberculars and, after they died, from their children. . . . Conventions of concealment with cancer were even more strenuous. In France and Italy it is still the rule for doctors to communicate a cancer diagnosis to the patient's family but not to the patient; doctors consider that the truth will be intolerable to all but exceptionally mature and intelligent patients. . . . Since getting cancer can be a scandal that jeopardizes one's love life, one's chance of promotion, even one's job, patients who know what they have tend to be extremely prudish, if not outright secretive, about their disease." S. Sontag, *Illness as a Metaphor* 7-8 (1977).

<sup>19</sup> Sontag also writes that modern medical advances will help improve cancer's connotations: "(Cancer will be partly demythified; and it may then be possible to compare something to a cancer without implying either a fatalistic diagnosis or a rousing call to fight by any means whatever a lethal, insidious enemy." *Id.* at 84. Cancer will no longer be viewed as a "demonic pregnancy" or serve as the standard euphemism in obituaries for "died after a long illness." *Id.* at 14.

<sup>20</sup> Because of this myth, cancer is often associated with moribundity. President Ronald Reagan's publicly scrutinized cancer surgery may help to dispel this myth.

In the past, public officials concealed their bouts with cancer. In 1893, President Grover Cleveland had secret surgery to remove malignant tissue from the roof of his mouth. The surgery was performed on a yacht anchored in New York's East River to mislead to press, which was told that Cleveland needed dental work. President Cleveland fully recovered and died fifteen years later from a gastro-intestinal attack, complicated by kidney malfunction and a failing heart. Keen, *The Surgical Operation on President Cleveland in 1893, Saturday Evening Post*, September 22, 1917, at 17 (news story that first disclosed details of President Cleveland's cancer surgery). The tumors removed from President Cleveland's mouth are on display at the Mutter Museum, College of Physicians and Surgeons, Philadelphia, Pennsylvania.

The frank and detailed media coverage of President Reagan's colon cancer was recorded by a New York Times headline proclaiming "chances excellent" and "normal life seen." Altman, *Reagan's Doctors Find Cancer in Tumor But Report Removal Leaves His Chances Excellent*, N.Y. Times, July 16, 1985 at A1. President Reagan's prompt return to an active schedule and his perpetual optimism contributed to a public association of cancer with life and employment. In addition, as with the public posture of Former First Lady Betty Ford's breast cancer, public education campaigns generated by Reagan's illness will undoubtedly increase early detection and save lives.

<sup>17</sup> See *Cancer Facts and Figures supra* note 3, at 3-4. Metastasis is the movement of cells from one part of the body to another. *Taber's Cyclopedic Medical Dictionary* M-41 (1977).

<sup>18</sup> See generally, *National Institutes of Health, U.S. Dep't of Health & Human Services, Cancer Prevention Research Summary: Viruses*, (NIH Pub. No. 84-2612) (1984) (viral infections that increase risk of cancer may be contagious, but cancer itself is not contagious) (hereinafter cited as *Cancer Prevention Research Summary*).

<sup>19</sup> This case history is based on the author's interview with the student on April 30, 1985.

<sup>20</sup> *Id.* University officials subsequently apologized for the Medical Director's actions.

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The medical director caused the student and his new roommate unnecessary distress by attempting to isolate a perfectly healthy young man from his peers. Some employers who express similar fears ask their employees with cancer to work alone.<sup>21</sup> Such irrational ostracism harms self esteem, jeopardizes worker morale and promotes the myth that cancer is contagious.<sup>22</sup>

The misconception that cancer patients or former cancer patients are an unproductive drain on their companies and fellow employees is based in part on the erroneous beliefs that cancer is always fatal and that people with a cancer history are not productive or reliable.<sup>23</sup> Cancer is often not fatal and it seldom has a long-term effect on an individual's ability to work.<sup>24</sup> The productivity, absenteeism and death rates of people whose cancer has been cured does not vary significantly from those of people with no cancer history.<sup>25</sup>

Some cancer survivors are more productive after facing cancer than they were prior to their illness because many are eager to prove themselves healthy and reliable. Many cancer survivors report that after recovering from cancer, they were less likely to stay home with a minor ailment than they were before their illness, and that they were anxious and able to put in a full day's work.<sup>26</sup>

Eliminating people with a cancer history from the workplace is a costly and inefficient practice. For example, one commentator noted that in 1980, illness and disability from cancer resulted in the loss of \$2.6 billion in wages and salaries because of idled laborers and housekeepers.<sup>27</sup> Unnecessarily unemployed workers are a drain on the economy because they produce fewer goods, pay fewer taxes, spend less money and accept more public assistance than they would if they had been allowed to work to their full potential. Ensuring full employment opportunities for all qualified workers would mitigate this problem.

Excluding employees with a cancer history from participation in group health plans is another form of discrimination against people with a cancer history. In many cases, the medical claims of an employee with cancer have no effect on group insurance rates.<sup>28</sup> Even if an employer, especially a small employer, could prove that the claims of an employee with cancer jeopardized the insurance program of other employees, the employer has many alternatives other than completely barring the employee from the group plan. Employees could be given complete insurance coverage except for the type of cancer that they have or have had. Employers could create high-risk pools for people with a cancer history. Exclusion of employees from a group health plan often means exclusion of their entire families. In such cases, employees should be permitted to waive their right to full coverage as long as coverage for their family members are not affected.

### C. Case histories

Many employees lose their jobs when they are diagnosed with cancer. An experience nurse, interviewed by the author<sup>29</sup> who does not want to disclose her name for fear of future discrimination, worked at a large metropolitan hospital for many years until she was diagnosed with ovarian cancer. She took a four month leave of absence for an operation and strenuous chemotherapy treatments. After she returned to work part-time, she was told that her full-time position would not be held

<sup>21</sup> See Feldman Testimony, *supra* note 1, at 7.

<sup>22</sup> See T. Hodgson, *supra* note 15, at 147-48 (psychosocial costs of cancer may result in economic dependence, social isolation, emotional problems, and undesired changes in life plans for cancer victims and those around them).

<sup>23</sup> See G. Monaco *Socioeconomic Considerations in Childhood Cancer Survival: Society's Obligations* 8 (April, 1985) (unpublished manuscript) (productivity of cancer victims does not vary from productivity of other employees). See *Statistical Bulletin*, *supra* note 16 at 6 (compared with other employees of same age, work performance of employees treated for cancer was satisfactory).

<sup>24</sup> See *Statistical Bulletin*, *supra* note 14 for a discussion of the productivity of former cancer patients.

<sup>25</sup> See G. Monaco, *supra* note 23, at 8 (discussion of impact of cancer on employee performance and insurance costs). Grace Powers Monaco, Esquire is the President of Candlelighters Childhood Cancer Foundation, a nonprofit organization of parents of children with cancer, 2025 Eye Street, N.W., Suite 1011, Washington, DC 20006. See also *supra* note 14 and accompanying text for a discussion of the performance of employees with a cancer history.

<sup>26</sup> This information stems from the author's interviews with former cancer patients, and a telephone interview with Pat Fobair, L.C.S.W., Division of Radiation Therapy, Stanford University Medical Center, Stanford, California (April 24, 1985).

<sup>27</sup> See T. Hodgson, *supra* note 15, at 152.

<sup>28</sup> See G. Monaco, *supra* note 23, at 8 (citing G. Koocher, "Surviving Childhood Cancer: Issues in Living" *Living With Childhood Cancer*, 178-180 (1981)).

<sup>29</sup> Interviewed on March 5 and 8, 1985.

open. The hospital refused to allow her to split her shift with another nurse who offered to fill in until her friend could resume full-time hours.

Sometime after the nurse was forced to cease working, she saw an advertisement for her job. Although she was perfectly healthy and able to resume her duties, she was forced to reapply for her old position, and was eventually rehired because of her superior work record. Because she was forced to retire from her job of many years and then reapply, however, she was treated as a new employee with no seniority and limited benefits.

Gary Wells, also interviewed by the author,<sup>30</sup> saw seventeen years of job security vanish when he was diagnosed with Hodgkin's disease. Wells scheduled chemotherapy treatments for Friday afternoons to avoid interfering with his work. Nevertheless, three weeks after Wells was diagnosed, his employer discovered that Wells had cancer, and told him that he had two weeks either to retire, or to move to another state and accept a demotion. Although the employer did not speak to Wells' doctor, and did not know Wells' personal chances for survival, he maintained that Wells was no longer reliable as a back-up to the company president because of his health. Because moving to another state would interrupt his chemotherapy treatments, the forty-five-year-old Wells was forced to retire and accept disability payments even though he wanted to remain on the job.

Many people are unable to find new jobs when their cancer history is revealed. For example, Barbara Serviss, also interviewed by the author,<sup>31</sup> is a young New Yorker who passed the written and agility tests for admission to the New York Police Department. Despite her test performances, Serviss was rejected in August, 1984, solely because she once had Hodgkin's disease. Serviss has been totally free of cancer for more than five years. According to the New York Police Department's own testing standards, she is a healthy, strong and intelligent young woman who is qualified to serve on the force. Her first appeal of the NYPD's decision was rejected and Serviss filed a second appeal in November, 1984. After waiting for nearly a year for the Police Department to reconsider its decision, in July, 1985, Serviss was again rejected because of her cancer history.<sup>32</sup>

Similarly, a young Philadelphia woman, interviewed by the author, had been cured of cancer for seventeen years when she decided to make a career change. She applied for several sales positions and successfully completed a number of interviews. One company assured her that she was a very strong candidate, but rejected her two days after she told company officials that she had been in remission for cancer for seventeen years. When this interview pattern was repeated with several other companies, the woman decided to hide her cancer history if asked. The next interviewer offered her a job without probing into her medical history. Six months later, she won a national sales contest and today is a healthy and successful salesperson.

