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ABSTRACT

Presented is the report of the comprehensive service needs study for the severely handicapped as authorized by section 130 of the Rehabilitation Act of 1973. Chapters focus on the following aspects of the study: definitions; the vocational rehabilitation (VR) system; estimates of the severely disabled population not in institutions; the most severely handicapped in institutions; VR and the severely disabled; analysis of individuals rejected by VR; analysis of individuals most severely handicapped who received services at comprehensive medical rehabilitation centers; analysis of dependency; architectural barriers; georgaphic mobility of the handicapped; transportation; employment and labor force participation; social interaction; communication barriers; the mentally ill; the mentally retarded; the blind and visually impaired; the deaf; spinal cord injury, autism, and Hansen's disease; survey of providers of rehabilitation; rehabilitation facilities and workshops; technology; a benefit/cost analysis of service to severely handicapped accepted for service by VR; other programs assisting the handicapped; disincentives in income transfers; programmatic options for providing services; financial options; summary of major findings; research and demonstrations; and policy interpretations. (CL)

REPORT OF THE COMPREHENSIVE SERVICE NEEDS STUDY

Authorized by: SECTION 130,
REHABILITATION ACT OF 1973

CONTRACT # HEW 100-74-0309

June 23, 1975

THE URBAN INSTITUTE
2100 M Street, N.W., Washington, D.C. 20037

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FOREWORD

This study was begun in controversy and for a good deal of its time has continued in such. There were conflicts between Administration and Congress on how it was to be funded, on the mix between research and demonstrations and on the due date.

If these were not enough, it became clear early in the course of conducting the study that different people had different ideas of what it was to be about and what it was to accomplish. For some, it was to be a simple codification of research on the severely handicapped. For others it was to tell everything that rehabilitation could or should be for all the disabled. For some it was to be an evaluation of how well Vocational Rehabilitation works, and for others it was to be a set piece focusing on the implementation of a long-sought new program for independent living rehabilitation. Each group of advocates for a given program or disability urged that it highlight their particular interests and concerns. Various providers of rehabilitation services wanted to be sure their special needs and concerns were presented. Some wanted to make the case for more funding for VR before moving to a new program; others simply did not know what they wanted; the work scope put out by the Rehabilitation Services Administration wanted to know everything.

In the course of this study we have tried to accommodate as many points of view as was reasonable, we tried to present as fair a picture as possible without being advocates for any side, and we tried to be faithful to what we took to be the basic intent of the directive to do the study. We reviewed with care the recorded testimony and talked with actors involved with the compromise. We knew that in the time available we would be lucky to even skim the voluminous literature, and we knew that much of it would not answer many of the key concerns as we understood them. We felt that the mandate was for "comprehensive" and we tried for it, at the expense of depth in some instances. Our computerized review scanned tens of thousands of titles. The literature review covered hundreds of reports and studies. In a given time frame with a given set of resources one can go broad or deep but not both.

Our strategy was to try to blend a set of experienced researchers, some handicapped people, and a lot of effort into creation of a report which could capture the main outlines of the situation and problems faced by the severely handicapped and to look at how they were being treated in our society. We tried to blend some new data with the literature reviews. We were also concerned with not merely repeating the conventional wisdom. We wanted to focus on those aspects which were policy manipulable and technically implementable. The question of "feasibility of methods" suggests technical possibility, practical delivery systems, and the will to put the resources forward. No attempt to fill the needs of the severely handicapped or any group numbering in the millions, will be cheap. Suffice, we hope, to say that as a society we could spend many billions and still have much to do. We did attempt to show what might have been bought with the $80 million which would have been the FY 75 authorization under the vetoed bills. It isn't much.

In some instances we may have wandered afield from those who have a myopic eye glued to the VR program. Some of the adjustments which are necessary to permit the most severely handicapped to benefit from VR services extend well beyond what VR alone can be expected to do, even in the wildest dream of the greatest VR expansionist. To ignore these programs, though, is to deny important realities. We decided to show it rather than deny it. The cost, as there are always costs, came in the other things we could not show or do. Thus some of the data analysis is less than the material deserves but what the time permitted.

The alternatives to those with myopic vision are those sitting and wondering what we convey that is new. There may be little new for those with great wisdom and experience with the severely handicapped, but they are very few.

The legal basis for this study comes under Section 130 of the Rehabilitation Act of 1973, P.L. 93-112. Those provisions in their entirety are as follows:

> Sec. 130. (a) The Secretary of the Department of Health, Education and Welfare shall conduct a comprehensive study, including research and demonstration projects of the feasibility of methods designed (I) to prepare individuals with the most severe handicaps for entry into programs under this Act who would not otherwise be eligible to enter such programs due to the severity of their handicap, and (2) to assist individuals with the most severe handicaps who, due to the severity of their handicaps or other factors such as their age, cannot reasonably be expected to be rehabilitated for employment but for whom a program of rehabilitation could improve their ability to live independently or function normally within their family and community. Such study shall encompass the extent to which other programs administered by the Secretary do or might contribute to the objectives set forth in clauses (1) and (2) of the preceding sentence and the methods by which all such programs can be coordinated at Federal, State, and local levels with those carried out under this Act to the end that individuals with the most severe handicaps are assured of receiving the kinds of assistance necessary for them to achieve such objectives.
>
> (b) The Secretary shall report the findings of the study, research, and demonstrations directed by subsection (a) of this section to the Congress and to the President together with such recommendations for legislative or other action as he may find desirable, not later than February 1, 1975.

The Department of Health, Education and Welfare developed a plan for implementation of the study by seeking consultation with various public and private experts in the field of rehabilitation. Initially, a strategy was developed to award a series of grants to various researchers and analysts. After objection to this procedure by Congress, this strategy was abandoned in favor of a competitive contract procedure. The competitive contract was won by the Urban Institute, a nonprofit research firm located in Washington, D. C. The contract to perform the study was awarded on June 29, 1974. At the time, the report was due to Congress in seven months on February 1, 1975. Subsequently, the Congress approved an extension of the Report due date to June 30, 1975. The bill carrying the extension provisions was vetoed by President Ford and revised provisions for extension were not approved until December 7, 1974.

The work statement issued by HEW in its request for proposal, which forms the contractual basis for the work performed by the Urban Institute, can be summarized as follows:

Objective I -- To define and delineate IMSH (Individuals Most Severely Handicapped), distinguishing them from other handicapped with regard to demographic and epidemiological factors.

Task 1. -- Identify IMSH by definition, description, and statistically.

Task 2. -- Relate demographic characteristics of IMSH to eligibility to VR.

Task 3. -- Differentiate IMSH with VR potential from those without.

Objective II -- Determine kinds, sources, and availability of existing and new services to prepare IMSH for entry to VR.

Task 4. -- Identify service needs of IMSH to prepare for VR.

Task 5. -- Identify providers of services needed by IMSH to prepare for VR.

Objective III - To investigate, seek out, and determine kinds, sources, approaches, and availability of existing and new services which could assist IMSH to increase their capacities for dependent living or more normal functioning in community society through the attainment of non-VR goals.

Task 6. Identify services needed by IMSH for activities of daily living (ADL).

Task 7. Identify providers for services needed by IMSH for ADL.

<u>Objective IV</u> - To study specific VR concerns which could facilitate or impede successful rehabilitation of IMSH, so that feasible adaptations or modifications can be tested as service alternatives.

Task 8. Identify employment factors which tend to increase or restrict employment opportunities for IMSH.

Task 9. Identify early casefinding and early identification methods for locating IMSH.

Task 10. Identify relevant technological advances to improve services and employment opportunities for IMSH.

Task 11. Identify environmental barriers for IMSH.

<u>Objective V</u> - To study, assess, and make recommendations for (1) general and special policy and implementation considerations, and (2) demonstration projects to test feasibility of service methods to meet rehabilitation needs of IMSH.

Task 12. Identify HEW programs for coordination of problem-solving efforts to meet the needs of IMSH.

Task 13. Identify cost and impact of services.

Task 14. Identify research and demonstration requirements and implementation areas.

Task 15. Identify and evaluate policy options.

It is to these objectives that this report is devoted.

We can make no pretense that this report is as full and as extensive as we would have liked it to be. Such reports are never complete, only ended. It would take another year or more just to get what we would like spelled out more completely in terms of the data on hand. Entire areas which were encompassed in a page or two warrant greater elaboration. The data are available but the time is not. We are confident, though, that we have reported faithfully on the needs of the severely handicapped and on feasible methods to meet those needs. The rest is up to Congress and the Administration.

ACKNOWLEDGMENTS

Studies as large, pressured, and complex as this owe special thanks to many individuals, many more than can be cited in an acknowledgment. To single out a few is not to slight the efforts of the rest, but to recognize performance beyond the call of duty. All of the study participants worked diligently and my special thanks goes to them all. But I must give high recognition to the efforts of Jeffrey Koshel in managing this study. Without his skills and insights, it would probably have foundered on more than one occasion. Melissa Penney as project secretary probably worked harder than anyone, especially in the last months of endless revisions. Joseph LaRocca brought a degree of experience and wisdom in so many areas it would be impossible to recount his contribution. Frederick Fay divided his time between doing research and educating the rest of us on what handicap is about. He kept us honest. I must recognize the role of Dr. Louis Nau, the project officer for RSA. He opened doors, got clearances, made decisions, and provided the kind of guidance and assistance every study director wishes for in a contract monitor.

The Council of State Administrators and its Executive Director, Joseph Owens, Jr., were very helpful and cooperative. I wish to especially recognize the efforts of the State Directors of our twelve survey States and their staffs for taking on the onerous task of finding and contacting the handicapped people we would interview. These survey States were: Colorado, Connecticut, Georgia, Idaho, Indiana, Maryland, Minnesota, New York, North Carolina, Ohio, Oklahoma, and Washington.

The ten cooperating comprehensive Medical Rehabilitation Centers likewise deserve special thanks for their contribution to the study. They opened their records and permitted followup interviews which have made major

contributions to the findings. The centers are: New York University Medical Center, New York City; Rancho Los Amigos, Downey, California; Rehabilitation Institute of Chicago; Rehabilitation Institute, Detroit; Tufts-New England Medical Center, Boston; Spain Rehabilitation Center, Birmingham; Texas Medical Center, Houston; University of Minnesota Hospital, Minneapolis; University of Washington Hospital, Seattle; and Woodrow Wilson Rehabilitation Center, Fischersville, Virginia.

The voluntary agency staff who participated in our workshop with NRA and wrote papers, as well as our Provider and Consumer Advisory Committees, helped influence our work in numerous ways and I appreciate their effort and wisdom.

Thanks are also due the 1200 rehabilitation providers throughout the country who responded to our mail survey.

Finally, I wish to especially thank the 1200 handicapped people who shared their experiences with us. Without them there could have been no study.

The work upon which this publication is based was performed pursuant to Contract SRS-74-54 with the Department of Health, Education and Welfare. The interpretations or conclusions are those of the research team and its Project Director and do not represent an official policy position of the Urban Institute, its Trustees or the agencies which sponsor its research.

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Chapter 1

INTRODUCTION

In this study we attempt to describe a comprehensive overview of the needs of the most severely handicapped. The focus was on needs which can be met with current or developing technology and methods, although in some instances political and fiscal considerations may place constraints on the feasibility of these methods. It is our view that feasibility of methods to meet these needs means more than just the technical possibility. It also means the degree to which methods could reasonably be implemented at expenditure levels society may be willing to accept.

The time constraints for the study were severe. Consequently, the range and depth of the material only begins to reflect that which the subject deserves. The material presented focuses on the areas and data which we felt were most important and which would be most faithful to the multiple concerns of the Congress, the Administration, and the constituency involved with the issues underlying the mandate for this study. It was not possible to fully deal with every concern, every group, every aspect, and every service possibility.

After an extensive search of the literature on the most severely handicapped and rehabilitation, we conclude that the status of the research technology is deficient in several respects. By this we mean that no fundamental set of pre-existing research studies adequately addresses the issues relevant to the needs of the severely handicapped. This is not to say there was no prior research, or that some of it was not good research. In fact, the amount of literature is immense. But much of it is clinical in nature, much is advocacy and exhortation, much is grossly outdated, and much is methodologically poor, the primary problems being lack of controls and imprecise definition of the population under study.

Most disheartening, however, was the fact that many areas--labor market participation of the most severely handicapped, for example--were virtually unresearched. Where studies exist, they have usually analyzed one or two sources of data, which were in turn not studies specifically designed to investigate labor force participation of the severely handicapped. Examples of these shortcomings are extensive. The most severely handicapped today are as unresearched as were the poor before the War on Poverty.

In addition, the amount of basic information on either the severely handicapped population or on specific subgroups is sparse. While the advocacy groups have considerable expertise and wisdom, they have few data. While this does not lessen the validity of their positions, it does make it difficult to determine the extent of needs and to set intergroup priorities.

We have severely limited our estimates of overall program costs. The shape of a desired program is not established. There are not enough data on utilization patterns, enough demonstrations, or enough cost data to reliably estimate costs of a large number of alternatives. Of course, any authorization level can be used productively. If one wishes a really comprehensive program, however, one is talking about a great deal of money. In two exercises looking solely at 5-year costs to remove transportation and mobility barriers and for a modest program for 1.8 million largely homebound persons, the respective estimates were $8 billion for the transportation program and a like amount annually for the homebound program. We do make some suggestions about what is possible for smaller amounts such as the $80 million which would have been the top authorization in the vetoed bills.

Of course, the cost of disability is high in any case. The costs borne by th individual are in lessened incomes, higher outlays for medical care, and equipment and physical assistance to substitute for lost function. In addition, there are the psychological costs to the individual and family imposed by enforced dependenc

There are social costs as well--the public costs. One measure of these is government expenditures. Dr. Monroe Berkowitz of the Bureau of Economic Research, Rutgers University, estimated for the Department of Health, Education, and Welfare (HEW) that $35.5 billion in 1970, $51.6 billion in 1973 (in constant 1967 dollars), and $222.8 billion by 1990 will be the "cost" of disability, counting governmental and industry expenditures and wage losses.[1] His estimate of "actual" dollars by 1990 is $348 billion. Examining public programs in this study with respect to actual expenditures, Dr. Berkowitz estimated that $21 billion was spent on the severely disabled alone in 1973--excluding vocational rehabilitation, and counting only the Federal share. About $13 billion was spent by HEW. In that same year, Federal expenditures for Vocational Rehabilitation (VR) were $375 million. Assuming the present structure of income transfer programs, inflation, and historical growth rates alone, estimated expenditures for 1990 for income maintenance to the severely handicapped would be $123 billion.

If some of our suggestions were to be included, the outlays might be even greater. We would see cities removing transportation and architectural barriers, as well as income maintenance programs which permit the severely handicapped to work and earn as much as they can without arbitrary rules which cut off benefits before their earnings are adequate for self-support. Of course, we also think this could reduce government expenditures in the long run.

We have been struck with how much the Administration, the Congress, and the constituency expect of Vocational Rehabilitation, and yet how limited are the resources provided. Of actual expenditures for the severely handicapped in 1973, Vocational Rehabilitation accounted for 2 percent of the HEW Federal

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[1] Monroe Berkowitz, Cost Burden of Disability and Effects of Federal Program Expenditures, Final Report (New Brunswick, N.J.: Disability and Health Economics Research, Bureau of Economic Research, Rutgers University, 1974).

share. Yet from testimony on bills passed since 1972, the impression remains that VR maintains a more important place in expectations than its appropriation level would suggest.

The reason for this seems apparent. Vocational Rehabilitation alone stands as a target for all those who feel needs, live with needs, advocate for needs. It alone is committed to all categories of disabled individuals with a service philosophy, delivery system, and a way of doing business that can meet needs. It seems to have the value system, accomplishment, philosophy, and flexibility to do more than its present charter permits. That the implications of changing that charter could vastly alter the character of the system is not particularly well understood.

In designing this study it would have been possible to place primary emphasis on the severely handicapped or to do a kind of evaluation of VR. The scope of work issued by HEW, and agreed to by The Urban Institute, suggested the best approach was to look at the people and see where VR and other programs helped in meeting their needs. We felt that the major point of contention, the most difficult analytically, and the most in need of explication for legislation, was the area of independent living rehabilitation (ILR) needs. Less is known about this area than any other in the underlying dispute between Congress and the Administration over the role and function of VR. We tried to look at how independent living needs were being met, whether the service technology had the means for meeting those needs, and what the constraints might be.

Legislative Background

Congressional interest in the rehabilitation of the severely disabled and in the inclusion of services for independent living goes back over a decade before President Nixon's vetoes of the 1972 and 1973 bills authorizing such an expansion. H.R. 361 was introduced in early 1959 by Representative Elliott and reintroduced later in the year by Representative McGovern as H.R. 5416. These bills contained titles relating to Independent Living Rehabilitation Services. The stated purpose was to assist "...the States in rehabilitating handicapped individuals who, as a result of such rehabilitation, may be expected to achieve such ability of independent living as to dispense with, or largely dispense with, the need for institutional care or, if not institutionalized, to dispense with, or largely dispense with, the need for an attendant, thereby reducing their burden upon others and contributing to their dignity and self-respect."

The definitions used in the bill were:

> (a) The term "independent living rehabilitation services" means counseling, psychological and related services (including transportation) rendered seriously handicapped individuals and in the case of any such individual found to require financial assistance with respect thereto, after full consideration of his eligibility for any similar benefits by way of pension, compensation, and insurance, such term shall include physical restoration and related services, including corrective surgery, therapeutic treatment, and hospitalization, needed prosthetic appliances and other devices which will contribute to independent living and training in the use thereof, and maintenance needed to assure the availability of such services.
>
> (b) The term "handicapped individual" means an individual of employable age, as defined by regulations of the Secretary, who is under such physical or mental disability as to require institutional care or attendance in his household continuously or for a substantial portion of the time, but who can be reasonably expected, as a result of rehabilitation services to achieve such ability of independent living that he will no longer require such institutional care or such attendance in his household.

In 1961 five Representatives[2] introduced bills written primarily by the National Rehabilitation Association which had a title on "Independent Living Rehabilitation Services." The purpose of this provision expanded on the 1959 bill and would authorize "....the States in rehabilitating handicapped individuals

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[2] Representatives John Fogarty of Rhode Island, Dominick Daniel of New Jersey, Robert Giaimo of Connecticut, Albert Quie of Minnesota, and Kenneth Roberts of Alabama.

who, as a result of such rehabilitation, may be expected to achieve substantial ability of independent living, thereby reducing their burden upon others and contributing to their dignity and self-respect...." First year authorizations were $15 million, with $25 million for the second year. The title was focused on the physically and mentally handicapped and was to be administered by the State agency administering or supervising the administration of vocational education or vocational rehabilitation, with the usual provisions for administration by relevant blind agencies. The bills provided for cooperative arrangements between the State agency to administer the independent living provisions and State agencies administering public assistance and public health programs, Social Security, and other agencies providing services "relating to independing living rehabilitation services."

The term "independent living rehabilitation services" was defined as:

> counseling, psychological and related services (including transportation) rendered seriously handicapped individuals and in the case of any such individual found to require financial assistance with respect thereto, after full consideration of his eligibility for any similar benefits by way of pension, compensation and insurance, such term shall include physical restoration and related services, including corrective surgery, therapeutic treatment and hospitalization, needed prosthetic appliances, mobility and other devices, and other goods and services which will contribute to independent living and training in use of appliances, personal adjustment services, maintenance needed to assure the availability of such services, and followup services to insure maintenance of rehabilitation gains.

"Seriously handicapped individual" was defined as:

> an individual of employable age, or below such age if in special circumstances defined by regulations of the Secretary, who is under such physical or mental disability as to be unable to perform the ordinary functions of daily living, but who can be reasonably expected, as a result of rehabilitation services, to achieve such ability of independent living as to eliminate or substantially reduce the burden of his care.

Of the five persons who introduced the bills, two are still in Congress.

In 1961 the National Rehabilitation Association, when asked whether substantial numbers of such severely handicapped persons can benefit from Independent Living Rehabilitation services, responded affirmatively, stating that, "Rehabilitation services of the kind contemplated in this Act are no longer experimental."[3]

In response to the question of why a separate title (program) was established rather than a single program, the response was: "Until experience has been gained in the administration of Independent Living Rehabilitation ... it is considered best to have the two separate, although administered by the same agency. This arrangement will assure that attention given to the new program will not detract from emphasis upon vocational rehabilitation."

It was also required in that bill that, except for counseling, psychological, and related services, economic need was to be required as a basis for "rendition of services." Then, as in 1972 and 1973, the Administration opposed these provisions. The nature of the earlier opposition is unclear, but persons involved in the process at the time recollect that the opposition was due to the inability of the Department of Health, Education, and Welfare to settle who might administer the provisions. Public health, rehabilitation, and social services units had all expressed interest.

This history illuminates the nature of the issues in several respects. While it appears that little has changed in the 16 years or more since the concept of independent living rehabilitation for the severely handicapped was set forth in a bill, much in fact has changed. The concept of severe disability now refers to a vastly different population than was conceived of at that time. Many other programs providing benefits to the disabled have sprung up with

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[3] National Rehabilitation Association, Newsletter, February 1, 1961.

resources which dwarf the Vocational Rehabilitation (VR) effort. Advances in the technology of prosthetics and orthotics, in medical care, and in the provision of services have vastly altered who can be vocationally rehabilitated. The concept of independent living rehabilitation has also changed. Many of those who would have been targets for independent living in the 1960's are now routinely rehabilitated by VR.

Testimony over the years continues to recount stories about persons for whom no services were available when needed. Stories of persons who achieved significant success with the help of services offered by some public or private program have also been told. While these types of stories are true, they are emotional in nature by design. One must be cautious in using such examples to serve as prototypes of the severely handicapped. They are a heterogeneous group. Labeling and stereotypes, for good or ill, should not be the basis for design of public programs. In designing such programs, one must look for the most probable case. Within the bounds of a shared desire to help the severely disabled there is ample room for fair-minded persons to recommend alternative solutions. When placed within the confines of a budget constraint, the disagreements can become pronounced and sharp.

After a prolonged period of testimony establishing that the severely disabled without vocational outcomes should be provided with independent living rehabilitation, and after years of concern that Vocational Rehabilitation should begin to focus services on the most disabled, provisions were written into the vocational rehabilitation bills of 1972 and 1973 (92nd and 93rd Congresses). These provisions would have focused VR on the severely disabled and authorized a formula grant program which would have allowed States to provide services to persons without vocational potential to live more normally and independently. Both bills were vetoed by President Nixon. Efforts to override the vetoes were unsuccessful.