One of the country's leading employers—the military—openly rejects healthy men and women for enlistment solely because of cancer history.<sup>33</sup> One man, identified as D.F., was diagnosed with acute lymphocytic leukemia in January, 1978 at the age of sixteen.<sup>34</sup> He was successfully treated and free of cancer when he tried to enlist in the armed services. The Navy, Air Force, Army, Coast Guard and Marines rejected him because of his medical history.<sup>35</sup>

In another instance, a man identified as G.P. was diagnosed with Hodgkin's disease when he was sixteen, and was treated and cured.<sup>36</sup> G.P. had dreamed of being a Navy pilot since the age of ten. He ultimately passed his written and naval aviation reserve officers' candidate examination and flight physical. During his physical, the naval doctor asked G.P. the source of a surgical scar. G.P. revealed that he had

<sup>30</sup>Interviewed on May 28, 1985.

<sup>31</sup>Interviewed on February 14, March 14, May 20 and August 7, 1985. See also, D. Polman, After cancer: The fight for employment, Philadelphia Inquirer, March 10, 1985, F-1, col. 1. See also House Hearings on H.R. 1294, supra, note 1, at 6 (prepared statement by Rep. Mario Biaggi (D-NY) discussing the case of Barbara Serviss).

<sup>32</sup>Interviewed on August 7, 1985.

<sup>33</sup>See G. Monaco, supra note 23, at 15-17. See infra notes 41 and 42 and accompanying text for a discussion of military regulations regarding the discharge of enlisted personnel with a cancer history.

<sup>34</sup>Id. at 16. See also House Hearing on H.R. 1294, supra note 1, at 124 (prepared statement of Grace Powers Monaco).

<sup>35</sup>The Marine officer who rejected D.F. told him that it was one of the hardest things he had ever had to do because D.F. at six-foot, three inches tall and 190 pounds, and in perfect health, looked like the perfect Marine.

<sup>36</sup>See Monaco, supra note 23, at 17. See also House Hearing on H.R. 1294, supra note 1, at 124 (prepared statement of Grace Powers Monaco).

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Hodgkin's disease, but that he was completely cured of cancer. G.P. was rejected by the Navy solely because of his cancer history.<sup>37</sup>

#### D. Discriminatory policies of the Federal Government

The federal government sets a poor example as one of the country's largest employers by systematically barring employment of individuals with a cancer history solely because of their status. The United States Military and the Department of State strictly limit employment of individuals with a cancer history.

The United States Military (Army, Air Force, Navy, Army Reserves, Coast Guard, and the service academies) severely restricts active duty service by men and women with cancer histories.<sup>38</sup> People with a cancer history are automatically rejected for active duty positions. Causes for rejection for appointment, enlistment and induction include benign and malignant tumors as set forth in Chapter Two, Sections 2-40 and 2-41 of Army Regulation 40-501.

Those who have been rejected may apply for a waiver, the merits of which are determined on a case-by-case basis by medical personnel in each service. Circumstances under which an individual may receive a waiver include: (1) when cancer has been in total remission for at least five years (including all therapy and medical care associated with the cancer) or (2) when certain cancers with very low recurrence rates (such as testicular cancer) have been in total remission for two to three years and medical documentation justifies a waiver.

Waivers are granted only rarely.<sup>39</sup> The military assumes that a person with a cancer history is unfit for active duty and shifts an arduous burden to the individual to prove fitness. The five year limitation is especially difficult for many young adults who had cancers such as Hodgkin's Disease, which disproportionately strikes young people, yet has a five year survival rate of 88%.<sup>40</sup>

A member of the service who is diagnosed with cancer is automatically removed from active duty if the cancer is diagnosed during the first 120 days of service and usually removed from active duty if the cancer is diagnosed after the first 120 days of service. Personnel whose cancer is diagnosed during the first 120 days of service are given a non-medical discharge. Those whose cancer is diagnosed after the first 120 days of service are usually given a medical discharge. Only in unusual circumstances is the individual treated and returned to active duty.

The Department of State requires all applicants to be cancer free for five years before being eligible for foreign service, including service in the Peace Corps. Virtually no exceptions are made to this five year rule.

### III. PRESENT STATE AND FEDERAL LAWS DO NOT PROTECT MOST VICTIMS OF CANCER BASED EMPLOYMENT DISCRIMINATION

#### A. State laws

##### 1. State statutes

Because no federal law protects all employees against discrimination based on handicap or medical condition, individuals with real or perceived disabilities must turn to more pervasive state laws for relief.<sup>41</sup> Forty-five states and the District of Columbia presently have laws prohibiting employment discrimination based on handicap. Only Arizona, Delaware, North Dakota, South Dakota and Wyoming do not statutorily prohibit employment discrimination based on real or perceived disabilities. Six states, Alabama, Arkansas, Idaho, Mississippi, South Carolina and Tennessee, limit coverage to public sector employment.

Although each state that statutorily prohibits employment discrimination based on handicap describes the protected class as either "handicapped" or "disabled," state statutes vary widely in their definitions of "handicap" and "disability." Some statutes use very broad language, while others explicitly refer to particular medical

<sup>37</sup> *Id.*

<sup>38</sup> For purposes of this testimony, the United States military includes the Army, Air Force, Navy, Army Reserves, Coast Guard, and the service academies.

<sup>39</sup> Interview with Captain Peter Flynn, M.D., Director for Professional Activities, Office of the Secretary of Defense (Health Affairs), United States Navy, (May 20, 1985 and September 18, 1985). See Department of Defense Directive 1332.18, Uniform Interpretation of Laws Relating to Separation from the Military Service by Reason of Disability.

<sup>40</sup> See *Cancer Facts and Figures*, *supra* note 3 at 3 (since 1960's, cancer survival rate has increased from one of every three patients to three of every eight patients). See also *id.* at 4, 5, 11, 15 and 23, for a discussion of survival rates and trends in cancer diagnosis and treatment.

<sup>41</sup> See Appendix A for a compilation of state laws prohibiting employment discrimination based on physical or mental handicaps.



conditions.<sup>42</sup> At least fifteen states borrow language from Section 706(7)(B) of the Rehabilitation Act to protect not only those who suffer a disability, but those who are regarded or perceived to be disabled.<sup>43</sup> Many people with a cancer history may be covered by these laws because employers often perceive every type of cancer as a disability, regardless of the health of the individual.<sup>44</sup>

At least two states specifically protect employees with a cancer history. California's Fair Employment and Housing Act prohibits employment discrimination on the basis of "medical condition."<sup>45</sup> Under California law, "medical condition" includes "any health impairment related to or associated with a diagnosis of cancer, for which a person has been rehabilitated or cured, based on competent medical evidence."<sup>46</sup> Similarly, Vermont law includes cancer as a physical or mental impairment.<sup>47</sup>

At least one other state has considered expanding its discrimination laws to protect explicitly people with a cancer history. The New Jersey State Assembly unanimously passed a bill on December 12, 1986 to amend state law to prohibit employment discrimination on the basis of "cancer history."<sup>48</sup> The bill unanimously passed the New Jersey State Senate on January 13, 1986. However, Governor Thomas Kean "pocket-vetoed" the bill, along with 68 other statutes passed at the end of the legislative session.<sup>48</sup>

## 2. Cases brought under State laws

Courts in at least four states have addressed the rights of employees who have been the victims of discrimination based on their cancer histories. California views cancer as a "medical condition" covered by state law, and the New York State Division of Human Rights holds that cancer is a "disability" under state law prohibiting employment discrimination based on disability. In addition, Wisconsin courts regard cancer as a "handicap" within the meaning of the Wisconsin Fair Employment Act. Illinois courts, however, do not regard cancer as a "physical or mental handicap" under state fair employment laws.

a. *California.*—In *Department of Fair Employment and Housing v. Kingsburg Cotton Oil Company*,<sup>49</sup> the California Fair Employment and Housing Commission ("Commission") found that Kingsburg Cotton Oil Company fired Virginia Austin "because of her medical condition and her perceived physical handicap." Thus, the Commission held, Kingsburg in violation of the Fair Employment and Housing Act.

Austin had worked for Kingsburg for seventeen years as a receptionist and had been promoted in 1974 to a sales position because of her excellent work record and knowledge of the buyers. In 1975, Austin had emergency cancer surgery to remove eighteen inches of her colon. Although she missed and was compensated for seven weeks of work, Austin returned to work that year, but decided not to take most of her three week vacation time. In 1976, Austin underwent a hysterectomy because the cancer had metastasized to her ovaries. She missed five additional weeks of work due to this illness, and subsequently underwent chemotherapy from January to July, 1977. During this period, however, she was able to complete all of her assigned work.

Following Austin's second surgery in 1976, Kingsburg began to dock her for each full day missed, even though no other employee was ever docked for time off from work due to illness. In 1980, Austin trained a new employee to handle a sales posi-

<sup>42</sup> For example, New Jersey's statute protects an individual with an "atypical hereditary cellular blood trait", such as Tay-Sachs or sickle cell. N.J.Stat. Ann. section 10:5-12a (West Supp. 1985) (unlawful for employer to refuse to hire or discharge on basis of individual's hereditary blood trait).

<sup>43</sup> See Fla. Stat. Ann. 760.22 (1984); Iowa Civil Rights Commission Rules 6.1(5), FEPM 453:3101 (1979); La. Rev. Stat. Ann. 46:2253 (1982); Md. Anti-Discrimination Regulations 14.03(c), FEPM 455:717 (1979); Ann. Laws of Mass. 151B Section 1(17) (1985); M.S.A. 363.01(25) (1984); N.M.S. Ann. 28-1-2(k) (1983); N.Y. Exec. Law 292(21) (1984); Okla. Stat. tit. 25, sec. 1301(4) (1984); Or. Rev. Stat. 659.400(2) (1981); Pa. Human Relations Commission Handicap Discrimination Guidelines, 16 Pa. Code 44.4(d), FEPM 457:863 (1978); R.I. General laws 28-5-6(H) (1984); Vt. Stat. Ann. tit. 21, sec. 495(d)(7) (1982); Wash. Adm. Code 162-22-040(b)(iii), FEPM 457-2941 (1975); and Wis. Stat. Ann. 11.32(8) (1984).

<sup>44</sup> The scope of protection provided by these laws is uncertain because few state courts have issued opinions on whether cancer based discrimination is prohibited by state law.

<sup>45</sup> Cal. Gov't Code section 12940 (Deering 1985).

<sup>46</sup> Cal. Gov't Code section 12926(f) (Deering 1985).

<sup>47</sup> Vt. Stat. Ann. tit. 21, sec. 495d(7)(7) (1984).

<sup>48</sup> Assembly Res. 2880, 201st Leg., 1st Sess., 1984 New Jersey Laws. An identical bill (S3349) was introduced in the New Jersey Senate by Senator Raymond Lesniak on September 12, 1985.

<sup>49</sup> No. FEP 80-81, slip op. (Cal. Fair Emp. & Hous. Comm. Dec. 7, 1984).

tion and, in addition to her own job, Austin performed many of the duties of a receptionist who was on maternity leave.

Kingsburg fired Austin just after Christmas, 1980 for "excessive absenteeism" maintaining that she would be absent in the future because of her cancer history. At the time, she was fifty-seven years old, had no sign of cancer, and had been with the company for twenty-three years. Although she missed several working days due to illness and follow-up examinations, the Commission found that Austin had adequately fulfilled her job duties. The Commission held that her cancer was a "medical condition" as defined by the Fair Employment Practices Act because Kingsburg believed that Austin's health would be impaired in the future, and that Austin had a health impairment related to a diagnosis of cancer. The Commission awarded Austin reinstatement, retroactive seniority and benefits, back pay and damages of \$40,000. On appeal, the Superior Court of California vacated the Commission's order reasoning that although Austin had a handicap as defined by the Fair Employment Practices Act, her job termination was unrelated to her handicap.<sup>50</sup> Austin is appealing this decision.

*b. New York.*—Lisa Goldsmith, Ph.D., applied for admission to the New York Psychoanalytic Institute in 1976.<sup>51</sup> The approval of three committees was necessary for admission. Two of the committees found her to be highly qualified and gave her excellent evaluations. The third committee disapproved her application, because she once had Hodgkin's Disease. Dr. Goldsmith had been in full remission since April, 1974. The Institute allowed reapplications two years after submission of the first application. Dr. Goldsmith reapplied, but was again turned down.

The New York State Division of Human Rights found that the Institute engaged in an unlawful discriminatory practice because it denied Dr. Goldsmith admission solely on the basis of her cancer history. Administrative Law Judge Amos Carnegie held that Hodgkin's Disease is a disability within the meaning of the New York Human Rights Law. New York law prohibits employment discrimination on the basis of a "disability," or "a condition regarded by others" as a disability.<sup>52</sup> The Institute regarded Hodgkin's Disease as a disability. The New York Supreme Court, Appellate Division, affirmed Judge Carnegie's decision because "it is clear that the rejection of complainant's application constituted a violation of complainant's right to 'an equal opportunity to enjoy a full and productive life' (Executive Law 290)."

*c. Wisconsin.*—The Wisconsin Circuit Court of Dane County held that a person with acute lymphocytic leukemia has a "handicap" within the meaning of the Wisconsin Fair Employment Act.<sup>53</sup> Chrysler refused to hire Complainant because it feared future absenteeism and higher insurance costs. At no point did Chrysler contend that Complainant was unable to perform the job.

The Court held that leukemia in this case was a handicap because it made it more difficult for Complainant to find work. The Court found immaterial Chrysler's contention that Complainant may at some future date be unable to perform the duties of the job: "An employer's refusal to hire a person solely on the basis of a handicap operates to discriminate against him regardless of the intent of the employer."<sup>54</sup>

*d. Illinois.*—Unlike California, New York and Wisconsin courts, Illinois courts have refused to grant relief to victims of employment discrimination on the basis of cancer history. In *Kubik v. CNA Financial Corporation*, the Illinois Appellate Court held that colon cancer was not a "physical or mental handicap" within the meaning of state law.<sup>55</sup>

Mr. Kubik had been employed by CNA for several years, during which time he received promotions and increases in responsibilities and salary. A malignant tumor successfully was removed from his colon in 1975. When he returned to work in January, 1976, he was fired. Kubik alleged that he was able to perform his job and was fired solely because of his cancer. The Court denied Kubik's claim on the ground that his cancer was not a physical or mental handicap under state law because it did not impose a severe barrier on his ability to perform major life functions.<sup>56</sup>

The following year, the Supreme Court of Illinois in *Lyons v. Heritage House Restaurant* construed the state statute even more narrowly than did the appellate court in *Kubik*.<sup>57</sup> Ms. Lyons alleged that she was dismissed from her job as manager of

<sup>50</sup> — Cal. App. Dep't Super. Ct. — (November 15, 1985).

<sup>51</sup> 22 Empl. Prac. Dec. (CCH) section 30,764, at 14,937 (1980).

<sup>52</sup> *Id.* at 14,942 (citing *N.Y. Exec. Law 292(2)*) (McKinney Supp. 1984-85).

<sup>53</sup> 14 Fair Empl. Prac. Cas. (BNA) 344 (1976).

<sup>54</sup> *Id.* at 345.

<sup>55</sup> Citing *Ill. Rev. Stat.*, ch. 38, sections 65-21 (1977). The Equal Opportunities for the Handicapped Act was replaced by the Illinois Human Rights Act in 1980. *Ill. Rev. Stat.*, ch. 68, sections 1-101 to 9-102 (1983).

<sup>56</sup> 29 Fair Empl. Prac. Cas. (BNA) 698 (1981).

<sup>57</sup> 89 Ill. 2d 163, 432 N.E.2d 270 (1982).

kitchen operations because she had cancer of the uterus and that her employer perceived her as handicapped. She alleged that her illness would have no effect on her ability to perform her duties.

The Court held that uterine cancer was not a "handicap" within the meaning of the Equal Opportunities for the Handicapped Act.<sup>58</sup> Because state law did not clearly define "handicap", the Court set forth its own definition: "the class of physical and mental conditions which are generally believed to impose severe barriers upon the ability of an individual to perform major life functions."<sup>59</sup> The Court stated that neither the Federal Rehabilitation Act of 1973 nor state law specifically define cancer as a handicap.<sup>60</sup> Because Ms. Lyons did not allege that her cancer substantially hindered her in any major life activities or that her employer perceived her condition as causing such a hindrance, the Court found that she was not handicapped within the meaning of state law.

## B. Federal legislation

### 1. General civil rights

Legal advocacy on behalf of victims of employment discrimination based on their real and perceived disabilities is relatively new in the history of the American civil rights movement. The early civil rights acts, codified at 42 U.S.C. 1981 and 42 U.S.C. 1983, were the first significant legislative attacks on discrimination.<sup>61</sup> Early employment discrimination laws were rooted in efforts to remedy racial bigotry.<sup>62</sup> The scope of 42 U.S.C. 1981 is still restricted to actions based on race or alienage.<sup>63</sup> Although 42 U.S.C. 1983 is no longer exclusively limited to race,<sup>64</sup> courts have yet to address whether it applies to cancer-based employment discrimination.

Subsequent laws aimed at prohibiting employment discrimination likewise fail to cover people with real or perceived disabilities. President Lyndon Johnson issued Executive Order 11246, which prohibits discrimination by federal contractors on the basis of race, color, religion, sex, or national origin.<sup>65</sup> Title VII of the Civil Rights Act of 1964<sup>66</sup> prohibits discrimination by private and public employers, employment agencies and labor organizations on the basis of race, color, creed, national origin and sex.<sup>67</sup> Despite more than a century of protective legislation focusing on race and gender, however, people with real and perceived disabilities were without significant federal remedies until the passage of the Rehabilitation Act of 1973.<sup>68</sup>

### 2. The Rehabilitation Act of 1973

a. *Scope of the act.*—The Rehabilitation Act of 1973 ("Rehabilitation Act") is applicable to some, but not all cases of employment discrimination based on cancer history. Section 504 of the Rehabilitation Act bans employment discrimination based on handicap in programs receiving federal financial assistance. Although section 504 provides a private right of action, its coverage is limited to "otherwise qualified

<sup>58</sup> Ill. Rev. Stat. ch. 38, sections 65-21 (1977).

<sup>59</sup> 89 Ill. 2d at 171, 432 N.E.2d at 274.

<sup>60</sup> *Id.* at 169-170; 324 N.E. 2d at 273.

<sup>61</sup> See 42 U.S.C. section 1981 (1982) (race discrimination) and 42 U.S.C. section 1983 (1982) (deprivation of legal and constitutional rights).

<sup>62</sup> See Brooks, *Use of the Civil Rights Act of 1866 and 1871 to Redress Employment Discrimination*, 62 *Corn. L. Rev.* 258, 268 (1977) (thirteenth amendment is constitutional foundation of section 1981 of Civil Rights Act).