The section of the Rehabilitation Act of 1972 on Independent Living defined its purpose:

> (a)...to assist the several States in developing and implementing continuing plans for meeting the current and future needs of handicapped individuals for whom a vocational goal is not possible or feasible, including the assessment of disability and rehabilitation potential, and for the training of specialized personnel needed for the provision of services to such individuals and research related thereto.
>
> (b) In order to make grants to carry out the purposes of this title, there is authorized to be appropriated $30,000,000 for the fiscal year ending June 30, 1973, $50,000,000 for the fiscal year ending June 30, 1974, and $80,000,000 for the fiscal year ending June 30, 1975.

The President pocket vetoed this bill. His Memorandum of Disapproval stated, in part:

> This measure would seriously jeopardize the goals of the vocational rehabilitation program and is another example of Congressional fiscal irresponsibility. Its provisions would divert this program from its basic vocational objectives into activities that have no vocational element whatsoever or are essentially medical in character. In addition, it would proliferate a host of narrow categorical programs which duplicate and overlap existing authorities and programs. Such provisions serve only to dilute the resources of the vocational rehabilitation program and impair its continued valuable achievements in restoring deserving American citizens to meaningful employment.

When the 93d Congress convened, some changes were made in the vetoed bill, but none affected the independent living provisions cited above. On March 15, 1973, the bill was sent to the President for signature. On March 27, 1973, he vetoed the bill, citing these reasons, among others, for his action.

> S. 7, if enacted, would result in an increase in Federal outlays of some $1 billion above my budget recommendations for fiscal years 1973-1975.....
>
> I would emphasize that, even if S. 7 were not fatally flawed by its large expense, I would have serious reservations about signing it, for it also contains a number of substantive defects. Among them:
>
> --It would divert the Vocational Rehabilitation program from its original purposes by requiring that it provide new medical services. For instance, it would set up a new program for end-stage kidney disease--a worthy concern in itself, but one that [can] be approached more effectively within the Medicare program, as existing legislation already provides.

> Vocational Rehabilitation has worked well for over half a century by focusing on a single objective: training people for meaningful jobs. We should not dilute the resources of that program or distort its objective by turning it toward welfare or medical goals.
>
> --Secondly, S. 7 would create a hodge-podge of seven new categorical grant programs, many of which would overlap and duplicate existing services. Coordination of services would become considerably more difficult and would place the Federal Government back on the path to wasteful, overlapping program disasters.

Testimony representing the Administration view objected to a new formula program which would duplicate existing authority or authority being proposed by the Administration. The spokesmen also indicated there was some doubt as to whether the service technology was advanced enough to actually provide services to those severely handicapped.

It seems clear, however, that the primary reason was that, given the perceived budget constraint at the time, the President's advisers did not want a new program which would have authorized $30 million the first year, expanding to $80 million by the third year. Their argument was that the country could not afford such a program either now or as it was sure to grow, and that to have a program on the books but unfunded would create a stigma on the Administration and a constant pressure to secure funding.

To soften this concern somewhat, it should be pointed out that there are many who argue that if more money is to be available, it should be for vocational rehabilitation, which, relative to need, is quite underfunded. Such a point of view may be seen with some sympathy upon considering the fact that the Vocational Rehabilitation program claims only 2 percent of the Federal funds going to the disabled.

Authorization of the Study

Following the failure of the second attempt to override, the Administration and the Congress worked out a compromise. The provisions establishing the new program were dropped. In exchange, the Administration agreed to conduct a study of the issues raised in the testimony about the nature of existing authority and the ability of rehabilitation to actually serve the most severely handicapped. These provisions were reflected in Section 130 of the Rehabilitation Act of 1973, P.L. 93-112.

Basic Issues

If one can put the study in an oversimplified perspective, a number of difficult issues and real concerns were behind the movement for an independent living program. From one perspective there is the notion that the nonvocational services which VR provides for persons with labor market potential could be provided for others with virtually no likelihood of vocational success. For example, consider two persons, both double amputees from an auto wreck. One is a college educated person in his late twenties with a rising career pattern as a white collar professional. The second is a 55-year-old semiskilled laborer with a sixth grade education and a history of intermittent employment. The VR program accepts the first, fits prostheses, teaches mobility, perhaps provides training for a slightly different position, and considers the person "rehabilitated," when placed in a gainful occupation. In the second instance, the man's age, education, and skills and the nature of the positions for which he can be trained are so limited that he is rejected as too severely disabled, receiving no services. Many proponents of independent living programs say that the second person should at least be fitted with prostheses and taught mobility to become self-caring, whether or not a job is feasible. The local medical facilities, it is argued, do not necessarily provide either the prosthetic devices or the training, and both of these are proper roles for VR. The benefits to the individual and the family are obvious, and the benefits to society in reducing the need for homemaker services and the like could be calculated. From such a perspective, it seems almost inevitable that one would agree that VR should be providing such services.

The real concerns, however, for a day-by-day program far outstrip such simple, though possibly true, characterizations. Rational, reasonable guidelines ought to be designed so that citizens know when the benefits of public programs are within their rights and program administrators know when services may be denied as outside their authorization. The range of disabling conditions presently served in the State-Federal program touches on virtually every possible classification. The analogue to the provision of prosthesis and mobility training in the example above is virtually missing when the diagnosis is end-stage renal disease, profound retardation, schizophrenia, cerebral palsy, etc. That is to say, there is no doubt that the resources available will be inadequate to serve all the potential clients of the agency for all the potential services they may desire. Thus rationing must occur. This rationing may be accomplished by establishing waiting lists, by limiting who may be eligible, by limiting the types of services that can be provided, or by all of these measures.

One way to ration is to require, as VR does, that certain conditions be met in addition to the presence of disability. Rationing in VR currently depends on the extent to which the individual with an impairment fits into a range of functional limitation between not very severe and too severe. The impairment must be an impediment to work, and acceptance to the program is based on some judgment that the person can benefit enough from services to end up in some gainful occupation, including that of homemaker. When these constraints are cited, it is entirely conceivable that the "equal protection" provision of the Constitution could justify all disabled persons in making demands on the program for services. If the authority to provide services were to encompass objectives as vague as independent living or to eliminate or substantially reduce the burden of care on family and community, it seems certain that the primary rationing device will be waiting lists. Accountability might very well be lost unless clearly specified criteria for inclusion and priority considerations are detailed for an independent living program.

The definition of severely disabled presented in the law itself is a recitation of disabling condition labels. One of the major themes encountered in exploring these issues is the tension between a program which has traditionally used functional limitation criteria to define eligibles on an "efficiency basis," accepting those for whom successful outcome looked probable, and the increasing movement toward a program which defines entitlement by impairment labels based on "equity" considerations, with less regard for successful outcomes. Although it may make good sense to allow the program to provide obviously needed assistance, for example, to a newly blinded person to learn all that is necessary to function on a day-by-day basis regardless of vocational outcome, the shape of such a program for all the disabled is less obvious, especially given limited resources.

Most major questions of this study, in effect, boil down to questions of boundaries. When does one accept a person for rehabilitation services when employment is not the relevant outcome--whether due to low employment potential of the individual or the fact that the individual may be already working but in need other assistance such as in remodeling a home or in recreation? When, in the provision of nonvocationally oriented services, can a public program manager say that sufficient effort and expenditures have been employed? Many examples can be cited of persons working with the retarded to make them able to function well enough to live in a group care facility. Expenditures for some of these services could have rehabilitated scores of paraplegics. Either expenditure could be justified on humanitarian grounds, indeed may be justified in terms of the reduced burden on public funds. But if, as a society, we are not prepared to pay for both, then which? We can try to do a little for each and do neither really well. We can share the collective guilt of serving one and leaving the other to languish.

Thus, once we address the issues beyond the initial humane concern for the severely handicapped and get into the serious issues of how to design a public program that can be equitable and reasonably consistent with regard to its rules, accountability, and efficiency, the questions proliferate.

The study strategy essentially addresses a few key questions: Who are the most severely handicapped individuals? How appropriate are alternative operational definitions? How many severely handicapped are there? What is their situation? What are their needs? How are their needs now being met?

We have also addressed the more subtle issue of efficiency versus equity. In an equity situation, all persons in similar circumstances are treated alike, regardless of benefit received. A disabled person is served because of the disability. Under efficiency mandates, only those with the greatest payoff are treated. Those who would benefit least are served last, if at all.

VR traditionally has been more on the efficiency side, partly because of pressure to produce an ever growing number of rehabilitations. This expectation of "numbers" often carried sufficient incentive for counselors as well as such political impetus in the appropriations arena that some persons who were not severely disabled received services. The concern for sizable numbers of successful rehabilitations is present at the State as well as the Federal level.

When the Rehabilitation Act of 1973 was passed, the rules changed and the signals became mixed. It was not always clear whether efficiency was to be abandoned for equity, based on diagnosis alone, or if some mixed system was required. There were fears that both efficiency and equity were expected; given that there were no additional funds, this expectation could not be reasonably met.

We investigated the question of vocational outcomes for the severely handicapped. One can understand the humanitarian concern in wanting to put services where the most need might be. But often this denies efficiency--the failure rate may increase, and funds spent on highly costly or intractable cases are unavailable for services to others.

Then too, the scope of inquiry explodes. To determine what might enhance vocational or independent living rehabilitation possibilities for the severely handicapped often extends well beyond the traditional counselor-to-client approach of VR. It may well be that non-VR programs, such as reforming income maintenance, tax relief for expenses of transportation, programs to remove architectural barriers, and programs to remove persons from institutions, may have greater impact on expanding the opportunities for the severely handicapped than any changes in VR's mandate. These issues are addressed through data file analysis, client surveys, a review of existing literature, and constituency impact assessments.

At least six national surveys have infor[illegible]ion relating to disability. Among the most significant are the 1966 So[illegible]l Security Survey of Disabled Adults, the 1966 Survey of Economic Opportunity, the 1970 Census, the 1972 Survey of the Disabled mounted by Dr. Saad Nagi of Ohio State University, and the Health Interview Surveys made annually by the National Center for Health Statistics. These surveys vary in terms of the number of households, definition of disability, and year mounted. In order to get estimates of the incidence and prevalence of severe disability, these differentials should be reconciled. In our work, we have tried to make the best estimates which would include all age groups, and the institutionalized as well as noninstitutionalized disabled.

The established surveys do not provide much detail about the situation of the disabled individual. To remedy this lack of information, a survey was developed by The Urban Institute. The target was to be a group defined as those too severely handicapped for Vocational Rehabilitation services--persons who were not accepted or were closed as not rehabilitated for reasons of severity of handicap. With the support of the Council of State Administrators of VR and the yeoman work of the VR directors and staff in Colorado, Connecticut, Georgia, Idaho, Indiana, Maryland, Minnesota, New York, Ohio, and Oklahoma, who contacted a group of these clients to get consents for the interviews, extensive data on about 900 such persons were received.

In addition to those severely handicapped persons who are rejected by VR, there are the severely handicapped persons who may never get to a State agency and who represent an important group to survey. Such persons may be found in the Comprehensive Medical Rehabilitation Centers (CMRCs). Data were received on 300 such persons who had been inpatients at 10 CMRCs, including New York University Medical Center (New York), Rancho Los Amigos Hospital (Downey, Calif.), Rehabilitation Institute (Chicago), Rehabilitation Institute (Detroit), Tufts-New England Medical Center (Boston), Spain Rehabilitation Center (Birmingham) Texas Medical Center (Houston), University of Minnesota Hospital (Minneapolis), University of Washington Hospital (Seattle), and Woodrow Wilson Rehabilitation Center (Fischersville, Va.). This survey supplements the information obtained from the VR survey in that an extensive assessment of the person's physical condition and functional limitations was performed over time--upon admission and discharge from the CMRC, and during the interview, roughly two years after admission. In addition, the length and cost of stay and services received at the CMRC are detailed, which provides more objective data than is otherwise available on the costs of rehabilitation.

The review of the literature, of course, is a vital element of any study such as this. The Medical College of Pennsylvania (MCP), with its excellent staff and computer capability, was asked to assist in screening the mass of published work. MCP developed computer-screened printouts of relevant published reports. These in turn were sent to the Center for Independent Living in Berkeley, California, which did the actual literature reviews. Subjects range from architectural barriers to the psychological effects of disability. Much of what has been written about the needs of the severely handicapped was reviewed.

It seemed wise to enlist the aid of the various voluntary organizations who work for program development and expansion and promote public education on the problems of specific disability groups. With the assistance of the National Rehabilitation Association, two sessions were held with representatives of these voluntary agencies. At the first session, the study was explained and agency input in the form of data and position papers was solicited. The second conference addressed specific issues of how to identify the hidden disabled, how to define severity, what services might be provided, and how these needs are currently being met.

In addition to developing information on service needs of the severely handicapped, it is necessary to provide information on how these needs can be met. What programs now serve the severely handicapped? What technology exists to help them? What do service providers in VR, workshops, facilities, and the like see as the main incentives, disincentives, possibilities, and limits of service to this group? Who might run an independent living rehabilitation program? What alternative organizational arrangements, financial incentives and manpower requirements are available for consideration?

The experience of service providers who had worked in the rehabilitation field was felt to be extremely valuable in considering policy options for the severely disabled. A mail-out survey was sent to 1,000 VR agency personnel (primarily counselors), 800 facilities and workshops, and 500 various professional organizations and individuals. The survey instrument raised questions about current practices in providing services to the severely handicapped and sought opinions on changes. We received 1,300 responses.

A review of programs was conducted, with emphasis on HEW programs which currently provide benefits to the severely disabled. Special papers by consultants were prepared on issues affecting certain groups (e.g., the retarded, the mentally ill, the blind, and the deaf) and special concerns such as the technology of rehabilitation.

As a result of these analyses of needs and service provision, a number of policy alternatives to improve and expand services were designed. Finally, the study recommends areas for further knowledge-gathering activities under research and demonstrations.

Outline of Report

The study report proceeds as follows. In Section II we describe the results of our analysis of existing data files in presenting estimates of the population at risk. Because the area of investigation is filled with semantic ambiguity, we offer an extended discussion of the definitional problems. Having presented our 1975 estimates of the population, we proceed to examine the characteristics of this population with respect to severity factors, income, housing, etc. We conclude the section with an analysis of the relationship between VR and the population of severely disabled.

In Section III we display the results of two of our surveys of the severely handicapped population. The first is a survey of individuals who have been to a VR agency and were either not accepted at intake or were closed as not rehabilitated, in each instance the reason given being the severity of the impairment which rendered the individuals infeasible for vocational rehabilitation. We also present our analysis of a random sample of severely handicapped patients served in comprehensive medical rehabilitation centers.

Section IV presents a series of selected problem areas and the findings from the literature and from our surveys as they relate to these areas. The areas of concern include dependency, architectural and transportation barriers, employment, and social interaction of the severely handicapped.

Section V examines some specific groups of the population which present unusual issues in program design and services. In some cases the issue is the presence of service systems which must be differentiated from any program of independent living rehabilitation that may be developed by Vocational Rehabilitation in order to avoid duplication and competition. Other issues show the nature of the existing special services which may be models for other groups.

Section VI describes the VR process and reports on our survey of rehabilitation service providers, both within and outside the State-Federal program. We point out some of the technology and benefit-cost issues.

Section VII reviews other HEW programs and non-HEW programs which may impinge upon the severely disabled and have implications for coordination and accomplishment of rehabilitation.

The options are presented in Section VIII. While many of these options are simply descriptions of logical alternatives, there is, in the absence of prescribed budget and political constraints, no compelling analytic reason that one or another should be preferred. That is, if the resources are to be relatively small, there are a great number of program design alternatives which can do a reasonably good job of serving the severely disabled. In the financial options chapter, we present a variety of approaches to the support of an independent living rehabilitation program. Among other things, more consideration of client cost sharing than is the case in VR is suggested, since many of the ILR services may offer the provision of maintenance. In this section we also present some options for defining severely handicapped persons for eligibility purposes which attempt to identify objective traits as much as possible, leaving the local discretion somewhat reduced and attempting to assure cross-State equity in treatment. If in VR different individuals are treated differently because of local labor market conditions, such variations are less supportable in an independent living program.

In Section IX we conclude with observations about the demonstration program which has been mounted in conjunction with this study and on the R&D areas for further research.

Chapter 2

DEFINITIONS

The language used in the field and in the political arena to describe the target population of this study is full of ambiguities. In the early stages of the study everyone asked us whom we would define as "most severely handicapped." This in itself suggests lack of ready consensus on the use of the term. Had we chosen to try to answer the question before proceeding on the work, we would still be embroiled in semantic debate.

There seemed to be enough general sense of whom we were talking about to at least get started. We felt, for example, that clients whom the State VR agencies rejected for services as being "infeasible due to severity" would constitute a population to be examined. We were reasonably sure that some of those persons would not be as disabled as others who were kept in the program. We expected some error to occur in such judgments, but we also expected a great many of those judgments to be quite correct, given the vocational orientation of the program. This generally is what we found from our survey.

We also believed that persons being served in the Comprehensive Medical Rehabilitation Centers would constitute another population to be examined. Because of the time frame, in which we had to work on several approaches simultaneously rather than sequentially (as would have been desirable), we also looked at existing data files on the disabled. Since these were to be key data sources and we knew their definitions varied, an a priori definition would have curtailed use of several very important files.

We looked at the definitions used by public programs for the disabled, such as Social Security Act Title II, Disability Insurance, and Title XVI, Supplemental Security Income, both of which require essentially complete labor force withdrawal because of severe impairment. We also looked into the available literature and research on the question. What we found was a melange of uses of the terms "impairment,""disability," and "handicap," and a melange of programs and purposes. It seems that the terms disability and handicap can mean what one wants them to mean.

The extreme or polar cases pose few difficulties. Most of us at one time or another suffer disease or an injury which leaves us with no after effects. Once the virus is conquered or the wound heals, we are back at our usual activities: work, keeping house, attending school, or social activities. At the other extreme, the blind quadriplegic with measurable brain damage may truly belong to the severely disabled category, with no questions raised.

Such polar extremes are comparatively rare, compared to the large number of people who receive cash benefits or services based on their inability to work, as documented by medical and vocational evidence. To decide whether such people are "most severely handicapped" or not becomes in large measure a matter of judgment. And in many cases it is a judgment on which reasonable people may disagree.

Such a conclusion may be the despair of the statistician and the program planner. The imprecise nature of the concept causes difficulty for legislative draftsmen and those charged with writing rules and regulations, but such imprecision avoids significant problems of labeling and recognizes the dynamic changes which can occur.

Despite the prevailing image of the disabled person as an amputee, blind, or paraplegic, others such as individuals with extreme heart conditions or psychotics may be much more restricted in their activities and in their ability to take care of themselves. There are many physical and mental limitations, and they affect some people more severely than others. Then too, people differ in their capacities to cope with the impairment, and therefore even between people with identical health conditions, the severity of the handicap may vary.

To make matters more confusing, the term handicap is used in conjunction with specific programs, and each program tends to have its own definition.

Disability, as described by Haber, may be identified with the onset of some disease process or trauma.[1] This is comparable to Nagi's concept of active pathology as the reaction of the body's defense and coping mechanisms to infection, metabolic imbalances, traumatic injury, or other etiology.[2] The latter concept involves onset of the event and efforts of the organism to reach a "normal" state. During the active aspect, which may be defined as the period from onset to stabilization or remediation, the process is usually considered acute and unarrested. In most common parlance, the person at this stage is ill or injured but not yet considered disabled. Acute care services and health insurance programs are designed to cover this stage.

Chronic disease or chronic illness is a concept which overlaps with disability but is not necessarily synonymous with it. Some chronic illnesses, such as bronchitis or asthma, are periodic in nature, but unless they are in a quite severe episode they tend not to place limitations on activity. Thus there are persons with chronic conditions who are not generally considered disabled.

On the other hand, it is clear that the results of the active pathology and results of other chronic conditions such as heart disease can cause deterioration over time, or there may be residual losses of function or abnormalities of appearance, structure, or function of the organism. Such abnormalities are most often described as impairments.

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1. One of the better summarizing discussions of the concept of disability is in Lawrence D. Haber, Identifying the Disabled: Concepts and Methods in the Measurement of Disability, Report No. 1, Social Security Survey of the Disabled: 1966 (DHEW, 1967). While the survey done by Social Security is much more narrow in focus than the nature of the discussion, some of the important conceptual problems are clearly described.

2. Saad Z. Nagi, "Disability and the Severely Disabled: Concepts and Prevalence," prepared for The Urban Institute's Comprehensive Needs Study of the Severely Handicapped.

Impairment, Disability, and Handicap

Haber described the activity losses and restrictions as functional limitations. Impairments may or may not lead to important functional limitations. Consider, for example, the case of a Vietnam veteran who loses his leg in combat and completes law school under the GI Bill and now practices tax law, earning $30,000 per year. Had that veteran been a truck driver prior to his impairment, his entire earnings and work strategy might have been different.

When the impairment leads to functional limitations in the ability to care for oneself or to perform the key expected social roles--especially with respect to work--and when the condition has some durational implication, the impairment may then be described as a disability.

Thus, society and the individual react to the disability and define the conditions where it becomes a handicap. A handicap is an event or environmental condition which interacts with a disabled person, causing a barrier to goal accomplishment that a nondisabled person may not face, and which would not impede the disabled person if the world could change. (Individuals with the most severe disabilities are almost always faced with the most severe handicaps.)

For most nondisabled persons, a sidewalk curb is not an impediment to crossing a street. For many of the disabled, however, it is like a wall to be hurdled. Of course, curbs are also impediments to people using crutches after spraining an ankle, to women carrying packages and babies at the same time, and to the old who are more infirm than impaired. A paraplegic may have a handicap when curbs are high and none when curb cuts permit ease of access. Also, for most of us the placement of a public telephone in a booth is no problem; a person in a wheelchair finds the booth too narrow for access and the telephone too high to reach.

When initially discussing the study outline with the staff of the Center for Independent Living (CIL), most of whom are persons with paraplegia, quadriplegia, cerebral palsy, or blindness, the question was raised as to who among them might be severely handicapped. Not one person at CIL felt that he or she was handicapped. It was the impediments placed in their way by a world insensitive to their needs which consistently put stumbling blocks in their ability to be self-caring and self-supporting.

To some extent, the problem of clarifying terms depends upon which of several one wishes to use as a base. For example, one can call the residual limitation left by disease or injury an impairment. When the interaction of the individual and the environment is such that life functions cannot be performed, then the impairment can be called a disability. On the other hand, one can call the person with the residual limitation disabled, in which case one calls his interaction and limitation with respect to the environment a handicap. It really does not matter as long as one is consistent.

Our preference is to call the residual limitation resulting from congenital defect, disease, or injury an impairment. A person with an impairment, then, may or may not have a disability, an inability to perform some key life functions. When the inability is such that the environment imposes impediments to the individual's goals for travel or work, for example, the individual has a handicap.