<sup>63</sup> See, e.g., *Johnson v. Ryder Truck Lines, Inc.*, 575 F.2d 471, 474 (4th Cir. 1978), (relief awarded to victims of race-based employment discrimination), *cert. denied*, 440 U.S. 979 (1979).

<sup>64</sup> Some courts have applied 42 U.S.C. section 1983 to employment discrimination based on handicap. See *Gurmankin v. Costanzo*, 556 F.2d 184 (3rd Cir. 1977) (school officials violated due process rights of blind teacher who sued under 42 U.S.C. section 1983 alleging that she was denied a teaching position because of her blindness), *aff'd in part, rev'd in part on other grounds*, 626 F.2d 1115 (3rd Cir. 1980), *cert. denied* 450 U.S. 923 (1981); *Drennon v. Philadelphia General Hospital*, 428 F. Supp 809, 813-814 (cause of action stated by epileptic who brought a 42 U.S.C. section 1983 action against hospital alleging she was unconstitutionally denied employment solely because of her epilepsy).

<sup>65</sup> Exec. Order No. 11,246, 3 C.F.R. 339 (1965).

<sup>66</sup> The Civil Rights Act of 1964, Pub. L. 88-352, Title VII, sections 701-16, 78 Stat. 253-66 (codified as amended at 42 U.S.C. section 2000e-2 (1982)).

<sup>67</sup> 42 U.S.C. sections 2000e-2, 1982). Presently pending before the United States House of Representatives is H.R. 370, a proposed amendment to Title VII of the Civil Rights Act of 1964 that would make discrimination against the handicapped unlawful in private and public employment. 2 *Cong. Index (CCH)* at 28,173 (1985-86). See also *House Hearings on H.R. 1294*, *supra* note 1, at 1-2.

<sup>68</sup> Rehabilitation Act of 1973, Pub. L. 93-112, section 2-504, 87 Stat. 355-94 (codified as amended at 29 U.S.C. sections 701-796i (1982)).

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handicapped" persons who are employed by a "program or activity receiving Federal financial assistance."<sup>69</sup>

b. *The act's definition of handicap does not cover all individuals with cancer history.*—Federal courts have not addressed the issue whether the Rehabilitation Act applies to cancer-based discrimination. The Act defines "handicapped individual" as "any person who (i) has a physical or mental impairment which substantially limits one or more of such person's major life activities, (ii) has a record of such impairment, or (iii) is regarded as having such an impairment."<sup>70</sup> Although courts are likely to find that the few cancer survivors who do have such serious impairments are clearly "handicapped individuals" covered by the Act, most people with a cancer history do not have a physical or mental impairment that substantially limits their major life activities. Thus, only a limited number of cancer victims fall within the Act's coverage. Similarly, the Rehabilitation Act defines "severe handicap" as a "disability that requires multiple services over an extended period of time and results from . . . cancer."<sup>71</sup> Cancer itself is not defined as a handicap, but this section indicates that it may result in a disability severe enough to be covered by the Act. The section offers narrow protection, however, because only a small percentage of cancer survivors are left with a disability that requires multiple services over an extended period of time.

The regulations that accompany the Act recognize that people with a cancer history often experience employment discrimination based on misconceptions about their illness long after they are fully recovered. The regulations provide that: "Has a record of such an impairment" means that an individual may be completely recovered from a previous physical or mental impairment. It is included because the attitude of employers, supervisors and coworkers toward that previous impairment may result in an individual experiencing difficulty in securing, retaining or advancing in employment. The mentally restored, those who have had heart attacks or cancer often experience such difficulty."<sup>72</sup>

Although this section recognizes the problems associated with employer misconceptions about people with cancer, it appears to require that employees at one time must have suffered from an impairment that substantially limited their major life activities. Many cancer patients, including those undergoing radiation and chemotherapies, are able to perform their jobs without interruption. Although these cancer patients can be victims of employment discrimination, they may not be covered by the "record of impairment" clause of the Act because cancer is not always an impairment that substantially limits major life activities. Some people withstand cancer treatments with little interruption to their lives and therefore, despite having a history of cancer, do not have "a record of . . . an impairment" that "substantially limits one or more . . . major life activities."

Although most of the five million Americans with a cancer history do not suffer from substantially limiting handicaps, many face employment discrimination because they are perceived to be handicapped. The effect of the language in the Rehabilitation Act that covers people who are "regarded as having such an impairment" is to protect victims of discrimination based on an employer's perceptions, whether or not those perceptions are accurate.<sup>73</sup> When an employer regards a cancer history as an "impairment which substantially limits one or more of" the employee's "major life activities", regardless of whether the employee is actually impaired, that employee is considered a "handicapped individual" under the Rehabilitation Act.<sup>74</sup>

Thus, the Rehabilitation Act provides relief to a small percentage of people with a cancer history: only those who are covered by the Act's definition of "handicap" and those whose employers receive federal financial assistance. The Act's definition of "handicap" does not describe all people with a cancer history because many cancer patients, both ill and recovered, are not substantially limited in their major life ac-

<sup>69</sup> See *Consolidated Rail v. Darrone*, 104 S.Ct. 1248, 1254-55 (1984).

<sup>70</sup> 29 U.S.C. 706(7)(B) (emphasis added).

<sup>71</sup> 29 U.S.C. 706(13).

<sup>72</sup> 41 C.F.R. section 60-741.54 app. A (1984).

<sup>73</sup> See, e.g., *E.E. Black, Ltd. v. Marshall*, 23 Fair Empl. Prac. Cas. 1253, 1260, 1262 (D. Hawaii 1980) (employee is "qualified handicapped individual" under Rehabilitation Act because employer perceived him as having impairment substantially limiting major life activity).

<sup>74</sup> 29 U.S.C. section 706(7) (1982). Regulations governing the Rehabilitation Act are issued by the Office of Federal Contract Compliance ("OFCC"). OFCC "Programs Guidelines on the Application of the Definition Handicapped Individual" provide at 41 C.F.R. section 60-741.54 App. A

"Is regarded as having such an impairment" refers to those individuals who are perceived as having a handicap, whether an impairment exists or not, but who, because of attitudes or for any other reason, are regarded as handicapped by employers, or supervisors who have an effect on the individual securing, retaining or advancing an employment."

activities, or are disabled to the point of requiring multiple services over an extended period of time.

In addition, the Act is designed to protect the handicapped. The popular meaning of "handicap" is "disadvantage that makes achievement unusually difficult; [especially] a physical disability that limits the capacity to work."<sup>75</sup> The use of the word "handicap" with regard to all people with a cancer history perpetuates the stereotypical image that cancer survivors are striving to shed. Most cancer survivors are not physically disabled in a way that limits their capacity to work. Nevertheless, such misconceptions by employers, and society in general, irrationally restricts the employment opportunities of qualified cancer survivors.

#### IV. AMENDING THE REHABILITATION ACT TO PROHIBIT CANCER BASED EMPLOYMENT DISCRIMINATION

##### A. Proposed new language

The Rehabilitation Act presently applies to "handicapped individuals" as defined by 29 U.S.C. 706(7)(B). As discussed above, this definition does not encompass all cases of cancer based employment discrimination. The Act would clearly provide protection to individuals with a cancer history if the following sentence were added to this definition:

"For purpose of Section 503 and 504, a cancer history is 'a physical or mental impairment which substantially limits one or more of such person's major life activities.' The term cancer history means the status of any individual who has, or has had cancer, who is diagnosed as having or having had cancer, or who is regarded as having or having had cancer. For purposes this subsection, 'cancer' means any disease characterized by the uncontrolled growth and spread of abnormal cells."

This single, brief amendment responds to many of the employment obstacles faced by the five million people in the United States with a cancer history. Because the Rehabilitation Act protects only "handicapped individuals," cancer survivors must be defined as handicapped individuals in order to be included within the scope of the Act. In another statutory context, individuals with a cancer history should not be labeled "handicapped" in order to mitigate the stereotype that underlies much of this type of discrimination.

##### B. Benefits of expanding the Rehabilitation Act to include individuals with a cancer history

First, the Act would, on its face, provide protection to cancer survivors who have a physical or mental impairment which substantially limits a major life activity as well as survivors who have no traditional handicap, but are perceived as having a traditional handicap. Moreover, such an amendment would provide clear guidance to federal courts, which at present must guess at whether the Rehabilitation Act applies to cancer based discrimination.

Second, the Act would provide a cause of action to many victims of cancer based discrimination. Other than the residents of a few states such as California and New York, cancer survivors have few legal remedies when they are unjustly denied employment opportunities because of their health history.

Third, the Act would encourage employers who receive federal funds to employ all qualified workers regardless of status. This furthers the original purpose of the Rehabilitation Act: to increase and expand employment opportunities for handicapped individuals.<sup>76</sup> Congress recognized that employment barriers furthered the segregation of handicapped individuals within society.<sup>77</sup> Unless the Rehabilitation Act clearly applies to individuals with a cancer history, many of these barriers will continue to deny cancer survivors equal employment opportunities.

Fourth, employers would be required to make "reasonable accommodations" to employees with a cancer history in accordance with present Health and Human Services regulations that govern the Act. The accommodation needs of workers with a cancer history vary considerably. Adjustment of working hours is the most common need of people with a cancer history. Employees who are undergoing treatment for cancer may need a leave of absence or reduced work hours. Others who

<sup>75</sup> Webster's Third New International Dictionary 1027 (1981).

<sup>76</sup> S. Rep. No. 318, 93d Cong., 1st Sess. 26, reprinted in 1973 U.S. Code Cong. & Administrative News 2076, 2092. One commentator has noted that Congress recognized that restrictions on the employability of the handicapped are a "national problem responsible for economic waste and social dislocation." Note, *Private Right of Action for Handicapped Persons Under Section 503 of the Rehabilitation Act*, 13 Val. U. L. Rev. 453, 453 (1979).

<sup>77</sup> 29 U.S.C. section 701.

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are not disabled by their treatments may need flexible hours to accommodate appointments for examinations, laboratory work, chemotherapy or radiation therapy. Additionally sick days may be necessary for those who suffer ill effects from radiation or chemotherapy. Workers who have completed treatment often need time for follow-up examinations.

The other major form of accommodation for people with a cancer history consists of physical accommodation. Cancer leaves some people with physical disabilities or limitations which require accommodations similar to those provided for people with traditional physical handicaps. Most employers are already familiar with these needs, such as wheelchair ramps and other physical modifications. For example, an office worker who has become confined to a wheelchair may need to be accommodated with wheelchair access and a larger desk opening. An employee weakened by surgery or treatments may need assistance in lifting heavy objects.

Modification of job requirements which does not result in an undue hardship on the employer is a third type of accommodation. For example, a postal worker who has a melanoma may need to be transferred from an outdoor to an indoor position to avoid overexposure to the sun. A high school teacher/coach may continue to teach in the classroom but take a leave of absence from coaching duties if his or her physical abilities are limited. Of course, employers are not required to make modifications which substantially reduce job standards, seriously disrupt the workplace or jeopardize the safety of others.

Flexibility in insurance coverage is another important accommodation. There are many alternatives to completely barring the cancer patient from a company policy. For example, the employee could be given complete insurance coverage excluding only the type of cancer he or she had. High risk pools could be created for workers with a cancer history. Additionally, an employee may accept limited coverage for himself or herself as long as coverage for spouse and children is not effected.

Fifth, the Act would discourage payment of costly disability and unemployment benefits to able-bodied people by increasing employment opportunities for those who can and want to work. Cancer related illness costs society billions of dollars each year in lost productivity and wages. A significant percentage of this cost would be eliminated by providing coverage under the Rehabilitation Act.

Sixth, an available legal remedy for cancer based discrimination would encourage honesty in the workplace. People with a cancer history are forced to choose the lesser of two evils when completing an employment application. They can tell the truth and risk being rejected solely because of their medical history or they can omit their cancer history and risk being fired and losing benefits if the truth is later revealed. Citizens who have never lied in their lives suddenly find themselves seriously considering being dishonest to save their jobs. A counselor of the Texas Employment Commission warns people with cancer histories:

"I'd advise them to say as little as possible about their health history when being interviewed. Don't lie, I'm not saying that. But don't tell everything you know, either. Just leave the section about health—if there is one—blank. If they like the rest of your qualifications it'll be a whole lot easier to explain the health thing, if they ask you. If an application says something like, 'Have you had a malignancy of any kind within the last five years?' and you put down, 'Yes,' you've cut your own throat before you even start."<sup>78</sup>

This Hobson's choice will arise less frequently if both employers and employees know that the federal government prohibits discrimination based on health history instead of individual qualifications.

#### V. CONCLUSION

Presently, the Rehabilitation Act of 1973 provides relief only to a small percentage of people with a cancer history. The Act's definition of "handicap" does not describe all people with a cancer history because many people (both the ill and recovered cancer patient) are not substantially limited in their major life activities or are not disabled to the point of requiring multiple services over an extended period of time. As a result, few cancer survivors have brought a claim under the Act and there are no reported court decisions on whether the Act applies to cancer history. The minimal change proposed by this testimony would clearly establish the right of cancer survivors to bring a claim under the Act.

At least one million Americans are denied job opportunities solely because of misconceptions about their cancer history. Employers routinely deny jobs to many qualified individuals because of unfounded fears, such as high absenteeism and im-

<sup>78</sup> Dotson, *Only a Ghost of a Chance*, *Texas Business*, August.

minent death. Healthy young men and women are denied the privilege of serving their country at a time when the military is searching for qualified volunteers.

The proposed language would mandate that all qualified workers be treated equitably, regardless of their health status. The more than five million people alive today with a cancer history are one of America's most wasted resources. The proposed clarification of the scope of the Rehabilitation Act is a significant step toward maximizing the potential of all people with a history of cancer by supporting their full integration into the American economy.

APPENDIX A.—STATE STATUTES GOVERNING EMPLOYMENT DISCRIMINATION BASED ON HANDICAP

State	Employers Covered	Protected Class
Alabama: Ala. Code, section 21-7-8 (1984).	Public only.....	"Blind, visually handicapped and otherwise physically disabled."
Alaska: Alaska Stat., section 18.80.220 (1918).	Public and private.....	"Physical handicap."
Arizona: no statute.....		
Arkansas: Ark. Stat. Ann., section 82-2901 (Supp. 1985).	Public only.....	"Visually handicapped, hearing impaired and other physically handicapped persons."
California: Cal. Gov't Code, section 12920 (West 1980).	Public and private.....	"Physical handicap, medical condition."
Colorado: Col. Rev. Stat., section 24-34-402 (1982).	.....do.....	"Handicap."
Connecticut: Conn. Gen. Stat., sections 46a-60 (1983).	.....do.....	"Mental retardation or physical disability, including, but not limited to, blindness."
Delaware: no statute.....		
District of Columbia: D.C. Code Ann., section 6-1705 (1981).	Public and private.....	"The blind and the otherwise physically disabled."
Florida: Fla. Stat., section 760.10 (1983).	.....do.....	"Handicap."
Georgia: Ga. Code Ann., section 34-6A-4 (1982).	.....do.....	"Handicapped individual."
Hawaii: Hawaii Rev. Stat., section 378-2 (Supp. 1984).	.....do.....	"Physical handicap."
Idaho: Idaho Code, section 56-707 (Supp. 1985).	Public only.....	"The blind, the visually handicapped, the hearing impaired and the otherwise disabled."
Illinois: Ill. Rev. Stat., ch. 68, section 1-102 (1984).	Public and private.....	"Physical or mental handicap."
Indiana: Ind. Code, section 22-9-1-2 (1976).	.....do.....	"Handicap."
Iowa: Iowa Code, section 601A.6 (1984).	.....do.....	"Disability."
Kansas: Kans. Stat. Ann., section 39-1105 (1981).	.....do.....	"Physical handicap."
Kentucky: Ky. Rev. Stat., section 207-150 (1982).	.....do.....	"Handicapped individual."
Louisiana: La. Rev. Stat. Ann., section 46:2254 (West 1982).	.....do.....	"Handicap."
Maine: Me. Rev. Stat. Ann., tit. 5, section 4572 (1979).	.....do.....	"Physical or mental handicap."
Maryland: Md. Ann Code, art. 49B section 16 (1979).	.....do.....	Do.
Massachusetts: Mass. Ann. Laws, ch. 151B, section 4(16) (Law Co-op. Supp. 1985).	.....do.....	"Handicap."
Michigan: Mich. Comp. Laws, section 37.1202 (1981).	.....do.....	Do.
Minnesota: Minn. Stat., section 363.03 (West Supp. 1985).	.....do.....	"Disability."
Mississippi: Miss. Code Ann., section 25-9-149 (Supp. 1984).	Public only.....	"Handicap."

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APPENDIX A.—STATE STATUTES GOVERNING EMPLOYMENT DISCRIMINATION BASED ON HANDICAP—  
Continued

State	Employers Covered	Protected Class
Missouri: Mo. Ann. Stat., section 296.020 (Vernon Supp. 1985).	Public and private.....	"Handicap."
Montana: Mont. Code Ann., section 49-2-303 (1983).	.....do.....	"Physical or mental handicap."
Nebraska: Neb. Rev. Stat., section 48-1104 (1984).	.....do.....	"Disability."
Nevada: Nev. Rev. Stat., section 613.330 (1981).	.....do.....	"Physical, aural or visual handicap."
New Hampshire: N.H. Rev. Stat. Ann., section 354-A:8 (1984).	.....do.....	"Physical or mental handicap."
New Jersey: N.J. Stat. Ann., section 10:5-4.1 (WEST Supp. 1985).	.....do.....	"Such person is or has been at any time handicapped."
New Mexico: N.M. Stat. Ann., section 28-1-7 (1983).	.....do.....	"Physical or mental handicap."
New York: N.Y. Exec. Law, section 296 (McKinney Supp. 1984).	.....do.....	"Disability."
North Carolina: N.C. Gen. Stat., section 143-422.2 (1983).	Public and private employers "which regularly employ 15 or more employees".	"Handicap."
North Dakota: no statute.....	.....do.....	"Handicap."
Ohio: Ohio Rev. Code Ann., section 4112.02 (Baldwin 1983).	Public and private.....	"Handicap."
Oklahoma: Okla. Stat. Ann., tit. 25, section 1302 (West Supp. 1984).	.....do.....	Do.
Oregon: Or. Rev. Stat., section 659.425 (1981).	.....do.....	"Physical or mental impairment."
Pennsylvania: 43 Pa. Cons. Stat. Ann., section 953 (Purdon Supp. 1985).	.....do.....	"Handicap or disability."
Rhode Island: R.I. Gen. Laws, section 28-5-7 (Supp. 1984).	.....do.....	"Handicap."
South Carolina: S.C. Code Ann., section 43-33-60 (Law Co-op. 1985).	Public only.....	"The blind, the visually handicapped, and the otherwise physically disabled."
South Dakota: no statute.....	.....do.....	"Physical, mental or visual handicap."
Tennessee: Tenn. Code Ann., section 8-50-103 (1980).	Public only.....	"Physical, mental or visual handicap."
Texas: Tex. Stat. Ann., art. 5221k, section 5.01 (Vernon Supp. 1985).	Public and private.....	"Handicap."
Utah: Utah Code Ann., section 34-35-6 (Supp. 1985).	.....do.....	Do.
Vermont: Vt. Stat. Ann., tit. 21, section 495 (Supp. 1984).	.....do.....	"Physical or mental condition" and "qualified handicapped individual."
Virginia: Va. Code, section 51.01-41 (Supp. 1985).	.....do.....	"Otherwise qualified person with a disability" and "physical and mental impairments."
Washington: Wash. Rev. Code, section 49.60.180 (1983).	.....do.....	"Sensory, mental or physical handicap."
West Virginia: W. Va. Code, section 5-11-9 (Supp. 1985).	.....do.....	"Blind or handicapped."
Wisconsin: Wis. Stat. Ann., section 111.321 (West Supp. 1985).	.....do.....	"Handicap."
Wyoming: no statute.....	.....do.....	