Having thus defined these terms, let us go on to say that for purposes of data analysis they are fairly inadequate. Most data collected from surveys on disability do not address these points at all. The definition of disability used in the surveys is usually related to the question of whether one has a condition limiting the kind or amount of work one can do.

Take, for example, the Vietnam veteran described earlier. Should he be considered as fitting some definition of disability? The Veterans Administration, of course, counts him so and probably sends him a monthly benefit to compensate for his loss of a leg. Yet, in the 1970 Census he may have responded negatively, to the question of whether he has a condition which limits his abilility to work.

Nor are persons over age 65 counted among the disabled in either the Census survey or the Social Security Survey of the Disabled. Old age, it appears, supplants disability.

There are additional examples of how the same terms can be used differently. When the VA measures "function" in a service-connected disability, it seems to mean organ or limb function. When the Social Security Administration discusses function, it seems to mean inability to perform some social function such as work. These varied definitions, then, make it difficult to estimate the number of people involved.

We wish to point out here that the existence of a physical or mental abnormality may only be a necessary, not a sufficient, condition for defining the disabled. The bulk of persons with some physical or mental abnormality--say, astigmatism or slight mental retardation--have virtually no limitation on their ability to perform in society. If they need income, it is because they are poor as others are poor, not because they have a disabling condition. If they need labor market brokering or skill training, it is because they are like others with similar age, sex, education, and the like. One need be concerned about them primarily to determine whether the general programs are treating them differently than they should be treated because of their conditions, and to recommend corrections to the general program.

Diagnostic Labels as Proxies

Diagnostic labels are also used sometimes as proxies for disability or handicap. Thus, one often hears that if a person has some condition--blindness, retardation, paraplegia--then one has a "disability" or "handicap." Yet our experience is that the individuals involved may object to such labeling and stereotyping. Within any given diagnostic label are an implied range of severity factors.

Table 2-1 presents severity data on 881 individuals rejected by Vocational Rehabilitation because of severity in one or more of 19 disability categories.[3] The severity scale is derived from the Barthel Index, which includes 15 items related to an individual's ability to care for himself and move around without assistance.[4]

As can be seen from Table 2-1, individuals closed by VR for severity fall in the "totally dependent" category in only 6 of the 19 disability groups. The most severe disability type by far was "3 or more limbs impaired." The only other diagnostic categories with sizable proportions in the totally and severely dependent ranges were "amputations," "impairment of one or both lower limbs," and "impairment of one upper and one lower limb (side)."

The disability types with the least impairment in self-care and mobility were communication impairments (visual, hearing, and speech), mental impairments, allergies, and epilepsy; between 71 and 89 percent of those disabled persons were considered independent.

These survey results have been supported by statements from various disability groups. For example, at our workshop for the voluntary agencies, the blind representative pointed out that not all blind persons are severely disabled, although few would deny the fact that total blindness is a very severe impairment.

The use of the diagnostic label as a proxy for disability or "severe handicap" has the administrative and political advantage of simplicity, especially

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[3] See Section III, Chapter 7, for a full description of the survey of individuals rejected by VR because of severity.

[4] The Barthel Index used in this study was adapted by Dr. Carl Granger.

Table 2-1

Disability Type by Severity

R-300 Disability Type 1/	TOTAL BARTHEL SCORES											
	Totally Dependent (0-20)		Severely Dependent (21-61)		Moderately Dependent (62-90)		Slightly Dependent (91-99)		Independent (100)		Tota	
	N	%	N	%	N	%	N	%	N	%	N	
Visual			1	5	2	10	2	10	15	75	20	1
Hearing					1	11			8	89	9	1
3+ limbs	17	19	22	25	24	27	10	11	16	18	89	1
Side			6	15	13	33	4	10	16	41	39	1
Upper limb(s)			1	3	7	23	7	23	15	50	30	1
Lower limb(s)	3	3	15	14	34	32	20	19	34	32	106	1
Trunk, back, spine	4	2	9	5	67	37	31	17	71	39	182	1
Amputations	2	8	3	12	8	33	3	12	8	33	24	1
Mental					2	17			10	83	12	1
Neoplasms					4	50			4	50	8	1
Allergies			1	2	7	17	4	10	29	71	41	1
Blood diseases					1	17	1	17	4	67	6	1
Epilepsy	1	2			7	16	4	9	31	72	43	1
Cardiac			6	4	48	30	17	11	90	56	161	1
Respiratory			2	7	7	24	6	21	14	48	29	1
Digestive					10	48	2	10	9	43	21	1
Genitourinary					4	29	2	14	8	57	14	1
Speech					1	20			4	80	5	1
Other	1	2	2	5	17	40	9	21	13	31	42	1
Total	28	3	68	8	264	30	122	14	399	45	881	1

1. These diagnostic categories are taken from the 1969 R-300 definitions, which were in effect during the time these individuals were closed from VR. R-300 disability categories were altered somewhat in 1973, but implementation of these changes occurred after our study period.

for program advocates. It is an easy way to talk about the problem. However, the other side of the coin is the stereotyping of all persons under the label as "severely disabled." This typing tends to give the impression that the individuals have less ability to function than they do in fact have.

Clarity with respect to this issue, however, can be disadvantageous to various disability groups, given the eligibility criteria associated with current public programs serving the impaired. As long as the primary benefit programs for the disabled have to do with income maintenance and their primary focus is on total disability, the disabled will not be well served by pointing out that they have the potential for self-care or vocational objectives, as may be true from a rehabilitation perspective. Indeed, as we will discuss in Section VII, the disincentives built into many of those programs work profoundly against maximum development of the abilities of the person with an impairment.

So it is with many of the diagnostic labels used as proxies. There is no necessary continuity between the label and the nature of the problem which would permit one to analytically and unequivocally describe one person with a given extent of impairment as severely disabled or not. A 50-year-old man with a third grade education who has spent his life as an unskilled laborer may be far more disabled by an amputation than a recently blinded, young, college-educated telephone salesman. The laborer is not more severely impaired, only more severely disabled by the impairment, and he is not more handicapped either, except in the labor market.

Thus some of the indicators of vocational abilities and inabilities are intrinsic to the individual, such as: (1) physical and mental capacities and limitations, (2) vocational skills, and (3) motivation and feelings toward work. Other indicators are of a situational nature, such as: (4) the physical and mental requirements of one's work, (5) vocational skills required by the work, and (6) the environmental factors which make employment accessible or inaccessible--that is, influence the availability of work. To account for the various types and degrees of vocational inability, indicators for these various dimensions must be included.

Problems with Operational Definitions

Several problems characterize operational definitions and measures of disability in studies and programs. The most common difficulty stems from the confusion between disability and impairment. This is most characteristic of Workers' Compensation[5] and Veterans Administration programs which combine aspects of indemnification of impairments with compensation for income loss due to disability. Benefits are often based on schedules specifying rates of compensation for anatomical losses, such as a finger, a hand, an arm, or an eye. These schedules are concerned almost exclusively with impairments, regardless of their effects upon earnings. The point here is not to argue whether impairments in themselves should be compensated for, but rather to illustrate the underlying conceptual confusion that led the American Medical Association's Committee on Medical Rating of Physical Impairment to conclude that "impairment" is, in fact, the sole or real criterion of permanent disability far more often than is readily acknowledged. This problem is becoming also characteristic of definitions of severe disability for the purposes of rehabilitation services where severity is equated with the presence of certain pathology and impairments--i.e., entitlement by impairment.

A second problem leads also to heavy reliance on impairments as indicators and criteria of disability. In spite of accepting a multiple causal model for disability, some agencies tend to operationalize their definitions around

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[5] Formerly the Federal bureau concerned with this program was the Office of Workmen's Compensation. "Workmen's Compensation" is still the title in many states.

the more readily identifiable indicators and measurable criteria. In other words, operational definitions may depart from the original concepts because of emphasis on the more measurable dimensions. A prevailing opinion states that "impairment can be measured with a reasonable degree of accuracy and uniformity on the basis of impaired function, as evidenced by loss of structural integrity, pathological findings, or pain substantiated by clinical examination."[6] The comparison in our survey is made with equally significant but less easily measured factors such as age, lack of skills, potential for retraining and placement, education, and disfigurement.

A report by the Subcommittee of the House Ways and Means Committee on the Administration of the Social Security Laws, states that "the Subcommittee recognizes the difficulty of developing and enunciating specific criteria for the weight to be given nonmedical factors in the evaluation of disability and the extreme sensitivity of this area. But the Subcommittee believes that the time has come, if it is not well overdue, to make a determined effort to develop and refine these criteria and make them available to the evaluators and to the public in the form of published regulations."[7]

The utility of indicators or criterion factors depends upon the degree to which (1) they are identifiable, (2) they are measurable, and (3) their contributions to disability are identifiable and measurable. The problem lies primarily in the third requirement, and in this respect medical factors are just as problematic as those of a nonmedical nature.

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[6] The Committee on Medical Rating of Physical Impairment, "Guides to the Evaluation of Permanent Impairment," Journal of the American Medical Association, March 1960.

[7] Disability Insurance Fact Book, prepared by the Subcommittee on the Administration of the Social Security Laws for the use of the Committee on Ways and Means, quoted in a communication from the Vocational Rehabilitation Administration.

A third factor that reinforces the heavy reliance upon impairments as indicators of disability is the interpretation of the term "cause" in the various statutes. Nonengagement in gainful activity may be due to disability, to unemployment because of weak labor market conditions, or to mere idleness. In order to draw the boundaries, most statutes state in one form or another that for nonengagement in gainful activity to be considered as an indication of disability, it must have occurred because of the presence of impairments. Often the term "because" is interpreted to mean that impairment is a necessary and sufficient cause for disability and that in this sense the two are equivalent.

Differences between impairment and disability in definitions and indicators negate such interpretation, except in cases where impairments are so extremely limiting as to become the sole determinants of disability. However, in most cases (including those allowed benefits under a variety of programs), impairments are actually a contributing cause. To interpret the term "because" as meaning necessary and contributing, rather than sufficient, cause would lead to a more fruitful inquiry into the definitions and measurement of disability.

Differences in criteria constitute a fourth influence on operational definitions. Agencies may agree on factors that contribute to disability but use different cutoff points when distinguishing the disabled from the nondisabled. For example, with most private insurance, at least for an initial period, an individual is considered disabled if he cannot perform work similar to his own job. In contrast, under Social Security programs, an individual must be unable to engage in <u>any</u> gainful activity in order to qualify for disability benefits.

Some agencies rely primarily on the judgments of professional groups or teams with few or no indicators or criteria to guide decisions. In effect, the operational definition of disability in such agencies is that it is what one or a group of professionals say it is. Welfare agencies leaned more in this direction in evaluating applicants for the program of Aid for the Permanently and Totally Disabled (APTD). The general acceptance of a physician's statement for the purposes of Temporary Disability Insurance (TDI) provides another example of this approach. Often, extraneous factors such as individual differences among professionals and variations in therapist-patient relationships strongly influence this as an operational definition.

Abstract concepts in studies and statutes usually evoke less controversy and disagreement than the indicators and measures used to operationalize them. In research, the relationship between concepts and measures calls into question the scientific issues of reliability and validity. In addition, the important legal and moral question of equity is often raised concerning measures used in establishing eligibility for benefits and services in the various disability programs.

In specifying operational definitions of concepts embodied in the statutes, administrative agencies exercise what actually amounts to legislative power. Operational definitions are used in many studies and programs as a way to deal with the complexity of concepts such as disability. Serious challenge to such definitions and measures employed by service agencies usually comes from the courts when cases go that far, which is less likely in the case of rehabilitation services than in relation to cash benefits.

In the sections which follow, we estimate numbers of severely disabled persons, always conscious of the fact that we deal with <u>survey</u> definitions. Our estimates are of the population of the long-term severely disabled, but to the extent that the educational, rehabilitative, or other service programs are successful, the population under study does not remain a fixed one. Even the stability of the aggregate totals over time should not obscure the fact that any individual with "severe disability" today may, with programmatic help, personal resolve, or technical breakthrough, emerge as a member of the work force or a person better able to perform in an ordinary social role.

This last is a crucial point, because it indicates the dynamic character of the problem. In 1955, the Department of Health, Education, and Welfare made a study of the homebound. There were many descriptions of the persons who at that time were so disabled as to be confined to their homes. Many, for example, were quadriplegics from trauma or polio. Most of these persons, if they lived at all, were confined to life in an iron lung or on a bed with an attendent on duty. Today the executive director of one of the organizations which participated in the Comprehensive Needs Study has quadriplegia from polio, gets around Berkeley unattended in his electric wheelchair, and travels across the country with his portable respirator. Such breakthroughs in technology, both in medicine and hardware, have freed from their beds many persons who were considered homebound 20 years ago.

What this development has done for the concept of disability is to identify a new set of persons for whom the labor market and vocational rehabilitation must make places. These persons have in turn identified architectural and transportation barriers because they are now able to get out of their homes.

A decade or two ago an intellectually unimpaired paraplegic or quadriplegic without doubt would not have been considered feasible for vocational rehabilitation. Today, many rehabilitation professionals, while considering most paraplegics severely impaired, would not say that they are automatically infeasible for rehabilitation. Many quadriplegics, if they have some residual limb movement, can be trained to be mobile and employed, although the need for attendants is still present and employer reluctance is great.

To a greater and greater extent, then, the most severely disabled or most severely handicapped are those in various institutions or those still homebound. For the most part, VR has done little for them because of its mandate to look to employability. But if independent living is the goal, then this is a key population. Many persons in institutions are there, not because they are so much more impaired than others in the community but because there is no one to care for them or they are poor. This is the way in which they can receive public care. There is no set of public programs oriented toward maximal self-care by these people in residential settings of their choice. To this extent, the issues get involved with questions of the deinstitutionalization of the severely impaired, including the elderly, as we will discuss in the section on Long Term Care.

However, the most severely disabled and those needing long term care are not synonymous. Many severely disabled persons do not need long term care, even if we define this care to include in-home services where one of the key requirements is some level of supervision. The reason is that many severely disabled persons can care for themselves, despite the inconveniences caused by architectural and transportation barriers and reduced income as well as the nature of their disability.

It is this distinction between ability to care for oneself and the need for assistance and supervision which distinguishes the target population of long term care (LTC) from the most severely handicapped, rather than the duration or severity of disability or the care setting. A paraplegic in a wheelchair may be quite capable of self-care. The individual may need more income, some social services, perhaps some VR services, but not necessarily long term care. Others--for example, the severely retarded or the very old senile person--may have no comparable severe disability condition with respect to mobility or in the sense of body damage but may require long term supervision and assistance.

Mental Conditions

The conceptual differentiation discussed so far is more clearly applicable to physical than to mental conditions. Many contend that models used in defining and identifying structural and physiological pathology and impairments are not suited to emotional and intellectual problems. Proponents of this position also maintain that the etiology and definitions of the latter problems are more socially grounded.

While examples can be found to fit the conceptual entities in the present scheme, three major difficulties are encountered in applying them to emotional and intellectual conditions. The first is that, except for certain types of cases including organic conditions, the indicators of pathology, impairment, functional limitations, and disability are not empirically separable. They are all inferred from the same behavioral manifestations.

The second difficulty lies in that, given the absence of signs and laboratory findings identifying many types of emotional problems, the diagnosis depends upon symptoms expressed by the patient. This relates to the third difficulty, the absence of well-established and widely observed criteria for consistent classification, even on the basis of symptoms.

The status of knowledge about mental disorders has led some researchers and administrators to concentrate on measuring limitations and disabilities, bypassing the identification of pathologies and impairments as an initial step. While less appropriate for treatment and clinical management of patients, this approach better serves the purpose of evaluating eligibility for disability-related benefits and assistance. It is also entirely consistent with the thesis embodied in the conceptual distinctions presented above--that disability is manifested at the social level rather than according to the degree of physical impairment, that different types of impairments may result in the same pattern of disability, and conversely, that similar impairments may result in differing patterns of disability.

Survey Responses to RSA Definition

The first question in Part I of the provider survey addressed one of the most basic questions in the Comprehensive Needs Study, namely: "Who is severely handicapped?" Respondents were presented with the definition of a "severely handicapped person" taken from the Rehabilitation Act of 1973, as implemented by the regulations of the Department of Health, Education, and Welfare. There, a severely handicapped person is defined as one who:

> Has a severe physical or mental disability which seriously limits his functional capacities (mobility, communication, self-care, self-direction, work therapy or work skills) in terms of employability;
>
> whose vocational rehabilitation can be expected to require multiple vocational rehabilitation services over an extended period of time; and
>
> who has one or more physical or mental disabilities resulting from amputation, arthritis, blindness, cancer, cerebral palsy, cystic fibrosis, deafness, heart disease, hemiplegia, hemophilia, respiratory or pulmonary dysfunction, mental retardation, mental illness, multiple sclerosis, muscular dystrophy, musculo-skeletal disorders, neurological disorders including stroke and epilepsy, paraplegia, quadriplegia, and other spinal cord conditions, sickle cell anemia and end-stage renal disease, or another disability or combination of disabilities determined on the basis of an evaluation of rehabilitation potential to cause comparable substantial functional limitation.

When the respondents were asked to consider whether the definition quoted above provides an adequate operational definition of a severely handicapped individual for vocational rehabilitation purposes, 86 percent answered affirmatively. The open-ended responses gave insight into the current definition's inadequacies, particularly when the respondents were asked to consider alternative definitions.

Table 2-2

Responses to Question About Adequacy of Current Definition of Severely Handicapped

Affiliation of Respondents	Definition Adequate		Definition Not Adequate		Total	
	N	%	N	%	N	%
State Departments of Vocational Rehabilitation	504	85.4	86	14.6	590	100
State DVR directors and blind agency directors	48	76.2	15	23.8	63	100
Sheltered workshops	83	93.3	6	6.7	89	100
Rehabilitation centers	149	85.1	26	14.9	175	100
Voluntary rehabilitation agencies	127	87.6	18	12.4	145	100
Developmental disabilities	15	78.9	4	21.1	19	100
Educators	35	87.5	5	12.5	40	100
Insurance rehabilitation staff	16	84.2	3	15.8	19	100
Rehabilitation specialists	31	79.5	8	20.5	39	100
Total	1008	85.5	171	14.5	1179	100

A total of 188 persons responded with write-in comments. Out of those responding, 45, or one out of four, felt that severe handicaps should be defined solely in terms of functional limitations. Thirty-one felt the definition should take into account extenuating personal characteristics (e.g., age, education, etc.) and/or outside factors that might affect rehabilitation, such as availability of services and the state of the job market. Some felt that the current definition was too restrictive, too vague, or too broad. Others believed that a severely handicapped person should be defined in terms of time and services required for rehabilitation, or as "one who in all probability cannot be employed."

Chapter 3

THE VOCATIONAL REHABILITATION SYSTEM

The Vocational Rehabilitation system, which includes the State-Federal program and private, non-profit organizations and facilities, attempts to serve a vocationally disabled population. Included in this group are individuals who, as a result of a mental or physical handicap are unable to develop or regain vocational skills necessary to employment. Consequently, they are totally or partially unable to carry on gainful employment. The Federal Government provides 80 percent of the funding for the Federal-State programs. Most vocational rehabilitation services are provided through the Basic Support Program and the Trust Fund Program of the Rehabilitation Services Administration (RSA). Other agencies engaged in or assisting rehabilitation include the Veterans Administration, Manpower Administration of the Department of Labor, the Office of Education, the Bureau of Education for the Handicapped, the President's Committee on Employment of the Handicapped, the Work Incentive Program, and the Federal Employment of the Handicapped program.

The range of services generally available under the vocational rehabilitation program for serving the various needs of the disabled include vocational training, income, health, educational, and other services to encourage self-support so that the individual can gain or regain the abilities necessary to engage in vocational activity. The program is tailored to fit the individual's needs, capabilities, and desires. In addition to vocational education and/or on-the-job training it offers extensive testing, restoration, services to the family, and other supportive services such that the individual has the greatest chance of achieving a rewarding vocational goal. If the individual cannot compete in the labor market because of functional limitations imposed by the disabling condition, he or she can still be productive in work such as housekeeping or sheltered employment.

Eligibility criteria specify that the client must have a physical or mental condition which is expected to be stable or become more severe and which causes loss of ability to engage in normal activities or a limitation on activities. In addition, there should be reasonable expectation that the services provided will allow the individual to engage in gainful employment in sheltered workshops, or in the home. These criteria generally disqualify individuals who fall into the following categories: 1) persons whose mental or physical condition does not prevent them from engaging in vocational activities; 2) those who are either too young or too old; 3) those for whom vocational rehabilitation is a remote possibility because of the severity of their disability; and 4) those who do not want to achieve a goal of vocational activity or see it as unrealistic.

One criterion for determining the need for Vocational Rehabilitation services is the incidence of disability. Attempts to estimate the number of disabled persons who need or are receiving rehabilitation services have produced widely varying numbers. This is because the criteria for acceptance are not clearly articulated from region to region and also because the receipt of services through the Vocational Rehabilitation system is not limited to a single program. Thus there are inevitable instances of double counting. In any case, the size of the Vocational Rehabilitation program and the number of rehabilitants have increased. The number of persons who applied for services during the year increased by 4 percent in FY 1973 over FY 1972, from 1,379,196 to 1,431,347. Of these cases referred in FY 1973, 71 percent (1,017,630) were new applicants as of July 1, 1972. Approximately 34 percent of these cases were accepted for services, 35 percent were rejected, 2 percent were accepted for extended evaluation services, and no decision had been reached concerning the eligibility of the remaining 29 percent as of June 30, 1973. There was an 11 percent increase in the number of persons rehabilitated, from 326,138 in FY 1972 to 360,726 persons in FY 1973.

Several problems have been cited which hinder the effective operation of the Vocational Rehabilitation program. These include insufficient funds, inadequate coordination among different agencies which provide services to handicapped persons, and lack of outreach to persons needing vocational services, especially the most severely disabled with low potential for vocational success. Another criticism suggests that counselors select the least disabled persons eligible to receive services under the program so as to increase the number of successfully rehabilitated clients. It is difficult to test this hypothesis, since in many studies the disabled are classified by type of disability rather than by severity of disability. Results of the 1966 Social Security Survey of the Disabled show little variation between the number of severely disabled who received services and those who were occupationally disabled or who had secondary work limitations. Of those accepted into the program, rougly 80 percent are successfully rehabilitated.

Table 3-1

Percent of Disabled Non-Institutionalized Adults
Aged 18-64, Receiving Services, 1966

Severity of Disability	Number in Thousands	Percent Who Received Services
Severely Disabled	6,100	13
Occupationally Disabled	5,014	13
Secondary Work Limitations	6,639	10

Source: Social Security Survey of the Disabled, 1966.

Jaffe, in a study of workers in New York who had sustained serious, permanent work-related injuries, found that only 1 in 10 had received vocational rehabilitation services following their injury. Two in 10 ended up with either a very poor job or no job at all, and nearly 6 in 10 held jobs that were no better than the ones they had held at the time of injury.[1]

Other studies have found that only small percentages of disabled employed in various occupations have found their jobs with the assistance of vocational rehabilitation services. For example, the National Committee for Careers in Medical Technology found that only 5 percent of disabled people working in medical laboratories had had the assistance of VR services. The authors further found that VR agency referrals to medical laboratory training programs did not increase, even after substantial efforts had been made to inform VR agencies and counselors of a special program for the disabled in medical laboratory training.[2]

While studies indicating that very small percentages of employed disabled people have received VR services are not conclusive in that no estimation is made of the proportion of these workers who could have benefitted from them, they do tend to support the conclusion that these services fail to reach many who need them. It seems likely that among the employed disabled, a large proportion could have found their jobs faster, or found better jobs, with the aid of good VR services.

A Greenleigh Associates study finds that not only VR services but other services aimed at placing people in employment are greatly underserving the disabled population.[3] This is true, for example, of the U.S. Employment Service

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[1] A. J. Jaffe, Lincoln H. Day, and Walter Adams, "Disabled Workers in the Labor Market," Rehabilitation Literature, May 1969.

[2] Careers for the Handicapped in Medical Laboratories, Final Report (National Committee for Careers in Medical Technology, 1969).

[3] Greenleigh Associates, Inc., A Study to Develop a Model for Employment Services for the Handicapped (Chicago: The Associates, 1969).

and the Department of Labor's Manpower Development Training Act (MDTA) programs. Neither of these services has specialists or special programs for the disabled. The study found that the MDTA programs in particular were greatly underserving the disabled because of their tendency to take only able-bodied trainees.

Results of a study of selected demonstration projects to assess the delivery of Vocational Rehabilitation services for disabled public assistance clients reveal that the major reasons for non-acceptance into a project were: little or no functional capacity for work due to the limitations imposed by the disabling condition; refusal to accept services; the nonexistence of substantial disability; and a combination of disability, illiteracy and lack of skill.[4] Throughout the analysis, variables which indirectly indicated the severity of disability (e.g. receipt of Aid to the Permanently and Totally Disabled and the presence or absence of a secondary disabling condition) were consistently related to both client acceptance and rehabilitation rates.

Vocational Rehabilitation agencies rely on rehabilitation facilities for a great proportion of client services. Consequently, the success of the VR program is dependent on the growth and effectiveness of rehabilitation facilities which provide evaluation, treatment, and training for handicapped persons, particularly the severely disabled who could not be effectively rehabilitated without the assistance of these operations. Facilities include sheltered workshops, comprehensive rehabilitation centers and a variety of centers for the treatment of specific disabilities such as disabilities in speech, hearing, and sight, and mental retardation, and illness.

Sheltered Workshops play an important rôle in the rehabilitation system. Generally, these facilities not only expose the disabled individual to the

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[4] Greg and Sherwood, A Report on Fourteen Demonstration Projects in the Rehabilitation of Public Assistance Recipients (Gainesville, Fla.: Florida State University, 1971).

experience of doing real work for real pay but also rehabilitate him to respond and adapt to the routine nature of work. They focus on vocational adjustment and/or training but may provide comprehensive rehabilitation services. Many of their functions may overlap with the roles of other agencies and facilities within the rehabilitation system. In addition, they have a potential for expansion to serve the more severely disabled. These organizations represent a heterogenous population motivated by different interest groups with different objectives. They operate as social agencies, business organizations, or production operations, serving individuals with a particular kind of disability or a wide range of disability types. However, Sheltered Workshops serve a client group which differs in several ways from the general population of rehabilitants in State-Federal VR programs. They represent a proportion of the VR population whose vocational and educational incapacities are greater than those of the average rehabilitant, who suffer from more severe impairments and are more economically disadvantaged. The majority of Sheltered Workshops are administered by the Department of Labor, which provides wage and hour certificates so that below-minimum wages can be paid to clients.

One of the strengths of the VR process is its expertise in case management and the brokering of community resources. However, VR has little experience with really long durational case management, as will be required for many in an independent living program. Persons in nursing homes or in retardation facilities may need tracking for years, for example.

THE REHABILITATION MODEL

The rehabilitation process is a sequence of services designed to move the handicapped client toward the goal of placement in a gainful occupation.

Along with the client, the rehabilitation counselor has the central role in the rehabilitation process. The counselor facilitates movement toward the achievement of a realistic vocational goal. Usually the counselor is concerned with the total process from eligibility determination through coordination of medical and restorative services, provision of training, placement, followup, and closure.

The most important function of the counselor is to help the disabled client acquire insight into his own capacities, attitudes, interests, alternatives, and personal characteristics in relation to the requirements, demands and possibilities of the local labor market. When a vocational objective is jointly agreed upon, a services plan is developed to reach that objective.

The core of the rehabilitation counselor's work is counseling. However, significant amounts of time are spent on coordination and integration of services, evaluation of client performance, management of caseloads, case reports, job-finding reports, and work flow.

Referral

The rehabilitation process is initiated when an individual comes or is referred to a local agency for services. Table 3-2 illustrates the sources of referrals to rehabilitation agencies.

Eligibility Determination

Once an individual has been referred to a local VR agency, the case is assigned to a rehabilitation counselor who arranges for the initial intake interview. The counselor's objective is to gather sufficient data to effectively determine eligibility for services. Basic information is collected concerning the individual's prior health and physical condition, intellectual capacity, educational experience, vocational background, and personal, family, and social relationships. Throughout the evaluation period this information is expanded and updated by additional counseling sessions, receipt of pertinent medical

Table 3-2

Sources of Referral of Persons Rehabilitated by State Vocational Rehabilitation Agencies, FY 1972

(percent distribution)

Type of Organization	Number of Persons	Percent
Educational Institutions		
Elementary or High School	37,937	12.4
Other	10,555	3.4
Hospitals and Sanitariums		
Mental Hospital	22,902	7.5
Other	21,135	6.9
Health Organizations		
Rehabilitation Facility	5,121	1.7
State Crippled Children's Agency	782	0.3
Other (Public and Private)	11,150	3.6
Welfare Agencies		
Public	26,914	8.8
Private	1,558	0.5
Public Organizations and Agencies		
Social Security Administration	8,857	2.9
Workers' Compensation	2,264	0.7
State Employment Service	12,161	4.0
Correctional Institutions, Courts	20,224	6.6
Other	13,708	4.5
Private Organizations		
Artificial Appliance Company	4,494	1.5
Other	3,793	1.2
Individuals		
Self-Referral	39,391	12.8
Physicians	30,711	10.0
Other	33,322	10.9

Source: Characteristics of Clients Rehabilitated in Fiscal Years 1968 - 1972 (Rehabilitation Services Administration, U.S. Department of Health, Education, and Welfare, 1972), Table 8.

data from hospitals, clinics, and physicians, and preliminary diagnostic medical and psychological studies to evaluate the client's rehabilitation potential.

Eligibility for services is based on three conditions:

1. The presence of a physical or mental disability.
2. The existence of a substantial handicap to employment.
3. A reasonable expectation that vocational rehabilitation services may enable the individual to engage in gainful employment.

Eligibility determination is based on the eligibility criteria and the preliminary diagnostic study. In most States the determination of eligibility is the responsibility of the rehabilitation counselor, made in consultation with the client.

In cases where the preliminary diagnostic study is insufficient to determine rehabilitation potential, the counselor may recommend certification of a period of extended evaluation not to exceed 18 months. The scope of services provided during extended evaluation may include any that are necessary to determine the individual's vocational potential. At any time prior to the completion of the 18-month period, termination of services shall take place if it has been determined that vocational potential is not present or the individual is found ineligible for services because it has been firmly established that rehabilitation services will be of no benefit in terms of employability.

A decision of ineligibility for rehabilitation services indicates that the criteria for eligibility cannot be met. An individual who has been found ineligible for services has the right to:

-- Appeal the decision and request an administrative review.

-- Request a fair hearing if he is not satisfied with the administrative review.

-- Have the eligibility decision reviewed on an annual basis.

-- Know that his individual case record will be kept confidential.

The Individual Written Rehabilitation Program

The development of an Individual Written Rehabilitation Program (IWRP) marks the beginning of the disabled person's rehabilitation process. The first step in providing services or extended evaluation for eligible clients is a written rehabilitation plan jointly formulated by the client and counselor. The primary purposes of the IWRP are to define the long-range employment goal for the client and the specific intermediate services to be provided in the achievement of this goal.

Together the client and counselor develop the plan,based on a realistic assessment of the individual's potential achievement through the sequence of rehabilitation services to be provided. Intermediate objectives are determined that will detail the steps needed to be taken by the client and counselor in the implementation of the plan. As far as possible, the IWRP must specify the services to be provided, the projected initiation date of each phase, and the duration of each program sequence.

Provisions are made for periodic review and evaluation of the client's progress toward the rehabilitation objectives. The client and counselor decide what kind of criteria or evaluation procedure will be used to measure the individual's progress. Depending on the individual's program, some of the means of evaluation commonly used are medical reports, grades, training progress reports, client feedback and self-assessment, and the counselor's assessment.

The IWRP must also include the extent to which, if any, the client will participate in the costs of rehabilitation services. States may elect to apply an economic needs test in providing services to an individual. However, no needs test can be considered in providing the basic program services of evaluation of rehabilitation potential, counseling, guidance, referral services, or placement.

Revisions or amendments to the IWRP are made as required.

Rehabilitation Services

The range of services provided to the disabled individual may cover any goods and services necessary for the achievement of vocational potential. The rehabilitation counselor arranges for the purchase of services outlined in the individual's rehabilitation plan. Full use is made of all available public agency services. Services may also be purchased from private agencies and individuals who serve the general public. The scope of services available to the handicapped individual is comprehensive and may include:

1. Counseling and guidance.
2. Physical and mental restoration services.
3. Prevocational evaluation and training.
4. Vocational and other training services, including personal and vocational adjustment, books, tools, and other training materials.
5. Maintenance allowances during the rehabilitation process.
6. Transportation.
7. Services to the handicapped individual's family when such services are necessary to the adjustment or rehabilitation of the handicapped person.
8. Interpreter services for the deaf.
9. Reader services, rehabilitation services, orientation, and mobility services for the blind.
10. Telecommunications, sensory, and other technological aids and devices.
11. Work adjustment and placement counseling.

12. Placement services.
13. Occupational licenses, tools, equipment, initial stocks, and supplies.
14. Any other goods and services which can reasonably be expected to benefit the handicapped person in terms of employability.

Medical Restoration Services

Physical restorative services are furnished to a client when such services can reasonably be expected to eliminate or substantially reduce the handicapping condition within a reasonable period of time and the individual's physical condition is stable or slowly progressive in nature. These services include:

1. Medical or surgical treatment.
2. Psychiatric treatment.
3. Dentistry.
4. Nursing services.
5. Convalescent, nursing or rest home care.
6. Prosthetic devices.
7. Physical therapy.
8. Occupational therapy.
9. Physical rehabilitation in a rehabilitation facility.
10. Other medical or medically-related rehabilitation services.

Mental Health Services

Clients with emotional or psychiatric disabilities may be provided psychiatric services necessary to accomplish vocational rehabilitation. Treatment may include psychotherapy, marital or family therapy, group psychotherapy, or whatever is considered appropriate for the individual client.

Training

Vocational rehabilitation training includes any type of training that may be necessary for rehabilitation and can be categorized as vocational, prevocational, or personal adjustment training.

Vocational training for a specific occupation provides the knowledge and skills necessary for performing the tasks of that occupation.

Prevocational training is basic training given for the acquisition of background knowledge preparatory to vocational training or employment where the primary skills are learned on the job. Prevocational training may also be provided for the removal of educational deficiency which interferes with the utilization of job skills already possessed by the client.

Personal adjustment training includes training given to:

1. Assist the individual to acquire personal habits, attitudes, and skills that will enable effective functioning with a disability.
2. Develop or increase work tolerance prior to engaging in prevocational or vocational training or employment.
3. Develop work habits.
4. Provide skills or techniques for the purpose of compensating for the loss of limbs or sensory function.

The training components of vocational rehabilitation services are broadly defined so that the training needs of the handicapped individual being served can be met. Training may be provided at schools, colleges, or universities; workshops or rehabilitation facilities; by tutor or correspondence, apprenticeship or on-the-job training; or other training programs.

Work experience is primarily obtained through sheltered workshops. Transitional workshops are used for clients between the medical restoration phase of rehabilitation and more advanced training or final placement in employment. The workshop experience for many clients is an interim employment opportunity to gain training and self-confidence in an on-the-job environment. For those unable to compete in a regular employment situation, the sheltered workshop offers permanent employment.

Supportive Services

Materials necessary for the training of the client are provided. These include books, supplies, tools, learning aids, materials used in mechanical or technical training, uniforms, fees, small equipment used in technical, mechanical, or commercial training, or any other materials required by the individual training program.

Driving aids may be purchased for a client who needs them to operate an automobile in order to secure or retain employment.

Transportation may be provided when it is necessary for the attainment of the vocational goal for clients in financial need during the period of rehabilitation.

Clients found to be in financial need may be provided a maintenance allowance to assist with the costs of room, board, and incidental expenses during the period of rehabilitation and training.

Placement

The length of the rehabilitation process varies from individual to individual. In some cases successful medical restoration may be sufficient to return a disabled person to gainful employment or former occupation. For others -- particularly more severely handicapped persons -- the process may cover a period of years. For these individuals the rehabilitation program may include extended evaluation, restorative medical or psychiatric services, personal adjustment training, vocational training, and/or on-the-job experience in employment.

Placement represents to the client and the counselor the successful achievement of the objectives and goals of the rehabilitation effort. It is the long-range goal toward which all interim rehabilitation services are directed.

The rehabilitation counselor usually participates in the placement process, although sometimes specifically trained placement specialists participate in this service element.

The counselor is responsible for seeing that the client is placed in suitable employment consistent with the rehabilitation plan. For the counselor, the placement process involves contacting employers directly, visiting prospective job sites to conduct job analysis, and referring clients for job interviews.

The rehabilitation counselor or agency placement specialist is not always the direct placement agent for an individual. Many rehabilitated clients return to their previous occupation or place of employment, while some find suitable employment on their own or through the vocational training program that they have participated in. At times clients are referred to local Departments of Employment Security (public employment services). Placement of clients is not limited solely to the private business sector. Self-employment can be the vocational goal of a handicapped person. The Rehabilitation Act provides for funds to establish individuals in small business enterprises, including financial assistance to obtain required licenses, tools, equipment, and initial stocks and supplies. Management and supervisory assistance are also available to clients who establish their own businesses.

Post-Employment Services

After placement in employment the counselor has the responsibility of following up on the client's adjustment to employment. Supportive services are available to successfully rehabilitated clients to lend assistance in maintaining employment. These services are available to all clients when problems arise after placement related to the original handicapping condition.

VR FUNDING FOR THE SEVERELY HANDICAPPED*

The Basic Support Program of Vocational Rehabilitation is a program of formula grants to state rehabilitation agencies to provide and support

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*These totals include Federal expenditures plus State and local government matchings. We use these data for purpose of comparison of expenditures with those programs defined in Chapter 25 on other programs.

rehabilitation services for the handicapped, with priority given to the needs of the most severely handicapped. An analysis of the data from the agency files allows us to sort out those persons receiving vocational rehabilitation who would be considered severely disabled under RSA standards. Utilizing this technique, we have found that 40.56 percent of all vocational rehabilitation recipients can be considered severely disabled. We use this estimate for all vocational rehabilitation programs for which we have no more specific information. However, under some programs a person must be "severely disabled" to qualify for assistance. Therefore we count all expenditures for those programs as going to the severely disabled. For the basic program we use 41 percent as the share of the severely disabled and find that $301,862,000 can be allocated to severe disability.

The Service Project Activities of Vocational Rehabilitation is a program of project grants to State VR agencies to expand and improve services above those provided under the Basic Support Program. Priority is given to the needs of the most severely handicapped. Using the estimate of 41 percent severely disabled, we allocate a portion of these expenditures to the severely disabled. Expenditures on the severely disabled under this program thus amounted to $28,632,000 in 1973.

Vocational Rehabilitation for Social Security Disability Insurance Beneficiaries is a program designed to support State rehabilitation services for those DI beneficiaries who show sufficient potential to return to gainful employment; emphasis is on returning a maximum number to productive activity. The payments for this program originate from the Trust Fund and cannot exceed 1 1/4 percent of total cash payments to disabled OASDHI recipients (1 1/2 percent after the beginning of fiscal 1974). Due to the requirements of the parent program, we take 100 percent of these expenditures as benefitting the severely disabled. That is, we do not consider the fact that the recipients have rehabilitation potential as a basis to consider them less than severely disabled. We therefore calculated that $45,169,000 was spent on the severely disabled in 1973 under this program.

Vocational Rehabilitation for Supplemental Security Income Beneficiaries is a program of Federal payments to State agencies for the referral and vocational rehabilitation of Supplemental Security Income recipients. Since the emphasis here is on "vocational rehabilitation," we assume that few persons in this program are past age 65 and therefore "old age" recipients. Thus enrollees in the program are most likely to be either blind or permanently and totally disabled. We therefore assume that 100 percent of them are severely disabled, again based upon the entrance restrictions of the parent program. We note that those people who are closed as successfully rehabilitated very likely will not be severely disabled at closure. Still, since SSI requirements at entrance are the key factor, we consider 100 percent as initially severely disabled, for a total expenditure on the severely disabled of $39,674,000 in 1973.

Chapter 4

ESTIMATES OF THE SEVERELY DISABLED POPULATION NOT IN INSTITUTIONS

The few major surveys conducted to determine the extent of disability among the noninstitutionalized disabled population in the United States include the Social Security Survey of Disabled Adults (1966), the Health Interview Survey (1969-70), the Ohio State Survey (1972), and the Census of Population: Persons with Work Disability (1970). All of these surveys address the problem of estimating the number disabled. Following the definitional conventions of the previous section, then, they do not provide estimates of the number of handicapped, because they do not deal with the concept of the interaction of the disabled person and the environment.

The definitions adopted for this review of existing surveys are close to, but not the same as, the terminology developed by Lawrence D. Haber of the Social Security Administration.[1] The SSA terminology is very clear and useful because it isolates such factors as physical impairment, functional limitation, and work disability. It is not sufficient just to identify the disabled; for this study, it is also necessary to identify those with functional limitations in certain areas in order to plan programs for them. The major common element in most surveys is the effect of impairment on work behavior, and for that reason we focus on it here.

The Social Security terminology focuses on the term "disability," which is rooted in a physical or mental impairment. An impairment is a defect which comes as a consequence of disease, accident, or abnormal birth. Examples of physical impairments include muscle atrophy following a stroke, paralysis following an accident, or brain damage coming as a result of abnormal birth.[2]

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[1] Lawrence D. Haber, <u>Identifying the Disabled: Concepts and Methods in the Measurement of Disability</u>, Report No. 1, Social Security Survey of the Disabled: 1966 (DHEW, 1967).

[2] This sequence is not clear in the case of mental impairments. For example, it is not clear that schizophrenia is a disease which causes certain behavior impairments, as opposed to being a catchall label which conveniently describes people who are in some way different from a prescribed norm.

A physical impairment might lead to functional limitations, that is, to restrictions or losses in physical activities such as walking, lifting, dressing or eating. These functional limitations in turn might cause restriction of normal activity such as going outside the home less frequently, working less than full time, or quitting work altogether. The activity limitations impinge upon a person's ability to perform a particular role, for example, the roles of mother or father, housewife, or worker.

Disability is defined as the inability to perform a certain role. The Social Security Survey concentrated upon work disability; more specifically, long term disability was defined as "a limitation in the kind or amount of work (or housework) resulting from a chronic health condition or impairment, lasting 6 months or longer."[3]

For the purposes of comparative statistical analysis, we have chosen to define the following three groups of vocationally disabled people:[4]

1. Most Severely Disabled--Those individuals who reported that their health kept them from working at all and who actually were not in the labor force during the year prior to the survey, or who had become permanently disabled during that year.[5]
2. Severely Disabled -- Those individuals with a health condition which

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[3] Kathryn H. Allan and Mildred E. Cinsky, General Characteristics of the Disabled Population, Report No. 19; Social Security Survey of the Disabled: 1966 (DHEW, 1972), p. 2.

[4] This analysis deals only with the noninstitutional population 18 to 64 years of age; other sections of the study will deal with children, old people, and the institutionalized populations.

[5] More specifically, the respondents must have had a health condition which prevented them from working for at least a year prior to the survey; they must not have been looking for work at the time of the survey; and they must not have expected to work in the year subsequent to the survey. Or, if they had become disabled within the year prior to the survey (less than 1 percent of the individuals most severely handicapped), they must have responded that they (a) did not expect to work for the duration of the survey year or (b) were receiving Social Security or APTD payments because of disability.

allowed them to work but only occasionally or irregularly. This group also includes those persons who had said that their health prevented them from working but who did not satisfy the other criteria necessary to be considered most severely disabled.

3. Partially Disabled -- Those individuals who were able to work regularly but had a health condition which limited the amount or kind of work (including housework) they could do.

DESCRIPTION AND RECONCILIATION OF PREVIOUS SURVEY ESTIMATES

To arrive at a 1975 estimate for the number of disabled, it was first necessary to make a comparison of estimates from the existing major surveys. The four surveys which were used are described in more detail below. Each of these surveys gave an estimate for the percentage of the population which is disabled, shown in the last column of Table 4-2. These estimates are quite different, ranging from a low of 8.9 percent from the Health Interview Survey to a high of 17.2 percent from the Survey of Disabled Adults. Furthermore, the terminology and disability categories used in the analysis below will be different from those which we have just defined, since each survey had its own set of definitions, which are of limited comparability.

Table 4-1 summarizes the estimates of the total disabled population and of the disabled with complete work disability from four surveys: the Social Security Survey of Disabled Adults (SDA), the National Center for Health Statistics Health Interview Survey (HIS), the Ohio State University Survey of Service Organizations and the Public (OSU), and the 1970 Census of Population and Housing. We have chosen to focus on estimates derived from these surveys, because these were judged to be most universal and most in conformity with the definition of disability adopted by this study.