PREPARED STATEMENT OF HON. BIRCH BAYH ON BEHALF OF THE AMERICAN CANCER SOCIETY

Mr. Chairman and Members of the Subcommittee, my statement is submitted on behalf of the American Cancer Society and the more than five million Americans who have a history of cancer. We want to thank you for providing us with this opportunity to address an issue with which we are all most deeply concerned—the discrimination against persons with a cancer history. We feel this is a most appropri-



ate occasion for this Subcommittee to examine this issue as it takes up the reauthorization of the Rehabilitation Act of 1973, an Act created by Congress to put an end to the practice of unjust discrimination of handicapped persons in the workplace.

We are all well aware of the prevalence of the disease of cancer in our society today. Approximately 73 million Americans now living will eventually have cancer; about 30 percent of the total population, according to present rates. Over the years, cancer will strike approximately three out of four families. We can expect in the coming year that about 930,000 Americans will be diagnosed as having cancer.

Moreover, there are over 5 million Americans alive today who have a history of cancer, 3 million of whom have a history of 5 or more years since diagnosis. Most of these 3 million can be considered cured in that they have no evidence of the disease and have the same life expectancy as a person who has never had cancer. Of the 930,000 Americans who will be diagnosed in 1986 as having cancer, approximately half will be cured. Each year the percentage of those who are cured increases. As a result, we can expect to see the ranks of the survivors of this disease to continue to swell in the coming years.

What is most unfortunate, and what few of us know little or anything about, is that many in the swelling ranks of these courageous survivors find that beating the disease is often only the first step in returning to a normal life. Many of these individuals, upon returning to their previous jobs, or in seeking a new job, face different forms of employment discrimination which include: job denial, wage restriction, exclusion from health insurance and other benefits, dismissal, demotions and denial of promotions, undesirable transfers, hostility, and the requirement that they submit to medical exams completely unrelated to job performance.

Persons with a cancer history find that they are being mistreated by their employers, in both the public and private sectors, solely because of their medical history, without consideration of their ability to perform the job. Studies and thousands of case histories have time and time again shown that persons with a medical history of cancer are as productive on the job as persons without such a history. Unfortunately, the blame for such discrimination may be found in erroneous stereotypes surrounding the disease as well as in poor and unsound business practices. Such discrimination not only costs our society millions of dollars annually, but also deprives vital income to the courageous cancer survivors who find themselves already overburdened.

The American Cancer Society estimates that approximately 25 percent of all Americans with a cancer history are victims of cancer-related employment discrimination. In one study conducted by the California Division of the American Cancer Society, it was found that most corporations and government agencies in the State of California discriminate against job applicants with a past history of cancer for a period of three to ten years after treatment. A recent study conducted by Stanford University of 314 Hodgkins disease survivors reported that 43 percent of these survivors suffered employment and insurance discrimination because of their history of cancer. In short, this discrimination is as widespread as it is unjust and costly for its victims and our society.

It is most appropriate for this Subcommittee to look into this issue as it considers the reauthorization of the Rehabilitation Act of 1973 (the "Rehabilitation Act"). When Congress enacted this law, it did so in the recognition that many valuable, manual and intellectual skills of handicapped persons were being unjustifiably wasted by the discrimination of these persons in the workplace. Given the prevalence of cancer-related discrimination now being identified in the workplace, it is our concern that the Rehabilitation Act may not afford adequate protection to all of the persons who find themselves victims of job discrimination based on their cancer history. The problem lies in the fact that the scope of the Rehabilitation Act's coverage is limited to those persons who fall within the Act's definition of "handicapped individuals" and those whose employers receive federal financial assistance. Unfortunately, the Act's definition of "handicapped individuals" does not expressly include all persons with a cancer history and this ambiguity may leave some persons who have a cancer history and who find themselves a victim of employment discrimination outside of the scope of the Act's protection. Furthermore, the problem of cancer-related job discrimination is not limited to the public or public-related sector. His discrimination is just as prevalent in the private sector as it is in the public sector.

In closing, it is our sincere hope that this Subcommittee and the Congress will take whatever steps it feels are most appropriate in order to assure all victims of cancer-related employment discrimination that they will be protected against such practices by the full authority of the Federal Government. We again thank you for

providing us with this opportunity to bring this most important issue to the Subcommittee's and the Congress' attention.

#### PREPARED STATEMENT OF THE NAVAJO NATION

##### INTRODUCTION

These comments are presented to be included in the record of the hearing on H.R. 4021 conducted by the Subcommittee on Select Education of the House Education and Labor Committee on January 29, 1985. The comments particularly concern the sections of that bill dealing with the funding of vocational rehabilitation programs operated by Indian tribes and with other provisions of the bill which address the vocational rehabilitation needs of American Indians.

The Navajo Nation is particularly interested in this bill because of its impact on the Navajo Vocational Rehabilitation Program. In addition we are concerned with improving the quality and availability of vocational rehabilitation services for American Indians throughout the country.

##### NEEDS OF THE HANDICAPPED AMERICAN INDIAN POPULATION

The situation of handicapped American Indians throughout the country reflects a number of differences from the rest of the handicapped population. A report prepared by the Native American Research and Training Center at Northern Arizona University indicates that the overall incidence of disabling conditions is one and a half times higher among American Indians than among the rest of the American population. Despite this higher incidence of handicapping conditions, disabled American Indians are only 60% as likely as disabled members of the general population to be successfully rehabilitated. American Indians are less likely to apply for rehabilitation services. If they apply, they are less likely to be accepted. If accepted into the caseload, they are less likely to be rehabilitated.

In written testimony to this Committee last summer, the Navajo Nation described in greater detail some of the unique characteristics of the American Indian handicapped population and the deficiencies with existing rehabilitation services being provided to this group. Excerpts from that testimony are appended to this testimony as Appendix A. The key fact is that here is a population with a greater than average need for rehabilitation services which receives, on the whole, less than the average rehabilitation services.

Factors which contribute to the lower rehabilitation rate for American Indians include the geographical isolation of many American Indian vocational rehabilitation clients. VR services tend to be clustered in the more settled, urban areas. Indian reservations are usually found in isolated, rural areas. There is often a gulf of language and culture between the American Indian VR client and the rehabilitation service providers in the dominant society. Based on the experience of the Navajo Vocational Rehabilitation Program, we believe that these barriers of geography, culture and language can best be overcome by providing vocational rehabilitation services through the tribe itself.

##### EXPERIENCE OF THE NAVAJO VOCATIONAL REHABILITATION PROGRAM

The Navajo Vocational Rehabilitation Program has been providing a tribally-based alternative to conventional rehabilitation services to the Navajo handicapped population since 1975. It is the oldest and largest of the Indian vocational rehabilitation programs, serving over 450 clients. Utilizing a professional Navajo Vocational Rehabilitation Program has been able to be effective in serving its Native American clients in many areas where state VR programs have been found lacking.

The Navajo Vocational Rehabilitation Program has counselors located in each of the five agencies of the reservation. These Navajo counselors are bilingual, serving both English speaking and Navajo speaking clients. NVRP program offices are located proximate to Tribal, BIA, and Indian Health Service agency service centers. This proximity facilitates such processes as receiving referrals, receiving supportive health services, referring to job or training opportunities and similar supportive processes. The program is able to interface local secondary schools, potential local employers and the tribal government. In addition, the program has effectively integrated Native healing services into the rehabilitation process.

One recurrent problem which the Navajo Vocational Rehabilitation Program (NVRP) has faced is financial uncertainty. The program provides basic VR service to the Navajo handicapped population. It operates like a state VR program. The

states of Arizona, New Mexico and Utah have not been able to effectively serve this population and look to the Navajo program to be the primary service provider in this area. Nonetheless, in the years since 1981 when Congress first appropriated funds under Section 130 for the program, NVRP has continued to be treated as a discretionary program. This has not only meant that NVRP has had to apply each year for its funds with no real assurance that the funding application would be accepted. It has also meant that the U.S. Department of Education has felt no obligation to seek funding for Section 130 of the Rehabilitation Act at a program maintenance level or to give priority to NVRP, as an established program, in the allocation of available funds.