Table 4-1

Estimates of the Disabled Population of Working Age Derived from Alternative Surveys, by Degree of Severity (in millions)

	All Disabled			Disabled With Complete Work Disability		
	male	female	total	male	female	total
Survey of Disabled Adults (1966)	8.4	9.3	17.7	1.6	2.1	3.7
Census of Population (1970)	6.4	5.7	12.1	1.8	2.8	4.6
Health Interview Survey (1969-70)	3.3	4.3	7.6	1.8	0.6	2.5
Ohio State University Survey (1972)	4.6	7.4	12.0	2.5	4.5	7.0

Sources: Urban Institute cross-tabulation of the SDA data file and the Census Public Use Sample file; U.S. National Center for Health Statistics, Series 10, No. 80, Tables 1, E; Nagi, "Disability and the Severely Disabled," Table 7, p. 35.

The estimates of the disabled population are standardized for differences among the surveys in the age composition of the population by limiting the numbers displayed in Table 4-1 to the population aged 18 to 64. We address the question of estimates of severely disabled populations outside this age range in the next section of our study.

Table 4-1 reveals that the estimates of the total disabled population range from a high of 17.7 million persons to a low of 7.6 million persons. The estimates of the severely disabled population show a considerably smaller amount of variation, ranging between 2.5 million and 7.0 million.

Much of the difference among surveys in their estimates of the partially disabled stems from differences in survey methodology. The largest estimates were derived from the survey (SDA) that employed trained interviewers who interviewed the disabled persons directly. The other surveys relied on either mail surveys (the Census) or did not necessarily interview the disabled person directly (the Census, the HIS). This could have resulted in an underreporting of marginally disabled persons by other members of the family.

Another factor that may have caused variations is the difference of the time at which the surveys were taken and the resultant differences in population associated with these time differences. In order to standardize for this, we have also summarized disability prevalence rates in Table 4-2. Prevalence rates also vary considerably, ranging from 8.9 to 17.2 per 100 total population in the relevant age range. Again, the prevalence rates for the severely disabled display considerably less variation, ranging from 2.2 per 100 total population to 6.3.

Other survey differences in definitions and methodology are discussed in greater detail below.

Table 4-2

Percent of Civilian Disabled Population[1] of Working Age Which is Not Institutionalized: Four Major Surveys

Survey	Date	Population Surveyed	Percent with Partial Work Disability[2]	Percent with Complete Work Disability[3]	Total
HIS	1969-70	17 - 64, disabled over 3 months	6.7	2.2	8.9
Census	1970	18 - 64, disabled over 5 months	5.8	4.1	9.9
OSU	1972	18 - 64, disabled	4.4	6.3	10.7
SDA	1966	18 - 64, disabled over 6 months	13.6[4]	3.6	17.2

[1] The disability categories in this Table are intended to serve only as a basis of comparison for the 4 data files shown. Differences of methodology and definitions make this comparison only approximate, since no 2 surveys defined complete disability in the same way.

[2] Limited in kind or amount of work or housework.

[3] Complete work disability refers to inability to perform major activity for HIS; vocational disability for OSU; and inability to work at all for SDA and Census. (HIS and OSU include housewives unable to work. SDA classifies these housewives as "partial" and Census does not classify them at all.) See text for more details.

[4] This group includes those listed by the Social Security Administration (a) as having secondary work limitations; (b) as having an occupational disability; and (c) as being unable to work regularly.

Sources: HIS: U.S. National Center for Health Statistics, Limitation of Activity due to Chronic Conditions, United States, 1969 and 1970, Series 10, Number 80, Table 1.

Census: U.S. Bureau of the Census, Persons with Work Disability, 1970 Census of Population: PC(2)-6C, Table 1 and Table 6 (for derivation of civilian population estimate).

OSU: Saad Z. Nagi, "Tabulations from OSU Disability Survey - 1972," (unpublished).

SDA: Allan and Cinsky, General Characteristics, Tables E and 1.

The Health Interview Survey

In the National Health Survey, of which the Health Interview Survey is a part, disability is defined as "any temporary or long term reduction of a person's activity as a result of an acute or chronic condition."[6] For our purposes, the most significant classification is between levels of activity limitation due to chronic conditions.[7] These four categories are: (1) persons unable to carry on major activity for their group, major activity referring to ability to work, keep house, or engage in school or preschool activities; (2) persons limited in amount or kind of major activity performed; (3) persons not limited in major activity but otherwise limited; and, (4) persons not limited in activities.[8]

Separate data are collected on those who indicate some mobility limitation. In 1970, the HIS estimated that 8.9 percent of the population aged 17 to 64 years are disabled; of this group, 2.2 percent are completely disabled.

The HIS has several important limitations when it comes to estimation of the disabled population. One is that it undercounts the number of disabled women. In HIS, a person is asked questions about limitation in his or her major activity, and major activity is defined as the activity the person did most during the preceding 12 months. For men, there are two possible major activities, working and doing something else. For women, there are three possible responses: working, doing something else, and doing housework.

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[6] Charles S. Wilder, Limitation of Activity of Mobility Due to Chronic Conditions, Series 10, No. 96, National Health Survey (DHEW, 1974), p. 51.

[7] The health conditions must have been of at least 3 months duration at the time of the survey or have been one of a number of conditions always considered to be chronic.

[8] Note that HIS disability categories do not correspond to the ones we have adopted in this study.

If a woman had become disabled more than one year prior to the survey and had quit her job (or given up looking for a job), she might have stayed home and done housework. In that case, the survey would have asked if her health limited her ability to do housework. She could have replied negatively, even though she may have had a work-related disability; hence, this work-related disability would not have been picked up by the survey. By contrast, the SDA asked <u>all</u> women if their health limited the amount or kind of work they could do.

Table 4-3 gives the HIS and SDA estimates for men and women who were unable to work because of a health condition in 1966.[9] While the SDA total is over twice the HIS total, most of that discrepancy is accounted for by women.

Table 4-3

U.S. Civilian Non-Institutional Population Unable to Work Because of Health Condition 1/, 18-64 2/ Years of Age, 1966: HIS and SDA (in thousands)

	HIS	SDA
Total	1,523	3,717
Men	1,142	1,610
Women	381	2,107

1. HIS data include some women unable to do housework; SDA data include only those unable to work at jobs outside the house. In SDA, women who could not do housework were included among those with a "secondary work disability," a category within partial disability. HIS data are for disabilities of at least 3 months duration; SDA are for disabilities of more than 6 months duration.
2. HIS data include 17-year-olds.

Sources: HIS: National Center for Health Statistics, Report #61, Series 10, July 1965-June 1967, Table 1.
SDA: Report #19, Table E.

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[9] The comparison was made for people who were unable to work because this is a more unambiguous category than partial disability. Furthermore, as will be described below, there are reasons to believe that the SDA was much more thorough than the HIS in its estimation of the partially disabled.

The second HIS limitation is the use of a rather broad questionnaire which covers a number of health-related areas, such as the presence of acute health conditions, number of doctor or dentist visits, types of treatment undergone. Everyone, disabled or not, is asked all the questions. It can be argued that the more focused a survey is on a particular subject, the more accurate the information it will produce on that subject.

Finally, in earlier years the HIS relied on what is known as the "condition approach," whereby a person was asked about limitations in activity only if he first stated that he had a chronic health condition. Anyone who did not have a chronic condition was never given the opportunity to state that he was limited in activity.[10]

1970 Census

The 1970 Census of Population and Housing included three questions related to disability. This was the first year that the Census included questions on disability, and while this was an important advance over previous censuses, the wording of the questions unfortunately was ambiguous, as discussed below. Census data on disability had two categories: (1) those with a health or physical condition limiting the kind or amount of work they could do at a job were classified as having "partial work disability"; and (2) those whose health

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[10] The NCHS, aware of this shortcoming, changed the HIS questionnaire beginning in 1967 and 1968, so that a person is now asked first if he has had to restrict his activity as a result of a health condition, and then is asked to identify the health condition which caused the activity limitation. After this change was made in the questionnaire, the percentage of people reported as limited in their major activity increased, and at least for men, the HIS figures became more comparable to the SDA figures. National Center for Health Statistics, Limitation of Activity Due to Chronic Conditions, United States, 1969 and 1970, Series 10, No. 80, National Health Survey (DHEW, 1973), pp. 3-4; also, Interviewing Methods in the Health Interview Survey, Series 2, No. 48 (DHEW, 1972), pp. 1-6.

or physical condition kept them from holding any job at all were classified as having a "complete work disability."[11]

The Census found that in 1970, 9.9 percent of the population aged 18 to 64 were disabled, and 4.1 percent were severely disabled (Table 4-2).

There were two important limitations in the Census estimates of the number of disabled people:

1. The questionnaire itself was very long and dealt with a number of different areas. As noted above, this may have biased the estimates for the number of disabled people downward.

2. The Census question relating to severity of disability was very ambiguous: "Does his health or physical condition keep him from holding any job at all?"

This last could be interpreted as meaning, "Is there any job that he cannot do because of his health or physical condition?" rather than "Does his health keep him from working altogether?" (which was the intended meaning of the question). Many of the partially disabled could have answered this question affirmatively and would have been classified as completely rather than partially disabled. Accordingly, Census data may have underestimated the total number of disabled people but overestimated the number of completely disabled. A comparison of Census and SDA data is consistent with this hypothesis.

When looked at more closely, the difference between the two surveys' estimates for those unable to work is accounted for in large measure by white women aged 50-64.[12] Further research would be necessary to determine exactly why the data are so different for this particular group of women.

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[11] It should be clear that the Census disability categories are somewhat different from the ones we have adopted in this study. Those differences should be kept in mind when reading the description of Census data.

[12] Michael Arnow, "Estimates of Disabled Population for 1972," unpublished paper prepared for the Urban Institute Comprehensive Needs Study, pp. 28-30.

Ohio State University Survey of Service Organizations and the Public

Unlike the HIS and the Census, the OSU Survey concentrated entirely upon disability, which was viewed according to two scales: (1) a scale of work disability, and (2) a scale of independent living disability. "The first scale was based on responses to questions concerning work status and work limitations. Probes in work histories sought additional information about change in jobs or work settings because of disability, and adjustments made by employers or workers to accommodate limitations in activities. Similarly, information was sought about the degree to which respondents considered themselves homebound or needing assistance in mobility and in other activities involved in non-institutional living."[13]

The OSU Survey found that 10.7 percent of the population had a work disability, including 6.3 percent who were severely disabled[14] (Table 4-2). In addition, it found that 11.6 percent of the population had limitations in independent living, and 5.3 percent needed assistance either for mobility or personal care.[15]

Since the OSU Survey concentrated entirely on disability, it did not suffer from the problem of having many unrelated topics on the questionnaire, as did the HIS and the Census. The OSU still gave estimates which were quite different from SDA (much higher for completely disabled and much lower for partially disabled).

The major difficulty with this survey is its size. While for statistical purposes it is representative, there were a little over 5,000 respondents to the survey, 556 of whom were disabled (of which 334 were severely disabled).

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[13] Saad Z. Nagi, "An Epidemiology of Disability," unpublished (Ohio State University, 1973), pp. 12-13.

[14] This category, also called "vocationally disabled," includes persons who were out of the labor market due to disability (including housewives unable to do housework), and a small number of persons who were working on a limited, part-time basis. Note that OSU's disability definitions are different from those used in our study.

[15] Saad Z. Nagi, "Tabulations from OSU Disability Survey," unpublished, 1972.

Survey of Disabled Adults (SDA) of the Social Security Administration

The Survey of Disabled Adults (SDA) was conducted in 1966 by the Social Security Administration on the civilian non-institutionalized population of working age.

> The sample was taken from a 243 first-stage area design, combining the Census Bureau's Monthly Labor Survey (MLS) and Current Population Survey (CPS) primary sampling units. About 30,000 households were selected from 7 population frames, including 18,000 from the CPS and MLS, 2,000 Social Security Disability Insurance beneficiaries, 1,700 persons receiving Aid to Permanently and Totally Disabled, and 8,000 persons whose applications for Social Security Disability Insurance benefits had been denied.16/

A number of reports on this survey have been published; in addition to presenting data from the survey, they describe in detail the methodology used. A followup was conducted in 1972, but results are not yet available from this survey.

As Table 4-2 shows, the SDA gave the highest estimates for the number of disabled: 17.2 percent of the population, including 3.6 percent who were completely unable to work.

On the basis of the SDA, Social Security estimated that 17.8 million of the noninstitutionalized persons between 18 and 64 were disabled for longer than 6 months in 1966. The total included 6.1 million persons (5.9 percent of the population) classified as severely disabled. Of this group 3.7 million, or 3.6 percent of the population, were unable to work at all. Another 5 million persons (4.9 percent of the population) were occupationally disabled, defined as being unable to work at the job held prior to onset of disability or unable to work fulltime. Another 6.6 million persons (6.4 percent of the population) had secondary work limitations, defined as able to work full time regularly but with limitations in the kind or amount of work they could perform.

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16. Allan and Cinsky, General Characteristics, p. 21.

The detailed analysis of the four surveys, which is outlined above, indicates that the wide differences in estimates are due primarily to differences in methodology and definitions. This is true not only for the estimates of all disabled, but for the estimates of the severely disabled as well.

In Tables 4-1 and 4-2, the category "complete work disability" was used as a lowest common denominator for comparing files. Methodological differences made a more exact comparison impossible. For example, the OSU estimate in column 5 of Table 4-2 includes some people who worked irregularly, while the SDA estimate does not. Similarly, the HIS estimate includes women unable to perform housework, while the Census does not. The SDA for its part, classifies these women as "partially disabled." The conclusion to be drawn from Tables 4-1 and 4-2 is that even when the categories of least severity are stripped away, when one tries to identify some basic group of disabled the various estimates differ substantially. Because of this fact, it was necessary to accept one estimate as more accurate than the others. The rationale for choosing the SDA is summarized below.

Rationale for the Choice of Data File

There are a number of reasons for preferring the SDA[17] to the other surveys discussed above.

First, the SDA used a short screening form. It contained only four questions, all direct and unambiguous, and all related only to disability.

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[17] Although data from the Social Security Survey are used in this report, our disability categories are grouped somewhat differently:

(1) Two SSA groups--"occupational disabled" and "secondary work limitations"--have been put together into one category, "partial disability."

(2) Of those called "severely disabled" by Social Security, those people who actually were not in the labor market have been defined as individuals most severely disabled. Those remaining are still called "severely disabled." For more specific details, see footnote 5.

Second, the screening form was mailed out, rather than being brought to the respondent in person (as was the case with HIS and OSU). This may seem to be a disadvantage, but in the months prior to conducting the survey, the Social Security Administration conducted a number of tests and found that a mail questionnaire gave more accurate results than a personal interview for the initial identification of the disabled.

Third, the Social Security Administration purposely oversampled certain groups which contained very high proportions of disabled persons (OASDHI beneficiaries; persons receiving public assistance because of disability; persons whose applications for OASDHI disability benefits had been denied). These groups were then assigned weights which would give corresponding population values of correct magnitude. It was important to survey these groups because a strictly random sample of the population would have identified relatively few disabled people, and sampling error alone could have seriously biased the estimates.

ESTIMATING THE DISABLED POPULATION FOR 1975

The SDA was used, for reasons outlined above, to obtain estimates for the number of disabled persons. Since data are not yet available for the more recent versions of the SDA, it was necessary to use the 1966 survey and to then update it.

Of the major data sources reviewed here, only the Health Interview Survey has been conducted repeatedly over a period of years. The other surveys give estimates which are very different from one another not only because of different time frames but because of differences in definitions and methodology as well. Because of this, these surveys cannot be used together to measure changes over time in the disabled population.

Despite the fact that the HIS cannot be counted on to provide realistic estimates of the number of disabled people, it can be used to examine whether the disabled population has changed over time. The key assumption to this method is that any other survey conducted consistently over time would have shown the same trend as that shown by HIS.

The 1975 estimates for the disabled population have been derived by taking 1966 prevalence rates from the SDA and updating them on the basis of linear extrapolation of HIS data.[18]

Level and Prevalence of Disability

The Urban Institute estimates that in 1975 there are 4.2 million most severely disabled individuals aged 18 to 64 (see Table 4-4).[19] This would constitute 3.4 percent of the population in that age group. The number of severely disabled and the partially disabled would be 3.9 million and 15.2 million, respectively. Altogether, the disabled (of all degrees of severity) in this age group would amount to 23.3 million people, or 18.7 percent of the population.

If one wished to include people over the age of 65, the estimate of most severely disabled would be roughly 8 million. This figure is arrived at by adding an estimate of 3.9 million persons over 65 who are substantially or severely limited in their physical performance (derived from the OSU Survey) to the 4.2 million most severely disabled aged 18-64.[20]

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[18] For details of the extrapolation technique, see Arnow, "Estimates of the Disabled Population for 1975," pp. 35-38.

[19] Estimates in this section refer to individuals who have been disabled for longer than 6 months.

[20] Nagi estimates that approximately 51.5 percent of the population age 18 or more that is either substantially or severely limited in physical performance is in the 18-64 year old bracket. The adjusted estimate is arrived at by adjusting the estimated 4.2 million most severely disabled upward according to this percentage. See Saad Z. Nagi, "Disability and the Severely Disabled: Concepts and Prevalence," unpublished paper prepared for the Urban Institute Comprehensive Needs Study, 1975.

In addition, one could add an additional 188 thousand to this number if one wanted to include most severely disabled individuals who are below the age of 18.[21] This estimate is arrived at from the 0.2 percent of the population below the age of 17 unable to perform in their major activity (usually school enrollment for this age group).[22]

Functional Loss

The set of functional limitation classes was established for this study, based on the classification scheme used by Social Security's Survey. Among the most severely disabled aged 18 to 64, a high proportion (over 50 percent) have severe functional loss or are functionally dependent (Table 4-5). Not surprisingly, the severity of functional loss increases drastically as one goes from partial to most severe disability (Table 4-6).

Age, Race, and Sex Composition of Disabled Population

The severely disabled and most severely disabled who were 18 to 64 years old had a higher proportion of women than the comparable partially disabled sample (Table 4-7). The proportion of nonwhite men was about the same for all severity groups, but the proportion of nonwhite women was higher in the two severe groups; thus, the total proportion of nonwhites was higher in these two groups.

The prevalence of disability was higher for older people (Table 4-8).

Geographic Distribution of Disabled Populations

The 1966 Survey of Disabled Adults and the 1970 Census showed similar distributions of noninstitutionalized disabled persons by geographic region (Table 4-9). This similarity is evident both for the total number of disabled

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[21] Ibid., Table 14; and U.S. Bureau of the Census, Current Population Report, Series P-25, No. 539.

[22] Ibid.

Table 4-4

Estimates of Noninstitutionalized Disabled Population, Aged 18 to 64, for July 1, 1975 1/

	Number in thousands	Percent
Total U.S. Population	124,800	100.0
Total Disabled Population	23,300	18.7
Most Severely Disabled	4,200	3.4
Severely Disabled	3,900	3.1
Partially Disabled	15,200	12.2

1. For Definitions and Methodology, see Text.

Source: Urban Institute cross-tabulation of Social Security 1966 Survey of Disabled Adults, updated by same methods described in Arnow, "Estimates of Disabled Population for 1975," section on methodology.

Table 4-5

Functional Limitations of the Individuals, Aged 18 to 64, Who Are Most Severely Disabled, Estimated for July 1, 1975 1/

	Number in thousands	Percent
Total Most Severely Disabled	4,200	100.0
Functionally Dependent	1,798	42.8
Severe Functional Loss	521	12.4
Moderate Functional Loss	1,096	26.1
Minor Functional Loss	554	13.2
Loss not specified	231	5.5

1. For Definitions and Methodology, see Text.

Source: See Table 4-4.

Table 4-6

Functional Limitations of the Disabled: Number (in thousands) and Percent of Disability Group with Given Functional Loss

	DISABILITY					
	Most Severe		Severe		Partial	
	N	%	N	%	N	%
Functionally dependent	1798	42.8	718	18.4	1414	9.3
Severe functional loss	521	12.4	429	11.0	973	6.4
Moderate functional loss	1096	26.1	1244	31.9	4545	29.9
Minor functional loss	554	13.2	994	25.5	4210	27.7
Loss not specified	231	5.5	515	13.2	4058	26.7
Total	4200	100.0	3900	100.0	15200	100.0

Source: See Table 4-4.

Table 4-7

Race-Sex Distribution of Disabled, by Disability Group (numbers in thousands) 1/

	DISABILITY					
	Most Severe		Severe		Partial	
	N	%	N	%	N	%
White female	1974	47	1950	50	6232	41
White male	1428	34	1131	29	6992	46
Nonwhite female	504	12	585	15	1064	7
Nonwhite male	294	7	273	7	912	6
Total	4200	100	3939	100	15200	100

1. Column numbers may exceed total due to rounding.

Source: See Table 4-4.

Table 4-8

Percent of Population Disabled, by Age and Disability Categories, Estimates for 1975

AGE	DISABILITY		
	Most Severe	Severe	Partial
17-44	1.2	1.4	7.5
45-64	7.4	6.1	21.0

Source: Arnow, "Estimates of Disabled Population for 1975."

Figure 4-1

Age Distribution of Disabled Population by Degree of Severity

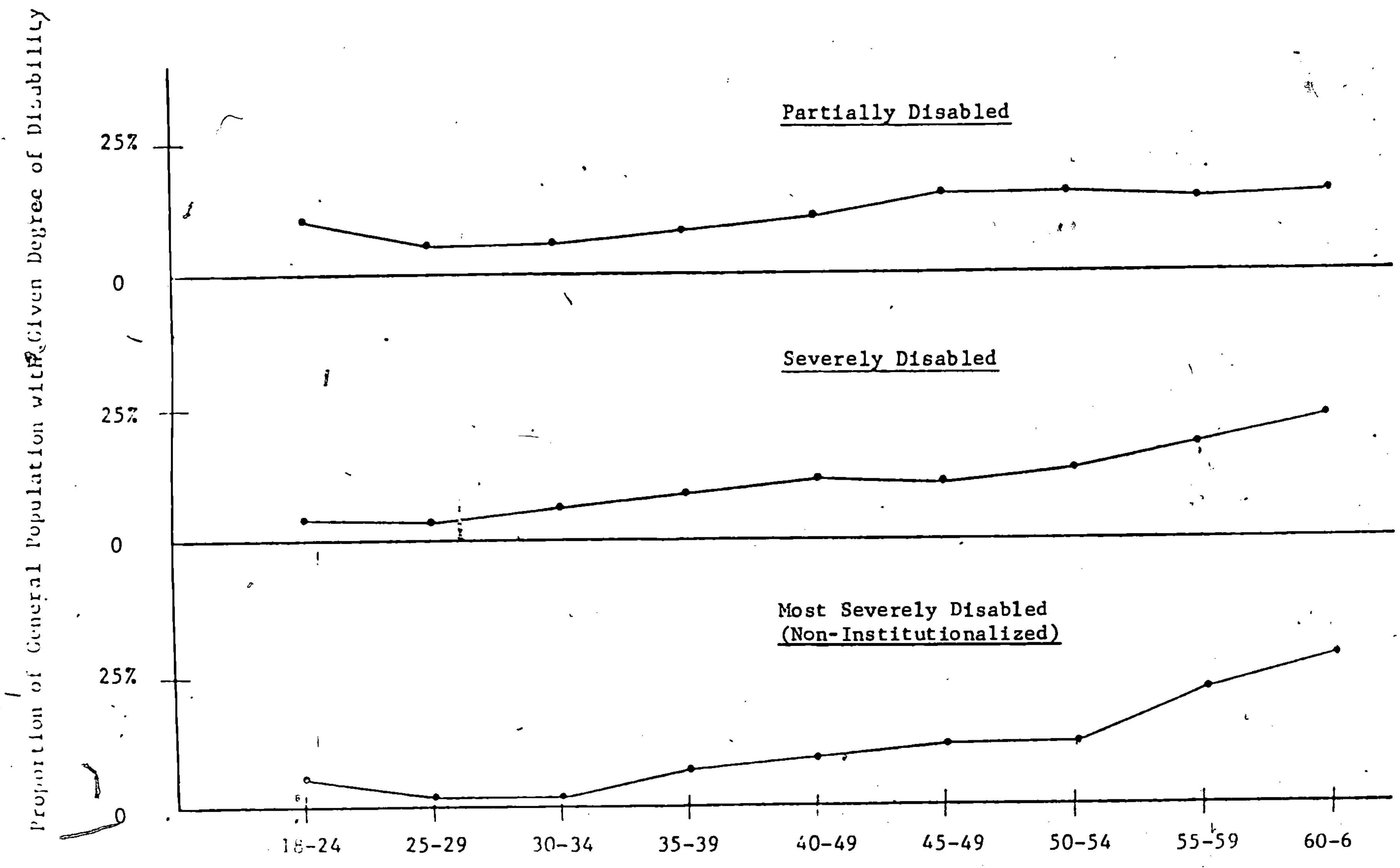

Table 4-9

Percentage Distribution of Disabled Population, by Geographic Region, 1966 and 1970

	1966 SDA		1970 Census	
	Disabled	Most Severe	Disabled	Unable to Work
Total	100.0	100.0	100.0	100.0
New England	5.3	5.1	5.0	4.4
Middle Atlantic	15.5	15.4	16.0	16.9
East North Central	18.4	14.9	18.6	17.0
West North Central	7.7	5.6	7.5	6.4
South Atlantic	18.9	22.1	16.6	18.3
East South Central	9.4	12.0	7.6	9.3
West South Central	9.1	10.1	10.3	10.9
Mountain	2.6	1.9	4.1	3.6
Pacific	13.1	12.9	13.9	13.2

Source: Survey of Disabled Adults: Urban Institute cross-tabulation; Census: General and Economic Characteristics, United States Summary, AC(1)-C1, Table 160.

and for the most severely disabled. According to both data sources, southern States accounted for a higher proportion of the severely disabled than the total disabled.

Individuals who are most severely disabled were found in all areas, with certain States, especially southern ones, containing a higher concentration. In five States, Alabama, Arkansas, Kentucky, Mississippi and West Virginia, the concentration of most severely disabled in the general population was at least half again as much as that in the country as a whole.

Five States had concentrations of lower than 70 percent of that in the Nation: Alaska, Connecticut, Hawaii, Minnesota, and Wisconsin. The largest absolute numbers of the most severely disabled were found, of course, in the largest States. Four of these--California, New York, Pennsylvania, and Texas--accounted for nearly 30 percent of all the most severely disabled (Tables 4-10 and 4-11).

Type of Disabling Condition

Musculoskeletal and cardiovascular disorders were responsible for disability in the cases of over one-half of all the disabled aged 18 to 64, as well as the severely disabled and most severely disabled in this age group (Table 4-12). Respiratory disorders ranked next for all the disabled, but mental disorders and nervous system disorders ranked next for the severely and most severely disabled.

As pointed out earlier, there are many more people who have chronic health conditions than there are disabled people. Table 4-13 presents available data on the number of people with selected chronic conditions. Note that there is no total given for the number of people with one or more chronic conditions, since adding up all of the figures given in the table would lead to serious problems of doublecounting.

Table 4-10

Individuals Most Severely Disabled, Percentage Distribution by State: 1975 estimates

	Percent		Percent
United States	100		
Alaska	*	Nebraska	.5
Alabama	2.5	Nevada	.2
Arizona	1.0	New Hampshire	.3
Arkansas	1.6	New Jersey	2.7
California	10.4	New Mexico	.5
Colorado	.8	New York	8.3
Connecticut	.9	North Carolina	3.2
Delaware	.2	North Dakota	.2
District of Columbia	.5	Ohio	4.9
Florida	4.0	Oklahoma	1.7
Georgia	3.1	Oregon	1.0
Hawaii	.2	Pennsylvania	5.9
Idaho	.3	Rhode Island	.4
Illinois	4.6	South Carolina	1.8
Indiana	2.1	South Dakota	.2
Iowa	1.0	Tennessee	2.6
Kansas	.9	Texas	5.1
Kentucky	2.4	Utah	.4
Louisiana	2.5	Vermont	.2
Maine	.5	Virginia	2.3
Maryland	1.7	Washington	1.5
Massachusetts	2.2	West Virginia	1.6
Michigan	4.1	Wisconsin	1.4
Minnesota	1.2	Wyoming	.1
Mississippi	1.8		
Missouri	2.5		
Montana	.3		

*Less than 0.1 percent

Source: Percentages computed according to Census (see Table 4-2)

Table 4-11

Number of Most Severely Disabled by State 1975 Estimates (in thousands)

	Number		Number		Number
United States . .	4,200				
Alaska	*	Kentucky	101	North Dakota . .	8
Alabama	105	Louisiana . . .	105	Ohio	206
Arizona	42	Maine	21	Oklahoma	71
Arkansas	67	Maryland	71	Oregon	42
California . .	437	Massachusetts .	92	Pennsylvania . .	248
Colorado	34	Michigan	172	Rhode Island . .	17
Connecticut . . .	38	Minnesota	50	South Carolina . .	76
Delaware	8	Mississippi . .	76	South Dakota . . .	8
District of Columbia . . .	21	Missouri	105	Tennessee . . .	109
Florida	168	Montana	13	Texas	214
Georgia	130	Nebraska	21	Utah	17
Hawaii	8	Nevada	8	Vermont	8
Idaho	13	New Hampshire .	13	Virginia	97
Illinois	193	New Jersey . . .	113	Washington . . .	63
Indiana	88	New Mexico . . .	21	West Virginia. .	67
Iowa	42	New York	349	Wisconsin . . .	59
Kansas	38	North Carolina .	134	Wyoming	4

*Less than 0.1 percent of the total.

Table 4-12

Percent of Disabled Population, Aged 18 to 64, with Given Major Disabling Conditions, 1966

Major Disabling Condition	Most Severely Disabled and Severely Disabled	Disabled, Total
TOTAL PERCENT	100.0	100.0
Arthritis, rheumatism, and other musculoskeletal disorders	25.2	30.9
Cardiovascular disorders	25.8	24.8
Respiratory-related disorders	8.7	11.2
Digestive disorders	5.5	7.2
Mental disorders	9.9	6.3
Nervous system disorders	9.6	5.2
Neoplasms	2.7	1.7
Urogenital conditions	2.8	2.5
Diabetes	3.0	2.7
Visual impairment	2.5	2.4
Other and unspecified conditions	4.3	4.9

Source: Allan and Cinsky, General Characteristics, p. 27.

Table 4-13

Prevalence of Selected Chronic Conditions

Type of Condition	Number of Persons (in millions)
Digestive	17.1
Respiratory	46.9
Skin	25.2
Musculoskeletal (mainly arthritis)	25.4
Circulatory	36.5
Visual	9.6
Hearing	14.5
Speech defects	1.3
Paralysis, complete or partial	1.4
Absence of extremities, all sites	1.0
Other impairments of limbs, back, trunk, all sites	18.8
All other impairments (includes mental retardation; absence, certain other sites; other deformities)	5.6
Cancer	1.0

Source: Cancer: American Cancer Society, <u>'75 Cancer Facts and Figures</u>, (The Society, 1974), p. 3.
All others: U.S. National Center for Health Statistics, Publication Series 10, No. 83 (Digestive), No. 84 (Respiratory), No. 92 (Skin and Musculoskeletal), No. 94 (Circulatory), No. 87 (all other).

A number of organizations serving different groups of handicapped persons provided estimates of their service populations for this study. Those estimates are found in Table 4-14. Only a small number of disorders is listed and the categories are not comparable to those in the other tables.

Table 4-14

Estimated Number of People with Selected Disabling Conditions

Type of Condition	Number
Cystic Fibrosis	40,000
Convulsive disorders (Epilepsy and others)	4,000,000
Multiple Sclerosis	500,000
Muscular Dystrophy	200,000
Cerebral Palsy (includes only persons 21 and over living in 13 metropolitan areas and needing services)	8,000
Mental Retardation	6,100,000
Mental Illness or Mental Disorders	Unavailable[1]

[1] No single estimate available due to problems of diagnosis and terminology: "A review of 25 field studies...revealed that in these investigations, the rate of mental disorders reported for the study population ranged from one percent to over 60 percent." The Advisory Panel on Financing Mental Health Care, American Hospital Association, Financing Mental Health Care in the United States, NIMH, 1973, p. 3.

Source: The following groups contributed information which was used in this table: United Cerebral Palsy Associations, Inc.; Cystic Fibrosis Foundation of America; National Association of the Deaf; National Multiple Sclerosis Society; National Association for Retarded Citizens; Muscular Dystrophy Association of America, Inc.

Chapter 5

THE MOST SEVERELY HANDICAPPED IN INSTITUTIONS

The institutionalized population is often neglected when estimating the number of persons considered severely disabled. Large numbers of disabled individuals are in institutional care settings.

Table 5-1 shows estimates of the institutional population for recent years (1968-1973) by age group and type of facility. Figures in parentheses are Census data for 1970.

Points of major significance for this study are:

1. Approximately 1.9 million persons are receiving institutional care. The figure is derived by summing up the latest available data for each type of facility and adding an estimated 25,000 persons residing in private institutions for the retarded. Of the institutionalized population, 93.3 percent (1.8 million) are estimated to be severely handicapped.

2. The majority of the population residing in nursing homes are primarily the aged (approximately 1 million).

3. A smaller number, about 500,000, are of working age, 18-64.

The data suggest that the character of the population in institutions is changing, particularly within various age groups. There appears to be a decrease in the number of persons in mental hospitals, institutions for the retarded, and chronic disease hospitals, and an increase in the number of persons in nursing homes. Some of these changes reflect State decisions about deinstitutionalization and the placement of individuals into alternative types of facilities, such as nursing homes, group homes, or other types of community settings. Much of this effort can be attributed to changes in financing mechanisms such as Medicaid, changes in technology such as psychotherapeutic drugs, and changes in the general philosophy favoring community based treatment. In comparison, the survey that was done in 1967 by Social

Table 5-1

Number of Persons in Institutions by Age, 1968-1973

(1970 Census Data in Parentheses)

Institutions								
	Under 18	18-24	25-34	35-44	45-54	55-64	65 and over	Total
Psychiatric Institutions[1]	16,915 (59,114)	40,404 (45,829)	41,588 (45,829)	52,320 (57,856)	70,281 (76,290)	73,424 (81,758)	99,882 (113,134)	394,814 [539,415][2] (433,890)
	Under 3	3-21	22-61			62 and over		Total
Facilities for Mentally Retarded --Facility Data (public only)[3]	522	73,132	91,938			8,532		174,124 [199,124][4]
	Under 14	14-24	25-44		45-64		65 and over	Total
Facilities for Mentally Retarded --Census Bureau Data (public and private)	(41,328)	(66,477)	(51,921)		(31,539)		(10,727)	(201,992)
		Under 65					65 and over	Total
Facilities for Aged[5] (nursing homes)		195,660 (131,707)					824,073 (795,807)	1,150,940 (927,514)
	Under 25		25-44		45-64		65 and over	Total
Chronic Disease Hospitals[6]	2,418 (8,066)		3,087 (10,297)		7,617 (25,409)		12,070 (40,260)	25,192 (84,032)
TOTAL--ALL INSTITUTIONS								1,914,671

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1. Psychiatric Institutions include Federal, State, and local mental hospitals, psychiatric wards or service in a general or veterans hospital, alcoholic treatment or drug addiction center, and residential treatment centers.

2. Not included in the total number of persons in Psychiatric Institutions was the number of persons for the federally funded Community Mental Health Centers, 1972-73. This total of 144,601, when added to the above total of 394,814, gave us a total of 539,415 in Psychiatric Institutions, which we were unable to break down by age groups.

3. Superintendents of Public Residential Services for the Mentally Retarded. Current Trends and Status of Public Residential Services for the Mentally Retarded, 1974.

4. Add 25,000 for private facilities (an estimate taken from Census).

5. National Center for Health Statistics, Health Resources Statistics, 1970 and "Master Facility Census", 1973 (unpublished). Department of HEW.

An estimation was made for each age group using figures from the National Center for Health Statistics. Using the 1969 NCHS data on Nursing Homes as the base year, projections were made to arrive at the estimated figure for 1973.

6. Data on Chronic Disease Hospitals and Tuberculosis Hospitals have been merged. An estimation within age groups

Security indicated that the median length of stay for an individual in a psychiatric institution was 6 years; for those in facilities for the mentally retarded, 14.7 years; and for those in chronic disease hospitals, 0.8 years.

Initially, it might be thought that all persons in institutions would be considered severely handicapped. However, many persons, especially in mental and acute care hospitals, are institutionalized for relatively short periods and then returned to the community.

Therefore, a distinction must be made between the severely and the non-severely handicapped in institutions. The proportions can vary. Frohlich[1] studied the institutionalized population and pointed out that any inmate who has been a resident of a long-term medical institution or ward or a school or home for the mentally or physically handicapped and has an average duration in the institution of 30 days or longer, can be considered to be severely disabled.

Table 5-2 shows the number of residents by age and institution who are considered severely disabled. To estimate the number of severely disabled persons in institutions, the following procedure was used.

Comparative data for State and county institutions for residents with a length of stay of less than 1 month were not available. If we use figures from the National Institute for Mental Health of 27 percent for residents with a length of stay less than 3 months, we would underestimate the number of severely disabled. These data also reflect a percentage of the number of persons discharged which is less than the number who are residents in the institution. We consider the resident population on average to be stable and

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[1] 1. Philip Frohlich, "Who Are the Disabled in Institutions?" Social Security Bulletin, October 1971, p. 4.

at least 80 percent of the total population receiving care in a psychiatric facility to be severely disabled.

We estimate the institutionalized mentally retarded who are severely handicapped at 90.3 percent of the resident population. This proportion, according to the National Association of Superintendents of Public Residential Facilities, would not be eligible for any type of noninstitutionalized setting during FY 1975, in part due to the inadequacies of community services. This would be about 180,000 in 1975.

Table 5-2

Estimated Number of Persons in Institutions Who Are Severely Disabled

Using as Percentages:

Psychiatric (80%)		Mentally Retarded (90%)		Aged (100%)		Chronic Disease (100%)	
Age	Total	Age	Total	Age	Total	Age	Total
18	13,532	3	470				
18-24	32,323	3-21	65,819			25	2,418
25-34	33,270						
35-44	41,856	22-61	82,744			25-44	3,087
45-54	56,225					45-64	7,617
55-64	58,739			65	195,660		
65+	79,906	62+	7,679	65+	824,073	65+	12,070
Total	315,851 (431,532)[1]		156,712 (22,500)[2] 179,212		1,150,940		25,192

Grand Total: 1,786,876 severely disabled, 93.3 percent of the total population in institutions.

1. Total including federally funded Community Mental Health Centers.
2. Total number of residents in private facilities.

It is difficult to obtain information on the number of severely handicapped who are in nursing homes or intensive care units. We assume that since the majority of this population has an average age of 75, we should consider 100 percent as severely handicapped. This is estimated as 1.2 million in 1975.

Individuals in chronic disease facilities have been declining in number, but because of the types of conditions their stay usually exceeds the length of stay estimate of 30 days, and therefore this population is considered 100 percent severely handicapped.

About one-third, 510,764, of the severely handicapped in institutions were of working age (18-64) and an additional number of 82,389 were children under 18 years of age.

We have estimated in total that 93.3 percent of the institutionalized population is severely handicapped. This amounts to 1,786,876 out of 1,914,671 of the total institutional population.

Chapter 6

VR AND THE SEVERELY DISABLED

Roughly one-third of the disabled population aged 18 through 64 can be classified as severely disabled on the basis of inability to engage in market work activity. Of these severely disabled individuals, roughly one-half can be classified as most severely disabled on the basis of (1) the duration of their disabling condition, and (2) their eligibility for welfare or Social Security payments from programs that serve only the permanently and totally disabled. We have pointed out that the prevalence of severe disability depends on a combination of social, economic, and labor market factors as well as on the nature of the impairment. Hence our estimates can only be used as general touchstones.

Based on an analysis of the 1966 Survey of the Disabled Population undertaken as part of this study, it was found that the severely disabled population tends to be disproportionately poorly educated and black. A disproportionate number have multiple disabilities, which tend to be concentrated in particular classes. Moreover, a disproportionate number of the severely disabled tend to be urban dwellers and welfare recipients.

The effect of welfare status is obviously a reflection of the disabling condition, although one could make the case for poverty being an important determinant of disability. Unfortunately, the analysis on which these findings are based did not permit us to investigate this point more thoroughly. Also, it should be noted that there is probably a considerable amount of variation in the prevalence rates within the particular class of disabilities reported here, which further disaggregation would have permitted us to observe.

Data from the Vocational Rehabilitation (VR) program indicate that roughly 1 million people apply to that program each year. If all these applicants are disabled, this represents about 4 to 5 percent of the disabled population. This probably understates the true rate of contact by the disabled population with the VR program, since it does not include disabled persons who applied in earlier years and were turned away. Roughly half of the applicants are rejected each year, and it is conceivable that an additional 3.5 million disabled persons in today's pool had applied to the VR program for services in earlier years. Even if we were able to adjust the rate of application upward so that it represented a rate of contact, the resulting share of the disabled pool would remain relatively small.

This does not necessarily mean that the VR program is not reaching its target population. Not all disabled persons are eligible for VR services. To be qualified, a disabled person must have a health condition that represents a significant impairment to ability to work and must have a good chance of finding employment after VR services are received. The labor market orientation of the program significantly limits the target group of VR. It has been estimated that this target group ranges between 3.5 and 5.0 million.[1]

Tabulations from the R-300 data file, a summary of data on all persons who apply to the VR program, indicate that only 6 percent of the applicants to the VR program in 1972 were rejected because their handicap was too severe or because their medical prognosis did not indicate a long life expectancy. Given that roughly one-third of the disabled population was classified as severely disabled, this suggests that fewer severely disabled than partially disabled apply to the VR program.

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1. John D. Worrall and Craig Schoon, Methodology for Estimating the Vocational Rehabilitation Target Population: An Exploratory Analysis (University of Arkansas Press, 1975).

A comparison of the disabled population with VR applicants classified by sex, race, and age seems to support this hypothesis (Table 6-1). Applicants are 62 percent male, partially disabled persons are 52 percent male, and severely disabled persons are 38 percent male. Thus VR applicants more closely resemble the partially disabled population in their distribution by sex.

Similarly, 72 percent of the VR applicants are 45 years of age of younger; 40 percent of the partially disabled, and only 27 percent of the severely disabled are in that age group. Thus, applicants more closely resemble the partially disabled population in their age distribution.

In contrast, applicants more closely resemble the severely disabled in their racial characteristics. VR applicants are roughly 24 percent black, the partially disabled population is 12 percent black, and the severely disabled population is 21 percent black.

While this evidence constitutes weak support of the hypothesis that the severely disabled are less likely to apply for VR services than the partially disabled, such behavior appears to be intuitively plausible. The likelihood that disabled persons will apply to the VR program will depend in part on their perception of the benefits to be expected from the program. Given the employment orientation of the current VR program, expected benefits would take the form of improved earnings potential that would result from the receipt of VR services. It can be argued that such an improvement is less likely for severely disabled persons. A recent study provides some indirect evidence to support this notion.[2] The likelihood of applying to VR is directly related to the expected increase

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[2] John D. Worrall, <u>An Evaluation of the Structure and Performance of Disability Programs</u> (New Brunswick, N.J.: Disability and Health Economics Research, Bureau of Economic Research, Rutgers University, December 1974).

Table 6-1

Comparison Between VR Applicants, the Partially Disabled Population, and the Severely Disabled Population, by Race, Sex, and Age Characteristics

	Percent Distribution With Respect To:					
	Race		Sex		Age	
	White	Nonwhite	Male	Female	45 or under	Over 45
Partially Disabled	87.7	12.3	52.2	47.8	40.2	59.8
Severely Disabled	79.7	21.3	38.2	61.8	26.5	73.5
VR Applicants	76.2	23.8	62.1	37.9	71.9	28.1

in earnings that will result from the receipt of VR services, which in turn is closely related to the probability of successful rehabilitation. The study finds that the probabiity of successful rehabilitation is inversely related to characteristics that contribute to severe disability.

In our survey of former patients in medical rehabilitation centers, we asked about reasons for nonapplication to VR. As shown by Table 6-2, 19.8 percent did not want or need VR, 31.8 percent felt they were too old for the program, and 15.4 percent didn't know about it.

Table 6-2.

Reasons for Not Applying to VR (N=201)

	Number	Percent
Don't want VR services	17	8.4
Don't need VR services	23	11.4
Physician did not want to refer	3	1.5
Didn't know how to apply	5	2.5
Don't feel would qualify	13	6.5
Unable to get assistance to get to Vr	0	0.0
Distance from VR agency	0	0.0
Didn't get around to it	2	1.1
Applied more than 3 years ago	3	1.5
Age	64	31.8
Poor health	4	2.0
Didn't know of VR	31	15.4
Other	15	7.5
Don't know	21	10.4
Total	201	100.0

Further analysis of the characteristics of VR applicants reveals that both accepted and rejected applicants more closely resemble the partially disabled than the severely disabled in sex, race, and age characteristics

(Table 6-3). However, the screening mechanism appears to focus on applicants who have characteristics of the severely disabled. Rejected applicants are disproportionately black and old; severely disabled individuals are also disproportionately black and old.

However, while rejected applicants are disproportionately male, severely disabled people are disproportionately female. A partial explanation of this may be that females can be classified as successfully rehabilitated as homemakers even if they do not have competitive employment and thus severely disabled female applicants offer better rehabilitation potential than do comparable severely disabled men.