In each budget cycle since 1981, the Navajo Nation has had to fight for NVRP's funding. In FY 1985, when a number of other tribes submitted applications for Section 130 funding, we sought successfully to have the funds available for Section 130 increased from \$715,000 to \$1,430,000. This increase was necessary if any other program was to be funded without gutting the Navajo program, since our program's budget was \$715,000. Despite the fact that Congress did authorize the supplemental appropriation for Indian vocational rehabilitation and that other tribes had applied for Section 130 funding, the Department of Education, in its FY 1986 budget sought to return the appropriation level to \$715,000. Again it was necessary for the Navajo Nation to advocate for the basic appropriation under Section 130. Once again, these efforts were successful, as Congress recognized the real need for the program, not only in the Navajo Nation but on other reservations. Yet, in its FY 1987 budget, the Department of Education is again apparently seeking to return the Section 130 appropriation to \$715,000. There is nothing in the rehabilitation law (nor, unfortunately, in H.R. 4021) to require a minimum level of funding for Section 130.

#### OVERVIEW OF H.R. 4021

H.R. 4021 addresses many of the concerns which the Navajo Nation has had regarding the provision of vocational rehabilitation services to American Indians. It assures that Indian tribes and tribal organizations will be included in eligibility for many programs under the Rehabilitation Act. Indian tribes and tribal organizations are specifically included in the definition of public and private agency. Specific requirements are placed upon the states in regard to consulting with Indian tribes and tribal organizations and in regard to serving the Indian population. For the first time, the Bureau of Indian Affairs and the Indian Health Service are specifically included in the federal agencies making policy in the area of rehabilitation services. The bill mandates a long needed study of the needs of American Indian populations for vocational rehabilitation services and the resources available to meet these needs.

The bill seeks to give some stability to existing Indian VR programs by authorizing three year grants and by requiring the Secretary of Education to give priority consideration in making grants under Section 130 to applications for the continuation of programs which have been funded in the past. These provisions are improvements over the existing law. They could be sufficient if the Department of Education could be counted upon to present to Congress a good faith budget for section 130, reflecting the needs of existing programs and the demand for new programs. In fact, however, for the past three years at least, the Department has presented Congress with an unrealistic budget request which not only makes no provision for the additional requests for programs now coming from other tribes, but seeks to reduce funding back to a level below the current funding level of the programs already in existence.

We feel that in its reauthorization of the Rehabilitation Act, Congress should recognize the problems created DOE's repeated failure to support Indian vocational rehabilitation and establish some minimum level or percentage of funding which must be maintained for Section 130 programs. At the least, this level should be established at the full FY 1985 level of \$1.43 million. We also believe that this base amount should receive the same protection from automatic sequestration under deficit reduction procedures which is accorded to basic state VR funding. We do not believe that it is either equitable or reasonable to demand the greatest cuts from the most underserved handicapped population.

With this said, the Navajo Nation does express its support for this legislation. It is encouraging that Congress has come to recognize that there is a great need for rehabilitation services for the American Indian handicapped population. The comments and recommendations contained in this testimony are offered to assist Congress in making the most appropriate provision to serve the needs of handicapped American

Indians and to support the positive momentum toward better VR services expressed in H.R. 4021.

#### SECTION-BY-SECTION COMMENTARY

This part of our testimony will review H.R. 4021 section by section, commenting on particular provisions, recommending where appropriate language for the bill and report language. These comments are offered with the intention of assisting with the development of this legislative proposal. As stated above, the Navajo Nation recognizes and appreciates the sensitivity of this legislation to the needs of the handicapped American Indian population as it stands.

#### *Sections 1 through 6*

The main area for comment in these sections is the definitions. The inclusion of Indian tribal organizations in the definition of public and non-profit organization is an important improvement in the existing law. While arguably tribal organizations can already be included in this definition, in practice they have often been excluded from consideration for grants under programs to fund "public or non-profit agencies or organizations." Specific reference to Indian tribal organizations will bring to the attention of those administering various grant programs the necessity of considering applications from Indian tribes and tribal organizations.

As a matter of clarification, we recommend that the definition of Indian be standardized with definitions applying in other federal laws dealing with Indians. The proposed definition would exclude American Indians who are recognized by the BIA and IHS as Indian but are not actually enrolled members of a tribe. A possible alternative would be to include enrolled members of tribes and persons who are at least one fourth degree Indian blood.

#### *Section 101*

This section contains the authorization for appropriations for Parts B, C and D of the Rehabilitation Act. The section includes authorization of appropriations for Indian vocational rehabilitation programs under Part D for fiscal years 1987 through 1991. Unfortunately, the section leaves intact the provisions of Section 100(b)(3) which set a ceiling on appropriations for Part D, but no floor. As is discussed above, the existing provision is not working. The Department of Education has consistently refused to seek appropriations at any reasonable fraction of the level authorized by Section 100(b)(3). In recent years, the Department has not even sought funding levels that would allow maintenance of effort at existing levels. Every increase in the appropriation for part D since at least 1983 has been authorized by Congress in spite of the opposition of the Department. In addition, it should be pointed out that the increases which Congress has authorized over the Department's resistance have done no more than to compensate in part for the impact of inflation on the Navajo Vocational Rehabilitation Program and open Section 130 up to a few more tribes without gutting the existing Navajo program.

Under these circumstances, we would strike the period at the end of subsection 100(b)(3) and insert language such as the following: "nor less than the full amount appropriated for Part D in Fiscal Year 1985." Such an amendment would at least assure that the current base for Part D could not be eroded by the Department.

In addition we would recommend report language such as the following:

"It is intended in section 100(b)(3) that the Secretary shall submit to Congress a request for funding for Part D which will permit existing tribally operated vocational rehabilitation programs to at least maintain their efforts to the same degree that State vocational rehabilitation programs are able to maintain effort under the state funding formula and which will permit the addition of some additional tribally operated vocational rehabilitation programs to the list of existing programs."

#### *Section 102*

This section includes a specific requirement that states "as appropriate" actively consult with Indian tribal organizations and Alaska Native organizations. This is an important addition to the law. We would recommend some report language to clarify the meaning of the phrase "as appropriate". Possible language could state:

"States are expected to consult with Indian tribal organizations existing within the state. The term 'as appropriate' is used to condition this requirement in recognition of the fact that not all states have Indian tribes within their borders. Consultation should include at the least the governing body of any Indian tribe within the borders of the State, intertribal organizations, and tribal organizations particularly concerned with the problems of the handicapped."

*Sections 103 through 108*

No particular comment is made on these sections except to note with appreciation the inclusion of Indian tribal organizations in Section 104 of the Act which allows funds donated for construction of rehabilitation facilities to be counted toward the non-Federal share.

*Section 109*

This section of the bill deals specifically with Part D of the Act. The amendments proposed in the bill permit grants to consortia of tribal governing bodies to operate vocational rehabilitation programs, permits a tribal governing body to include services it has traditionally received in demonstrating the comparability of its program, specifically authorizes three year grants under Part D, and gives funding priority to the continuation of ongoing VR programs. These amendments contain many safeguards which the Navajo Nation has sought for its VR program and for other tribal VR programs. We would, however, recommend some clarifications, either through report language or in the bill itself to strengthen the section.

Report language should be drafted to clarify that in order for the Commissioner to make a grant to a consortium of tribal governing bodies, each tribal governing body to be included in the service proposal must have authorized the agreement. This is the procedure used in the Self-Determination Act. It assures that an Indian could not become an involuntary part of an inter-tribal consortium and be deprived of its right to make a separate application for funds. for example:

"Grants may be made to a consortium of tribal governing only when each tribal governing body covered by the grant has authorized the consortium to seek the grant on its behalf."

Regarding the amendment to Section 130(b)(1)(B), it appears to assure that in demonstrating that it offers services comparable to those offered by state VR programs, a tribe may include the services it has traditionally received from the state program. This could be important particularly for smaller tribes which cannot be expected to establish a comprehensive VR program on grant resources and tribal matching funds alone. However, the language is somewhat unclear and might, without appropriate report language, be susceptible to another interpretation. Report language could state:

"In demonstrating that the rehabilitation services it provides or will provide shall be, to the maximum extent feasible, comparable to rehabilitation services provided to other handicapped individuals in the State, an Indian tribe may include those services which it and its members will continue to receive from the state program. Tribal governing bodies applying for grants under Part D are required to consult with the designated state unit of the state where the tribe is located. As a part of this consultation process, the tribal governing body and the state should clarify areas of primary responsibility for each program, referral procedures to be employed, and other matters necessary to assure that handicapped tribal members will have equal access to services comparable to those received by other handicapped residents of the state without occasioning duplication of services."

Report language may also be required to emphasize to the Department of Education the intent of Congress that existing tribally operated vocational rehabilitation programs be funded at levels which permit them to maintain program efforts, and that the integrity of existing programs should not be sacrificed to the creation of new programs. Possible report language could state:

"It is the intent of this bill to provide financial stability for existing tribally operated vocational rehabilitation programs. The Secretary is directed to give first priority to the maintenance of funding and service levels in existing programs. The integrity of existing tribally operated programs should not be sacrificed to the creation of new programs. The Secretary shall identify in budget justification documents submitted to Congress and in requests for proposal published in the Federal Register, the allocation of funds anticipated for the continuation of existing programs and the funds to be available for new applications and program expansions."

It should be noted, however, that for FY 1987, the Secretary is evidently seeking a funding level which would not even allow the maintenance of existing programs. For this reason, we continue to urge language placing a floor under funding for Part D of at least the FY 1985 appropriation, as supplemented. In addition, to assure program continuity, we recommend that language be inserted in Section 130 of the Act stating: "Moneys appropriated under Section 100(b)(3) to fund programs under this Part shall be subject to sequestration under deficit control procedures only to the extent that moneys for state programs funded under Section 100(b)(1) are subject to sequestration." Report language could be included with this bill language to clarify

that existing tribally-operated VR programs should be treated like state VR programs for purposes of sequestration under deficit control procedures.