A more sophisticated analysis of gatekeeping in the VR program, undertaken as part of this study, allows us to estimate the likelihood of being rejected for applicants with alternative sets of sociodemographic characteristics and with differing disabling conditions, who come from different sources of referral. Major factors affecting rejection rates include age, source of referral, and type of disability. Applicants aged 45 and over have higher rejection rates than comparable applicants who are younger than 45. Applicants referred from public organizations have higher rejection rates than comparable applicants referred by hospitals. Applicants with some disabilities (e.g., allergies) have higher rejection rates than those with other disabilities (e.g., amputations).

Employment conditions and finances have smaller but statistically significant effects on rejection rates. Such rates tend to be roughly 4 percentage points lower in States which allocate relatively large amounts of resources to the VR program (i.e., States which spend as much as $65 to $80 per disabled person living in that State). The resources effect implies that budgetary constraints may be operating at the gatekeeping level and that an increase

Table 6-3

Comparison of Accepted VR Applicants, Rejected VR Applicants, Partially Disabled and Severely Disabled in Their Race, Sex, and Age Characteristics

	Percent Distribution With Respect To:					
	Race		Sex		Age	
	White	Nonwhite	Male	Female	45 or Under	Over 45
Population						
Partially Disabled	87.7	12.3	52.2	47.8	40.2	59.8
Severely Disabled	79.7	21.3	38.2	61.8	26.5	73.5
Applicants						
Acceptances	76.9	23.1	60.8	39.2	73.5	26.5
Rejections	75.4	24.6	63.8	36.2	70.0	30.0

in the amount of resources available to the VR program could lower the number of applicants who are turned away.

An interesting finding also emerges when one compares the effects of disabling conditions on rejection rates with the effects of such conditions on the likelihood of being classified as severely disabled. If counselors screened on severity and if the type of disabling condition was an important determinant of severity, one would expect to find a close correlation in the rankings of disabling conditions according to rejection rates and likelihoods of being classified as severely disabled. Other things equal, one would expect the rejection rates to be lowest for persons with disabilities with the lowest likelihood of being classified severe.

Table 6-4 ranks the disabilities according to rejection rates and probabilities of being classified as severe and indicates that the correlation between the rankings is relatively low. While applicants with allergies and with blood, circulatory, and respiratory ailments have the highest rejection rates, they are ranked as only eighth and ninth out of 12 classes of disability in their likelihoods of being classified as severely disabled.

Similarly, while disabled persons who are mentally retarded or who have neoplasms are ranked first and third in their likelihood of being classified as severely disabled, they are ranked tenth and eleventh out of the 12 classes in their rejection rates.

This table suggests that while a disabling condition may affect one's current ability to work, that ability may not be fully predictive of the likelihood of one's ultimate ability to work after receipt of VR services. In our survey of persons rejected for severity, 6.2 percent were working at the time of the survey and at least another 5.5 percent had worked at some time since rejection.

Table 6-4

Ranking of Type of Disabling Condition by VR Rejection Rates and Prevalence Rates of Severe Disability

	Rejection Rates		Prevalence of Severe Disability
1.	Allergies	1.	Mental retardation
2.	Blood, circulatory, and respiratory ailments (other than allergies)	2.	Mental disabilities (other than retardation)
3.	Miscellaneous conditions	3.	Neoplasms
4.	Visual impairments	4.	Miscellaneous conditions
5.	Orthopedic conditions (other than amputations)	5.	Genitourinary conditions
6.	Mental conditions (other than retardation)	6.	Orthopedic conditions (other than amputations)
7.	Genitourinary conditions	7.	Visual impairments
8.	Digestive ailments	8.	Blood, circulatory, and respitatory conditions (other than allergies)
9.	Speech and hearing impairments	9.	Allergies
10.	Mental retardation	10.	Digestive ailments
11.	Neoplasms	11.	Speech and hearing impairments
12.	Amputations	12.	Amputations

Table 6-5

Percent of Successful Closures (Rehabilitations) and Unsuccessful Closures (Too Severe) by Age, Race, and Sex, 1972

	Rehabilitation Rate		Percent of Closures	
	Less than 45	45 or Over	Less than 45	45 or Over
Male	80	75	11	34
Female	83	87	06	24
White.	83	80	12	21
Nonwhite	76	85	02	14

We expect this to reflect an unknown undercount of rejects who work because the contact procedure used by most State programs (phone calls during working hours) may have missed many who were at work.

Given acceptance to the VR program, the proportion of clients who are successfully rehabilitated ranges in the neighborhood of 75 to 80 percent. There appears to be little consistent pattern when rehabilitation rates are classified by age, sex, or race (Table 6-5). The rate is somewhat higher for women, particularly in the older age group where the female rate is roughly 12 percentage points higher. For younger clients, the rate for whites is about 7 percentage points higher than it is for nonwhites. However, the pattern is reversed for older clients, for whom the nonwhite rate of rehabilitation exceeds the white rate.

The age pattern is also vague. Younger clients who are either male or white have better rehabilitation rates than their older counterparts. However, the pattern is just the opposite for female or nonwhite clients; rates of rehabilitation are higher for older clients.

Of those who were not successfully rehabilitated, approximately 15 percent were closed as too severe for rehabilitation. These severely disabled closures were concentrated among the old, male, and white clients.

A more detailed multivariate regression analysis indicates that successful rehabilitation depends heavily on factors that are closely related to labor markets. Since such rehabilitation generally requires a satisfactory job placement, this finding should not be too surprising.

Past employment history, race, marital status, type of disabling condition, and unemployment conditions were the factors found to be statistically significant in their association with rehabilitation rates. In particular, we found that clients who had past employment histories, were married, white, or amputees had significantly higher rehabilitation rates than clients with comparable other characteristics. We also found that clients aged 45-64 who were referred by public organizations or lived in States experiencing unemployment rates in excess of 6 percent had significantly lower rates of rehabilitation than clients with comparable other characteristics.

The pattern of rehabilitation rates is consistent with a model of rehabilitation that is based on employability of the client. Older workers have difficulties because employers are unwilling to invest hiring and training costs in someone who is going to have a relatively short work career; younger workers are generally less desirable because they lack skill and work experience. Nonwhites have more difficulty finding jobs than whites because of discrimination in labor markets. Employers generally prefer married job applicants to unmarried job applicants because they are considered more stable in their employment patterns and more dependable in their work habits. Less-educated workers are handicapped by their lack of skill.

It is also interesting to note that there is some consistency in counselor behavior in selecting clients at the gatekeeping level of the program and the likelihood of successful rehabilitation, although the correlation between the characteristics of accepted applicants and successfully rehabilitated clients is not a close one.

However, while there are these consistencies, there are also inconsistencies. For example, when applicants and clients are classified by their type of disability and ranked according to their rejection and rehabilitation rates, the rankings of disabilities other than those at the extremes is not very close. Similarly, applicants and clients classified by their source of referral and ranked according to acceptance and rehabilitation rates do not show a close rank correlation. While applicants from public organizations have the lowest acceptance and rehabilitation rates, applicants from welfare agencies have the second lowest acceptance rates but have the highest rehabilitation rates, with other factors held constant.

A word of caution is necessary in discussing these comparisons. The analysis of rehabilitation rates was able to take more factors into account than the analysis of acceptance rates. In particular, the rehabilitation rate analysis was able to include as independent factors level of school completed, marital status, welfare status, and family income, whereas the rejection rate analysis was not able to include these factors because information on these characteristics is not collected until applicants have been accepted to the program.

Summary of R-300 Analysis

To summarize this analysis of the R-300 data files, although we were able to determine from other data files that roughly one in three disabled persons is severely disabled, the data did not permit direct estimates of application rates for the severely disabled. Rough estimates indicate that the total application rate may be about 4 to 5 percent of the total disabled population, although this is probably an understatement of the true rate of application. Of these applicants, approximately 6 percent were rejected because their handicap was too severe. A comparision of characteristics of the applicants with the characteristics of the disabled population classified according to severity of disability indicated that they resembled the marginally disabled more closely than the severely disabled.

Of those who apply, roughly half are rejected, and of those about one in eight is rejected because the handicapping condition is considered too severe for successful rehabilitation. While rejected applicants seem to closely resemble the severely disabled in their race characteristics, they are less likely to be female. In addition, they do not resemble the severely disabled in their disability characteristics.

Possible reasons for the lack of similarity with respect to sex and type of disability are the ability to close female clients as successfully rehabilitated homemakers, and the difference between current ability to work (on which the definition of severity for the population estimates is based) and the ultimate ability to work after receipt of VR services (on which the definition of severity as the reason for rejection is based).

Of those accepted into the program, roughly 80 percent are successfully rehabilitated (i.e., placed in jobs in the competitive labor market, or as homemakers or unpaid family workers). While clients who are not successfully rehabilitated also resemble the severely disabled population in their age, sex, and race characteristics more closely than they do the partially disabled population, the determinants of successful rehabilitation are factors which are closely tied to labor markets. Other things equal, clients with past employment histories who live in States with unemployment rates below 6 percent are more likely to be successfully rehabilitated than comparable clients with similar other characteristics. Similarly, client characteristics such as age, education, race, and marital status that can be considered indexes of employability independent of disabling condition were also found to be significant determinants of successful rehabilitation.

Only one in seven of the clients who were not successfully rehabilitated was closed as too severe. However, these clients did not significantly differ in their characteristics from other clients who were not successfully rehabilitated.

Characteristics of the Severely and the Partially Disabled

Comparisons of the social and economic characteristics of the disabled were based on special tabulations generated from the Urban Institute sample of the disabled population derived from the 1970 Census. Severely disabled persons were defined as persons who, because of their health or physical condition, could not work at all. Partially disabled persons were defined as persons who, because of their health or physical condition, were limited in their ability to work. Our file produced 11,686 usable records representing 11.7 million disabled persons, of whom 6.6 million were persons with partial disabilities and 5.1 million were persons with severe disabilities. The total includes persons in institutions but not persons under 18 or over 65 not in institutions.

We found that families containing severely disabled persons had smaller incomes from earnings, larger incomes from public assistance and Social Security, and slightly larger incomes from other sources than did the partially disabled. However, because of the considerable amount of income variation within families classified by type of severity, these differences were never statistically significant. Thus, while the direction of the difference was always as expected, the size of the standard error of the estimate indicated the possibility that differences were due to chance.

We also found that the severely disabled had housing assets that were lower in value than the partially disabled, but again the differences between the groups were not statistically significant. Our findings with respect to other forms of assets were similar: the severely disabled had less, but the difference was not statistically significant.

Our tabulations revealed that the severely disabled were less likely to be married with spouse present, were more likely to live in substandard housing (defined as housing without adequate toilet, plumbing, or electrical facilities), and that, among persons with disabilities that had lasted for 5 or more years, the severely disabled were more likely to be in institutions. Moreover, among the long-term severely disabled who were institutionalized, over two-thirds were housed in mental institutions.

Table 6-6 summarizes family income and disabled person income by source. Total incomes of <u>families</u> of severely disabled persons are roughly 50 percent lower than <u>family</u> incomes of partially disabled persons. The major cause of this difference is the smaller income from earnings received by families containing severely disabled persons. This $4,470 family earnings loss is only partially offset by the additional $578 in income received from other sources, $481 of which comes from public assistance and Social Security.

Turning to disabled persons' income, our tabulations reveal that incomes of severely disabled <u>persons</u> are only one-third those of partially disabled <u>persons</u>. Again, the major cause of this difference is the lower average earnings of severely disabled persons. Severely disabled persons earned $4,041 less than partially disabled persons in 1969. Roughly 15 percent of the severely disabled had been disabled for less than a year. Thus, the small amount of earnings reported by severely disabled persons can be attributed to the earnings experience of the newly disabled prior to the onset of their disability. This $4,041 earnings differential between partially and severely disabled individuals is not completely offset by the $476 in additional income from non-earnings sources received by the severely disabled ($397 of which comes from public assistance and Social Security).

The picture that emerges from Table 6-6 is that government income transfer programs do not offset the differential earnings loss of the severely disabled relative to the partially disabled. Thus families of severely disabled persons have lower incomes than families of partially disabled persons.

Another perspective on the dynamics of income can be derived by examining in Table 6-6 the percent of family income contributed by disabled persons by source. Note that while partially disabled persons contributed almost two-thirds of total family earnings, the severely disabled contributed only one-fourth. Since the earnings difference is larger for families of severely disabled persons ($4,470) than it is for disabled persons ($4,041), this suggests that, on average, other members of families of severely disabled workers might have withdrawn from the labor force to care for the severely disabled members. The relative earnings loss from these family members' labor force withdrawal was smaller than the relative earnings loss of the disabled individual who withdrew. This suggests that the severely disabled individual who reported on the Census was likely to have been the primary earner before onset of disability.

Since most of the differences described above were not statistically significant, these findings should be treated cautiously. Obviously, there are factors other than severity of disability that ought to be controlled for before income comparisons between the partially disabled and the severely disabled are used for policy purposes. Our analysis, standardized for age, sex, and race, produced further tabulations of income by source. Our findings were not significantly altered; i.e., the differentials narrowed but they were not statistically significant. Clearly, more research into the determinants of family income and the role of disability in affecting family income will be required before more definitive conclusions can be drawn. For now, the

Table 6-6

Income by Source, Families of Disabled Persons and Disabled Persons, by Severity of Disability, 1969

	All Disabled	Partially Disabled	Severely Disabled
Family Income by Source	$ 6,367	$ 8,047	$ 4,155
Earnings[1]	5,409	7,339	2,869
Public Assistance and Social Security	397	189	670
Other Sources	561	519	616
Disabled Persons Income by Source	$ 3,752	$ 5,291	$ 1,762
Earnings[1]	3,037	4,782	741
Public Assistance and Social Security	298	126	523
Other Sources	417	383	462
Disabled Persons Income as a Percent of Family Income			
Earnings[1]	56.1	65.2	25.8
Public Assistance and Social Security	75.1	66.7	78.1
Other Sources	74.3	73.8	75.0

1. Includes wages, salaries and incomes from farm or non-farm businesses.

Source: Unpublished tabulations, Urban Institute 1-1,000 Sample of households with disabled persons drawn from the 1970 Census 1-1,000 Public Use Sample.

relatively larger amount of income variation that remains even after the disabled population has been classified by degree of severity makes the findings discussed in this report only tentative.

Table 6-7 summarizes the asset position of disabled persons. Note that the disabled population has an average of $12,000 in assets, $6,500 of which results from ownership of homes. Note further that the severely disabled have an average asset value that is only 55 percent of asset value of the partially disabled. Again, the differences between the severely disabled and the partially disabled are not statistically significant, suggesting that other factors are causing a significant amount of variation in average asset values even after the disabled population has been standardized for degree of severity. We further standardized for age and income class and found that differences in average asset values between partially disabled and severely disabled persons virtually disappeared. (Table 6-8). Indeed, once we have standardized for age and income, the severely disabled seem to have average assets that are slightly larger in value than the asset holdings of partially disabled persons of comparable age and income in all but two of the age-asset groups displayed in Table 6-8. This suggests that much, if not all, of the observed difference in asset holdings between severely disabled and partially disabled persons can be attributed to differences between those two groups in their ages and their incomes.

Table 6-9 summarizes the marital status of disabled persons. Significantly fewer severely disabled persons are currently married. While two-thirds of the partially disabled are currently married, only one-half of the severely disabled are classified in this marital category. Moreover, Table 6-9 further shows that this observed difference in marital status is not explicable by differences between the partially disabled and the severely disabled in their

Table 6-7

Value of Home and Other Assets by Severity of Disability, 1969

	Disabled			
	All	Partially	Severely	Ratio of Severe to Partial
Value of Home	6,468	7,819	4,689	.60
Value of Other Assets	5,847	7,464	3,721	.50
Value of Total Assets	12,315	15,283	8,410	.55

Source: See Table 6-6.

Table 6-8

Value of Home and Other Assets by Severity of Disability and Age, Disabled Persons with Incomes of $5,000 to $7,500, 1969

	Value of Home			Value of Other Assets		
	Disabled			Disabled		
Age	All	Partially	Severely	All	Partially	Severely
20-29	1,508	1,327	2,299	4,364	4,298	4,652
30-39	5,143	4,851	6,054	4,583	4,500	4,838
40-49	5,998	5,990	6,215	4,932	5,055	4,660
50-54	6,010	5,924	6,129	5,263	5,190	5,363
55-60	6,641	6,574	6,731	5,952	6,143	5,695
61-64	8,418	7,777	9,216	6,055	6,029	6,087

Source: See Table 6-6.

Table 6-9

Distribution of Disabled Population by Age, Marital Status, and Degree of Severity

	Total	Under 20	20-29	30-39	40-49	50-54	55-60	61-64
Total Disabled[1]	11,684	405	1,691	1,495	2,399	1,598	1,896	2,200
Number Currently Married	6,917	53	742	912	1,606	1,058	1,211	1,335
Percent Currently Married	59.2	13.1	43.9	61.0	66.9	66.2	63.9	60.7
Total Partially Disabled[1]	6,638	235	1,205	943	1,503	920	931	901
Number Currently Married	4,398	33	594	674	1,136	692	666	603
Percent Currently Married	66.3	14.0	49.3	71.5	75.6	75.2	71.5	66.9
Total Severely Disabled[1]	5,046	170	486	552	896	678	965	1,299
Number Currently Married	2,519	20	148	238	470	366	545	732
Percent Currently Married	49.9	11.8	30.5	43.1	52.5	54.0	56.5	56.4

[1] In thousands.

Source: See Table 6-6.

age composition. The age-specific differences in marital status are, if anything, even wider than the observed difference for all disabled persons. For example, in the age group 40-49, three-quarters of the partially disabled are currently married as against less than one-half of the severely disabled.

Table 6-10 summarizes the housing situation of the disabled population. Roughly 15 percent of the disabled population dwells in substandard housing. Moreover, Table 6-10 reveals that this percentage is systematically related to family income, falling dramatically as family income rises. One out of every five severely disabled persons dwells in substandard housing compared to only one out of ten partially disabled persons. This difference, while striking, cannot be attributed to severity of disability only. When the disabled population is standardized for income class, the difference between the severely disabled and the partially disabled in the percentage in substandard housing narrows dramatically. But it does not vanish, particularly in the lowest income class, where 34.5 percent of the severely disabled dwell in substandard housing in contrast to 23.9 percent of the partially disabled in the comparable income class. This suggests that a major factor determining the quality of the dwelling environment of severely disabled persons is income and that income transfer policies that increase the income of the severely disabled will go a long way toward enabling them to acquire a standard of housing that is more comparable in quality to that of the partially disabled.

Table 6-10

Number and Percent of Disabled Population in Substandard Housing by Income Class and Degree of Severity

Degree of Severity	Total (in thousands)	INCOME CLASS						
		<$2,500	$2,500 -4,999	$5,000 -7,499	$7,500 -9,999	$10,000 -12,499	$12,500 -14,999	$15,000 and over
Total Disabled	11,686	4,029	1,878	1,699	1,425	1,073	605	977
Number in Substandard Housing	1,689	1,242	241	116	54	19	7	10
Percent of Total	14.5	30.9	12.8	6.8	3.8	1.8	1.2	1.0
Partially Disabled	6,640	1,404	1,045	1,124	1,000	795	473	799
Number in Substandard Housing	606	336	128	75	39	12	6	10
Percent of Total	9.1	23.9	12.2	6.7	3.9	1.5	1.3	1.2
Severely Disabled	5,046	2,625	833	575	425	278	132	178
Number in Substandard Housing	1,083	906	113	41	15	7	1	0
Percent of Total	21.5	34.5	13.6	7.1	3.5	2.5	0.8	0

Source: See Table 6-6.

Chapter 7

ANALYSIS OF INDIVIDUALS REJECTED BY VOCATIONAL REHABILITATION

As part of the analysis of the needs of individuals with most severe handicaps, The Urban Institute surveyed a group who were rejected from their State Vocational Rehabilitation agencies as being too severely handicapped to achieve a vocational objective. These were persons closed in status 08, 28, or 30 for reason of severity.[1] This population represents a key group of potential targets for an independent living program and for other services such as those described in Section 130 of the Vocational Rehabilitation Act of 1973. Through a survey of approximately 900 persons a wide range of information was collected about their historical and current conditions, their perceptions about their disability, and their service needs.

Survey Instrument

Given the current emphasis on the severely handicapped in the Rehabilitation Act of 1973, and the lack of knowledge about them, the questionnaire designed by The Urban Institute covers a wide range of topics. In order to facilitate the interviewing process, participants were sent a portion of the survey (Mail Survey) a few days prior to being interviewed. The Mail Survey contained questions about demographic characteristics and participation in social activities which did not require explanation by an interviewer, as well as questions regarding medical expenditures, health insurance coverage, and family income, which in some instances required the respondent to examine personal records.

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[1] Status 08 refers to clients closed from referral, applicant, or extended evaluation. Status 28 refers to clients closed after a rehabilitation plan has been initiated. Status 30 refers to clients who are closed after completion of a rehabilitation plan who were judged to have unsuccessfully completed the program (i.e., a vocational objective was not achieved.)

Respondents were interviewed by experienced interviewers from Chilton Research Services. The interview form contained questions on service utilization, current service needs, equipment utilization and needs, transportation, architectural barriers, homemaking, labor force experience, education, residential mobility, and functional assessment.

Survey Design

In preparation for the survey of severely handicapped individuals, data from the FY 1972 R-300 file (the data file on all persons who contact RSA) were examined.[2] In that year, 67,962 persons were rejected by State VR agencies (closure status 08, 28, or 30) because of the severity of their impairment. The severely disabled who were rejected for this reason in 1972 were compared to the total caseload during this period by race, diagnostic type, sex, State, urban-rural character of the State, and regional location in order to select representative eastern, southern, midwestern and western States. Each State was characterized as "average," "above average", or "below average" with respect to the ratio of severely disabled individuals to its total disabled population. Finer discriminations, including the proportions of severely disabled individuals by diagnostic type, race, and sex within each State provided no useful patterns for selection of the States.

The States selected for the survey were Colorado, Connecticut, Georgia, Idaho, Indiana, Maryland, Minnesota, New York, North Carolina, Ohio, Oklahoma, and Washington, which provided a corss-section of geographic locale and proportion of severely disabled to the total disabled population.

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2. The RSA-300 data file is a comprehensive standardized system of statistical reporting on the complete rehabilitation process for every individual coming into contact with VR. FY 1972 covers the period from July 1, 1971 through June 30, 1972, which overlaps the months of this time period in which severely handicapped individuals participating in the VR survey were rejected.