We support the deletion of subsection (d) of Section 130, the section calling for a reduction in state VR funding proportional to the population of an Indian tribe operating a tribal VR program. This provision has never been implemented. Even if implemented, as interpreted, it would only decrease the state funds without enhancing the tribe's funds. The existing provision could be interpreted to permit a state to deny services to a member of a tribe which operates a tribal program, a particularly serious consequence for smaller tribes which cannot obtain the resources to provide the full range of VR services. Our one concern is that the Department may interpret the deletion of this section as justifying the treatment of tribally operated VR programs as supplemental, discretionary programs. We would urge inclusion of report language clarifying that deletion of this section will not justify the Secretary in treating grants under Part D as supplementary or in giving lower priority to Part D programs. As stated above, however, this concern can best be met by language establishing a floor for Part D funding and report language clearly expressing the intent of Congress to encourage sound tribally operated VR programs.

#### *Section 110*

This section adds to the requirement of evaluation of tribally operated VR programs a specific requirement to evaluate the degree of cooperation between the tribal VR program and other VR programs. This is a reasonable provision, particularly as more tribal programs are established, including programs which must rely upon state programs for some of their services. It might be appropriate to delete the words "vocational rehabilitation" from the amended language contained in lines 5 through 8 of page 11 of the bill. With this change, the evaluation could also assess the degree of cooperation between the tribally operated VR program and other support programs such as advocacy programs, research and training programs, independent living programs and other programs funded under the act. Report language should stress that the purpose of the evaluation is not only to determine if the tribally operated VR program is cooperating with other programs but if the other programs are cooperating with the tribal program as well.

#### *Section 111*

This section authorizes a comprehensive study of the special problems and needs of handicapped Indians. Such a study is definitely needed. Requests for appropriation which Congress receives from the Department of Education have not reflected the true extent of the need for VR services for American Indians. Without a comprehensive study, it is difficult to develop realistic alternatives to these official but inappropriate budget requests.

The Navajo Nation has been in communication with the Native American Research and Training Centers funded under the Rehabilitation Act and located at Arizona State University and Northern Arizona University. Staff of these R & T centers have recommended that the study authorized by Congress include identification of the need for any follow-up tribally specific studies. The staff feels that such studies will be needed to identify appropriate rehabilitation strategies for dealing with the unique social/cultural/economic situations of the various tribal groups. The R & T centers have also recommended that the section calling for a study of Indian rehabilitation needs specifically reference the Native American Research and Training Centers as appropriate entities to conduct such research. They have recommended a 24 month study, and a specific authorization of funds to conduct the study.

#### *Title II*

These comments will deal with this title as a whole. The Navajo Nation is very pleased with the amendments proposed in Title II of the bill. It is heartening to see Congressional recognition of the fact that the delivery of rehabilitation services to the handicapped in rural areas and on Indian reservations presents unique challenges and problems. Urban solutions often cannot be successfully transplanted to rural and reservation settings. Rural handicapped people are often neither willing nor able to move to urban areas just to take advantage of the rehabilitation service located there. The specific reference to research on rural rehabilitation needs and on the delivery of rehabilitation services to Indians residing on and off reservations are important additions to the Rehabilitation Act. Given the lower life expectancy of American Indians, we also believe that it is appropriate to include American Indians age 55 and over in research on the elderly handicapped. Specific provision for involvement of tribes and tribal organizations in research activities is an important addition to the Act.

Inclusion of the Assistant Secretary of Interior for Indian Affairs and the Director of the Indian Health Service on the Interagency Committee on Handicapped Research is an important step, as is the requirements for involvement of the BIA and IHS in the development and dissemination of research conducted by or through the National Institute of Handicapped Research. Coordination at this level should go a long way to assure that research priorities in the area of handicapped research include the conditions and needs of American Indians.

### *Title III*

The Navajo Nation is particularly encouraged by the inclusion in this title of specific provision for demonstration projects to operate programs to meet the needs of isolated populations, particularly American Indians. This language should result in some development at both the tribal and state program level of new approaches for getting services out to the reservation populations where they live. Inclusion of this section under demonstration projects should also help clarify the fact that Section 130 is to be utilized to fund the development and operation of long-term tribally operated VR programs. Programs funded under Section 130 should not be treated as never-ending demonstration projects. Possibly report language regarding this section could emphasize the distinction. For example:

"The bill provides in section 306 for demonstration projects to operate programs to meet special needs of isolated handicapped populations such as American Indians residing on or near Indian reservations. Inclusion of this language is intended to encourage innovative and to clearly distinguish the long-term programs funded under Section 130 from short term demonstration projects funded under this and other sections of the Act."

### *Titles IV through VII*

Little comment is needed on these titles other than to applaud the specific inclusion of Indian tribes and Indians in the language of Title VI of the Act (V of the bill) regarding employment assistance programs for the handicapped. Employment programs for the handicapped are extremely necessary for on reservation populations. The high unemployment rate on Indian reservations (over 30% according to official figures for the Navajo reservation with an equal percentage estimated to be unemployed but outside the statistics) makes it particularly difficult for handicapped persons to obtain employment through the usual public and private channels.

We would recommend report language in connection with Title VI of the act (regarding Independent Living Services) to direct states to make funds available to tribal organizations to establish independent living centers on reservation. The Navajo Vocational Rehabilitation Program has experienced real difficulty in obtaining resources to develop independent living arrangements for its clients on reservation. Housing on the reservation is always at a premium, with few private housing alternatives and little available for individuals with special needs. The need for independent living alternatives has been recognized as a major support need by NVRP.

The Navajo Nation had sought bill language which would specifically authorize direct grants to Indian tribes to develop independent living services. That is still our first preference.

In absence of such a specific provision in the law, we recommend report language such as the following:

"In utilizing funds authorized under Section 601 of this bill, states are directed to give particular attention to the need for independent living facilities and services on and near Indian reservations in the state and to make grants, where appropriate, to tribal governing bodies and tribal organizations for the development of independent living resources."

### CONCLUSION

The analysis contained in these comments is offered with appreciation for the work already done in developing this legislation and with the hope that these suggestions will be helpful to the Committee and its staff in refining the legislation prior to its passage. The Navajo Nation remains available to assist in any way it can in supporting this legislation through the provision of data that is available to us, commentary on proposed legislative alternatives, and otherwise.

## APPENDIX A—EXCERPT FROM THE TESTIMONY OF THE NAVAJO NATION

## HANDICAPPED NATIVE AMERICANS AND REHABILITATION

The situation of handicapped Native Americans throughout the country reflects a number of differences from the rest of the handicapped 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. Their rate of acceptance by rehabilitation services is lower, as is the rate of rehabilitation for those accepted for services. These characteristics will be discussed below and in supplemental information which is presented to this Committee as background information.<sup>1</sup>

A report prepared by the Native American Research and Training Center at Northern Arizona University indicates that the overall incidence of disabling conditions is 1½ 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 rehabilitated. Native Americans are less likely to apply for rehabilitation services. 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 accepted for vocational rehabilitation caseloads, Native Americans have reported higher incidents of disability than the general population in regard to accidental injury of the eye (1.28 times the general population), injuries to the spinal cord (1.13), infections of the ear (1.03), arthritis (1.17), accidental 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). Native American rehabilitation clients are more likely than the handicapped general population to have a secondary disability. This disability is most likely to be classified as alcoholism.

In 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 the cases of accidental eye injury accepted for rehabilitation services 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 rehabilitation 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 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 VR client and the concentration of VR services in the more settled, urban areas. It also reflects the gulf of language and culture between the disabled Native American and the rehabilitation service providers in the dominant society.

What these figures and reports demonstrate is that the Native American population has a greater need for 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 *American Rehabilitation* (Jan/Feb/Mar 1985), concluded:

<sup>1</sup>The Navajo Nation expresses its appreciation to the Native American Research and Training Center at Northern Arizona University for making its information on the incidence of handicapping conditions and rehabilitation of Native American handicapped available to the Navajo Nation for this document. Conclusions drawn from that data are those of the Navajo Nation.



"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 and Disabling Conditions in Native American Populations," by Jamil. L. Tobbeh)

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 likely that they will or even can come to VR in highly significant numbers."

PREPARED STATEMENT OF THE NATIONAL COUNCIL OF INDEPENDENT LIVING

TITLE VII PART B

We respectfully request that Title VII Part B that is presently funding Centers for Independent Living (CIL) be continued for the duration of the Rehabilitation Act amendments of 1986. It is our sincere hope that Title VII Part B will eventually become a core funded program that will maintain the effective network of community based CIL's around the country. If this funding were to be interrupted, it would most likely cause the demise of the majority of Title VII B funded centers in existence today. Finally, the membership of NCIL feels that Part B funds that presently go through vocational rehabilitation agencies in each state should be allowed to come directly to community based CIL's. In essence, we are asking that Part B funded Centers for Independent Living be allowed to exercise choice with regard to whether or not they desire to have Title VII B money come through the state agency or directly into their programs.

TITLE VII PART A

Although we realize that Parts B and A are not inextricably linked, we are compelled to comment on Part A as well. NCIL feels that Part A money should only go to CIL's that meet the National Council on the Handicapped standards. Further, we feel that a minimum of 50% of Part A allocations should go to CIL's that meet NCH standards.

NCIL is committed to working with Chairman Williams in the refinement of the entire Title VII program which is only a small part of the Rehabilitation Act. We also wish to stress that Parts A and B may be treated separately with regard to policy making decisions. That is to say that the proposed changes herein are not necessarily bound together as one absolute package.