The General Counsel of the Department of Health, Education, and Welfare issued an opinion on confidentiality which required the State Vocational Rehabilitation (VR) agencies to obtain consent from individuals participating in the study prior to being contacted by The Urban Institute. Utilizing the R-300 data file, the States provided The Urban Institute with a list of persons closed in status 08, 38, or 30 by reason of severity during the period from September 1, 1972 through August 31, 1973 who consented to participate in this study. This period was selected so that persons interviewed would have been rejected by VR within 1 to 2 years of being interviewed, so that a large proportion of the addresses were current and at the same time enough time had elapsed to study the adjustments these persons had made in the absence of VR assistance. People rejected by VR whose primary disability was mental illness, mental retardation, alcoholism, drug addiction, or character disorder, were excluded from the sample.[3] Many of these individuals would have required approvals of guardians or institutions and special questionnaires constructed to deal with their unique problems, for which there was insufficient time. Special analyses of these groups were obtained from other sources.

The final sample size of 889 persons interviewed comprises slightly over 1 percent of the persons rejected for severity during FY 1972. It was not possible to reach the original goal of 1,000 interviews within the time frame. The largest obstacle was that a significant number of persons rejected could not be located; some had died, many had moved, leaving no forwarding address or telephone, and some were working (most VR agencies did not attempt to locate persons after working hours). The resourcefulness and staff time

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[3] Twelve persons in these categories were included despite the instructions to exclude these disability types. Eight of these 12 were "character disorders."

available to the various State agencies differed widely also. At a minimum, the State agencies sent letters and then made at least one attempt to contact by telephone those who failed to reply; at maximum, the counselor who had dealt with the respondent at the time of VR contact went to his or her home, explained the study, and requested cooperation. These different techniques, as well as regional differences in willingness to participate, affected the size of the sample obtained in each State. Other difficulties encountered included suspicion or apathy on the part of individuals contacted, many of whom feared losing current benefits, such as Supplementary Security Income. Some feared that they would be "forced" to take a job even though they were physically unable, and others felt that a survey would serve no purpose. Persons in rural southern areas were generally more willing to participate and less fearful of the adverse consequences of participation than those in more industrialized northern States. Table 7-1 summarizes the regional and State differences between the original sample goals and the actual sample obtained. In addition to the problems encountered in locating and obtaining permission from a sizable number of individuals, a disproportionate number of them lived outside of large urban areas, so that interviewers often had to travel considerable distances or to forego interviews in many of the outlying rural areas (12.5 percent of the interviews were from population centers of less than 5,000 persons).

It appears that handicapped persons who live in areas of less than 100,000 people have a much greater chance of being rejected by VR agencies than those in large urban centers. For example, a few more persons were rejected in Utica, New York than in Buffalo and Rochester combined, despite the fact that the combined population of the latter two cities is more than seven times the population of Utica. The apparent reason for a greater degree of rejection in the smaller population centers seems to be lack of available supporting services.

Because of the difficulties in obtaining a sample of consenting individuals in each of the 12 States, it was not possible to further specify the sample by age, sex, race, and disabling condition. All consenting persons within a 30-mile radius of a major urban center and a minimum of a 10 percent rural sample were selected for study.

Table 7-1

Number of Persons Interviewed in VR Survey

Region	State	Original Number of Interviews Expected		Number of Interviews Actually Obtained	
EAST	Connecticut	55		18	
	New York	142		95	
	Maryland	75		114	
		272	(27%)	227	(25%)
SOUTH	Georgia	130		117	
	North Carolina	120		167	
		250	(25%)	284	(32%)
MIDWEST	Indiana	55		28	
	Minnesota	60		58	
	Ohio	130		118	
		245	(25%	204	(23%)
WEST	Colorado	68		38	
	Idaho	45		14	
	Oklahoma	45		73	
	Washington	75		49	
		233	(23%)	174	(20%)
NATIONAL TOTAL		1,000	(100%)	889	(100%)

The samples drawn from each region are roughly proportional to the actual number of severely disabled within each region. Owing to the factors mentioned before, State sample sizes varied from original sample estimates and are not to be considered representative of the number of handicapped in that State.[4]

As Table 1 indicates, the number of expected and obtained interviews by region are similar enough to permit appropriate statistical comparisons of regional and national data.

Major Areas of the VR Survey Analysis

This chapter of the report highlights some of the major areas of investigation covered by the survey. Additional survey results may be found in the chapters which discuss transportation issues, architectural barriers, geographical mobility, employment, and definitions of disability.

The first section of this chapter describes the basic sociodemographic and income characteristics of the surveyed population. The second section focuses on the physical condition of the sample; the different disability types are described as well as the level of physical functioning of the sample and the relationship between physical condition, age, and employment patterns. The last section focuses on the services and equipment which these individuals received and their perceptions of their current equipment and service needs.

MAJOR CHARACTERISTICS OF INDIVIDUALS CLOSED BY VOCATIONAL REHABILITATION

In presenting the salient characteristics of individuals interviewed, this section includes background data, which are important for understanding

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[4] Estimates of the number of severely handicapped individuals closed in status 08, 28, and 30 by reason of severity were based on the FY 1972 R-300 files: in a few instances, (e.g., Connecticut) state estimates were considerably higher than the actual number available during the time period selected for study and thus the obtained sample falls short of the expected sample. Shifts in the proportion of "mental" rejects (codes 500-534) accounted for most of the differences between expected and actual sample.

later sections on physical condition and service needs and help to illustrate the various factors that must be dealt with in defining severity of handicap and in developing public policies for this population.

The sample, like the total VR population, was predominantly composed of white males. Of the sample, 61 percent were male; and 72 percent of this total sample were white, 25 percent black, and only 3 percent Hispanic, American Indian, Oriental, or other race.

Table 7-2 illustrates that our sample of the severely handicapped rejected by Vocational Rehabilitation is largely urban. Fifty-eight percent of this population lives in a large city or a suburb of a large city.

Table 7-2

Area of Residence of VR Sample

	Number	Percent
Large City (over 100,000)	462	45.2
Suburb of Large City	111	12.5
Small City (25,000 - 100,000)	136	15.3
Suburb of Small City	31	3.5
Small Town (5,000 - 25,000)	98	11.0
Rural (farm, ranch, town of less than 5,000)	110	12.4
No Answer	1	0.1
TOTAL	889	100.0

Table 7-3 indicates that sizable numbers of the persons surveyed had a relatively low educational level. Fully 20 percent had less than a seventh grade education, 35 percent had completed between seventh and tenth grades of school. On the other end of the spectrum, 11 percent had gone to college or graduate school.

Table 3

Last Grade in School Completed by VR Sample

Grade	Number	Percent
0	15	1.7
1-6	163	18.3
7-10	311	35.0
11-12	301	33.9
13-16	81	9.1
17-28	15	1.7
Missing, No Answer, Don't Know	3	.3
TOTAL	889	100.0

Perhaps one of the most striking findings of the survey, which may have far-reaching implications for designing policy alternatives for the severely handicapped, is the age distribution of the sample. As Table 7-4 indicates, the individuals sampled are at the upper end of the age spectrum.

Table 7-4

Distribution by Age of VR Sample

Age Range	Number	Percent
16-30	81	9.1
31-40	120	13.1
41-45	97	10.9
46-50	135	15.2
51-55	174	19.6
56-60	177	19.9
61-65	83	9.3
66+	21	2.4
Missing	1	0.1
TOTAL	889	100.0

About half of the sample population are over 50 years of age, and approximately two-thirds are older than 45. Only a third of the sample are under 46. This age distribution has an important effect on the kinds of income these people have, the kinds of services they need, their employability, and their living situation.

As one would expect of an older population, a large percentage are married, live with their family, and are homeowners. As shown by Table 7-5, 60 percent of the sample are married, with only 15 percent single.

Table 7-5

Marital Status of VR Sample

Status	Number	Percent
Single	131	14.7
Married	531	59.8
Separated/divorced	160	18.0
Widowed	66	7.4
No answer	1	0.1
TOTAL	889	100.0

Given the large percentage who are married and the relatively high age range of the sample, it is not surprising that 81 percent live with their family, including 43 percent who have children living with them. The total number of persons in the household averaged between 2 and 3 persons. Three percent of the persons surveyed were living in nursing homes or other institutions, 15 percent lived alone, 31 percent lived with one other person, 20 percent were in households of 3 persons, another 20 percent had 4 or 5 persons in the household, and 11 percent lived in households with 6 or more persons.

The living arrangements of the population are illustrated in Table 6.

Table 7-6

Living Arrangements of VR Sample

Arrangement	Number	Percent
House - owned by self or family	483	54.3
House - rented	184	20.7
Apartment, condominium, or trailer - owned	38	4.3
Apartment, condominium, or trailer - rented	137	15.4
Rooming house, rented room, or hotel	15	1.7
Nursing home, sheltered care home, or hospital	30	3.4
No answer	2	0.2
TOTAL	889	100.0

In looking over Table 7-6, two interesting observations can be made. First, 59 percent of the sample live in a house, apartment, condominium, or trailer which is owned by the individual or his family. Second, only 1.7 percent live in a rooming house, rented room, or hotel, a situation which connotes social isolation and poor living conditions.

While the home ownership figure appears rather large at first glance, it should be noted that the home may not be owned by the disabled individual but by a member of his family. It should also be noted that in 1969, 71 percent of nonfarm families headed by an individual 65 and over owned their own homes.[5]

Income data were collected by household, not by individual, so caution should be maintained while looking at the distribution of income (Table 7-7). It should also be noted that the income data are self-reported and have not been validated through any means other than normal editing checks.

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[5] Survey Research Center, 1969 Survey of Consumer Finances (Ann Arbor, Mich., University of Michigan, 1970).

Table 7 -7

Total Family Income, 1973, VR Sample

Income (in dollars)	Number	Percent
1 - 1,000	12	1.5
1,001 - 2,000	78	9.5
2,001 - 3,000	120	14.5
3,001 - 4,000	99	12.0
4,001 - 5,000	76	9.2
5,001 - 6,000	78	9.5
6,001 - 7,000	60	7.3
7,001 - 8,000	54	6.5
8,001 - 9,000	47	5.7
9,001 -10,000	39	4.7
10,001 -12,000	52	6.3
12,001 -15,000	53	6.4
15,001 -20,000	36	4.4
20,001 +	21	2.5

Table 7-7 indicates the family income of severely handicapped rejected from VR covers a wide range. While a significant portion of the sample --about 19.6 percent--have incomes of over $10,000, a rather large percentage is in the poverty range. Eleven percent have incomes of $2,000 or less, and one-quarter of the sample have incomes under $3,000.

In order to further understand the family income picture of the severely handicapped, it is important to look at the various sources of income and assess their importance, as illustrated in Table 7-8, where a number of interesting points can be discerned. First, almost 43 percent of the families of the sample receive income from wages, which ranks highest in mean income. Since only a small percentage (about 11 percent) of the severely handicapped are working now or have worked in the last year, this indicates that other family members are supporting the disabled individual. Second, a rather high percentage receive substantial dividend and interest income. The mean income from this source is $1,550. Since the population is older, it is possible that this high dividend and interest income reflects interest on their lifetime savings from work. Third, while the mean family income is $6,811, it should be noted again that almost 25 percent of the sample have incomes under $3,000 (Table 7-7). Finally, Social Security reaches the largest number of the sample population, with 73 percent getting income from that source.

While the level and sources of income provide useful statistical information in the analysis of our sample, what financial insecurity can mean to a disabled individual is not really captured in numbers. Statements from or about handicapped individuals included in our survey more vividly illustrate the impact of financial deprivation on the severely handicapped.

The first statement concerns a 45-year-old man who lives in rural Indiana with his wife and three teenage children. At the end of the interview with him the interviewer had this comment:

> He was very nice and tried to answer to the best of his ability. His one question was how is he supposed to raise his three children on $120 a month. That is what he is getting from Social Security. He does not feel as if he is able to do his part. He tried to commit suicide.

Table 7-8

Source of Family Income of VR Sample, 1973

Source of Income	Number receiving income	Percent receiving income from source[1]	Mean income for those receiving from source
Wages	343	42.7	$7,172
Non-farm self-employment	14	2.0	5,902
Operating a farm[2]	10	1.1	5,076
Social Security	616	73.1	2,849
Dividends and interest	93	11.1	1,557
Public assistance	172	21.3	1,843
Unemployment compensation	202	23.8	2,556
Private pensions, trust	97	11.5	2,164
Receipts	76	9.4	3,219
Mean family income	823	----	6,811

1. Percentage totals exceed 100% because clients may have received income from several sources.
2. Part-time farmers not included.

Another comment which illustrates the devastating impact of poverty refers to a man who lives in rural North Carolina with his wife, three children, and two grandchildren. He suffers from hypertensive heart disease. At the end of his interview, the interviewer wrote this comment.

> The respondent told me about one condition at his home which I thought was absolutely terrible. He said his electric water pump failed so he put a hand pump on it and pumped rats out of his well. He thinks a rat probably stopped up his electric pump. His family now hauls water from a neighbor's home.

Another individual, a blind chemist who is currently completing work for his Ph.D., indicated he had pulled his own tooth because he had no money to pay a dentist. He is supported solely by Social Security, which pays him $300 per month.

PHYSICIAL CONDITION

The VR Survey contains three major types of indices to describe the respondent's physical condition. These measures were utilized in order to describe the type and extent of the disabling condition(s) in the VR population surveyed, as well as to determine the relationship between type and/or severity of disability and other factors such as age, service needs, and employment status.

The indices used were the R-300 disability code, the Barthel Index, which measures the need for assistance in self-care and mobility, and a functional limitations scale, which focuses on the degree of difficulty experienced by the disabled in performing activities of daily living.

Disability Types

The R-300 code is the statistical code used by the Rehabilitation Services Administration (RSA) to describe the primary and secondary disability of all applicants for vocational rehabilitation. In our survey of individuals rejected by VR because of severity, only the primary disabling condition was utilized.

The respondent's primary R-300 code was obtained from the State VR records, where it is entered at the time of first referral by the counselor. These diagnostic codes have several limitations.

1. Many of these codes involve a combination of etiologic factors and type of impairment, whereas others, such as epilepsy, focus on etiology rather than on type of physical impairment.

2. The codes appear to be completed somewhat inconsistently. In some instances the current reason for referral to VR is listed (as in the case of problems with teeth or gums) even though it may be quite minor in comparison to the major disabling condition of the respondent. In other instances, the major "physical" condition is listed, even though this condition was not relevant to the person's need for VR services and was at best secondary to the major disabling condition. For example, congenital heart disease might be listed, when chronic alcoholism best described both the major disabling condition and current reason for VR referral.

As discussed in the section on definitions, the diagnostic label is only minimally related to the severity of disability. Hence, we could not use the R-300 codes to clearly establish the degree of functional limitation of the disabled in our survey. However, R-300 data are provided to describe the physical condition of the disabled, since many people in rehabilitation are familiar with this classification system.

In the population surveyed, 450 respondents (51 percent) had some type of orthopedic impairment (Table 7-9). The most frequent type was impairment of the trunk, back, or spine, followed by impairment of one or both lower limbs and impairment of three or more limbs.

Table 7-9
R-300 Diagnostic Codes, VR Sample

R-300 Code	Description	Number	Percent of Total Population Surveyed
100-149	Visual Impairment	20	2.2
200-299	Hearing Impairments	9	1.0
	ORTHOPEDIC IMPAIRMENTS:		
300-319	Impairment involving 3 or more limbs	90	10.1
320-339	Impairment involving one upper and one lower limb.	39	4.4
340-359	Impairment involving one or both upper limbs	30	3.4
360-379	Impairment involving one or both lower limbs	106	11.9
380-399	Impairment involving trunk, back, spine, etc.	185	20.8
400-499	Amputations	24	2.7
500-534	Mental	12	1.3
600-609	Neoplasms	8	.9
610-619	Alergic, Endocrine, Metabolic	41	4.6
620-629	Diseases of the blood	6	.7
630-639	Epilepsy and other nervous system disorders	43	4.8
640-649	Cardiac and circulatory	162	18.2
650-659	Respiratory diseases	30	3.4
660-669	Digestive system	21	2.4
670	Genitourinary diseases	15	1.7
680-689	Speech impairments	5	.5
690-699	Other diseases, n.e.c.	42	4.7
	Undetermined	1	.1

The only other frequently occurring R-300 diagnostic category in our sample was "cardiac and circulatory conditions," comprising 18 percent of the total sample. Epilepsy and "allergic, endocrine, metabolic disorders" each comprised about five percent of the total.

Orthopedic impairments were analyzed by type of limb (or trunk) impaired and by etiology (cause) of the impairment. The most frequent <u>cause</u> for orthopedic impairments (Table 7-10) was "accidents, injuries and poisoning," followed by "arthritis and rheumatism."

Table 7-10

Etiology of Orthopedic Impairments, VR Sample

Etiology	Number	% of Total Population Surveyed
Cerebral Palsy	17	1.9
Birth Injuries	6	.7
Other diseases, infections and neurological disorders	54	6.1
Arthritis and Rheumatism	85	1.6
Stroke	34	3.8
Polio	12	1.3
Muscular Dystrophy	3	.3
Multiple Sclerosis	23	2.6
Parkinson's Disease	4	.4
Quadriplegia, Paraplegia, because of spinal cord injury	11	1.2
Accidents, Injuries, Poisonings	200	22.5
Undetermined	1	.1
TOTAL	450	50.6

Measures of Severity

The Barthel Index is a scale which measures a person's ability to physically function independently.[6] The Barthel Index contains "self-care" items which are considered basic to an individual's ability to care for himself (drinking, eating, dressing, grooming, washing, controlling urination and bowel movements, and putting on brace or artificial limb) and additional "mobility" items which pertain to the ability to move around without assistance (getting in or out of chairs, toilets, showers, walking 50 yards and walking up one flight of stairs). Respondents were asked whether they could perform each activity "by themselves," "with assistance or in the presence of another person," or not at all.

The Barthel Index was originally used in clinical settings to evaluate a patient's state of independence before treatment, his progress during treatment, and his status when maximum benefit had been attained. Thus, it provided a measure of an individual's progress toward independent functioning in the areas mentioned. Environmental factors such as availability of help (e.g., for dressing, eating), architectural barriers, or presence of special devices (e.g., stairs, grab bars, ramps, etc.) can influence the Barthel score, since an individual who can perform the activity alone, even with

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[6] The original Barthel Index was modified by Dr. Carl Granger at Tufts New England Medical Center Rehabilitation Institute for the purposes of this study. Originally, the scale was to be completed by trained physical therapists or nurses after observation of the patient's behavior. In the VR survey, interviewers asked the respondents whether they could perform each activity by themselves, with assistance from others, or not at all.

the help of special devices, receives a perfect score. One of the limitations of the Barthel Index is that it does not differentiate between people who can do activity with no difficulty and those who have considerable difficulty but can still manage alone, nor does it indicate the length of time needed to perform the task. Therefore, the score must be construed as the interaction of the person's physical condition with environmental conditions. In the VR survey, Barthel scores were used as an index of severity in determining the extent to which physical condition was related to type of disability, age, functional limitations, service needs, and employment status.[7]

As a supplement to the Barthel Index, 11 survey items pertaining to ability to function in other areas of daily living were added: operating household appliances, taking medicine, getting in or out of bed, sitting for more than one hour, lifting or carrying weights of 10 pounds, stooping or kneeling, reaching with both arms, using hands and fingers, using the telephone, operating a TV or radio, and admitting visitors. Answers to these questions would indicate whether respondents could perform activities which are required almost daily if one is to perform minimal household tasks, such as cooking, cleaning, and lifting items, and to maintain communication with others, as by admitting visitors or using a telephone.

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[7] Total Barthel scores were computed using a scoring system devised by Dr. Carl Granger (see footnote 5). Dr. Granger's description of the scoring categories varies slightly from the briefer presentation in Table 7-7; 21-61 was labeled "markedly to moderately dependent," and 62-90 was "moderately to slightly dependent."

Survey Findings

On the basis of the Barthel Index, 45 percent of the surveyed population were found to be completely independent in self-care and mobility. Another 14 percent were "slightly dependent", 30 percent were "moderately dependent", and only 11 percent "severely" or "totally" dependent (Table 7-11).

Table 7-11

Total Barthel Scores for VR Sample

Total Barthel Score	Number	Percent
0-20 (totally dependent)	28	3.2
21-61 (severely dependent)	68	7.7
62-90 (moderately dependent)	263	29.6
91-99 (slightly dependent)	122	13.7
100 (independent)	398	44.8
Undetermined	9	1.0
TOTAL	888	100.0

Using the Barthel Index, there is strikingly little evidence of overwhelming physical limitations of people in our sample who were rejected from VR because of the severity of their disability. It must be remembered that a "perfect" Barthel score can be obtained if a person can perform all tasks independently, regardless of the degree of difficulty involved. However, even after difficulty in performance of daily functions was examined (Table 7-12), the overall conclusion remains the same—most people rejected for severity can perform almost all activities of daily living (ADL) and perform them without difficulty. Only two of the 11 items (lifting weight of 10 pounds and "stooping, bending, or kneeling") were either impossible or difficult for a majority of those people in our sample.

Table 7-12

Degree of Difficulty in Performing Activities of Daily Living, VR Sample

Functional Limitation	Can do with no difficulty Percent	Can do with some difficulty Percent	Cannot do at all Percent	Total[1] Percent
Operating household appliances	56	24	17	97
Taking medicine	85	6	5	96
Getting in or out of bed	71	22	6	99
Sitting for more than an hour	64	29	7	100
Lifting or carrying weights of about 10 pounds	31	27	41	99
Stooping, bending, or kneeling	24	41	30	95
Reaching with both arms	55	27	17	99
Using hands and fingers	64	29	7	100
Using the telephone	85	10	4	99
Operating TV, radio, or stereo	90	6	4	100
Admitting visitors to your home	84	9	7	100

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[1] Total may not equal 100 percent because of rounding and/or some small number of respondents who were undecided about the appropriate response.

In light of these startling findings, we examined the survey data in considerable depth in order to learn of possible reasons for rejection other than the severity of disability. Of particular interest were variables such as age, previous work experience, and motivation. In our survey of providers of VR services, these three items were ranked highest in actually influencing most counselors' decisions to accept or reject severely handicapped individuals. (See Section VI.)

Age and Severity of Disability

A strong relationship was found between age and severity of disability, as measured by the total Barthel score (Table 7-7: The most severely disabled age group surveyed was the young (ages 16 to 30), with 10 percent being totally dependent for self-care and mobility and 32 percent severely dependent. As age increased, the percentage of respondents who were totally or severely dependent decreased (43 percent in the 16-to-30 age range, 14 percent of those 31-to-40, 8 percent of respondents 41-50 years of age, and 4 percent of the respondents who were 51-60 years of age.

Respondents who were classified "independent" in ADL functioning, however, were almost equally distributed throughout the age groups.

Table 7-13

Age and Severity of VR Sample as Measured by the Barthel Index

Age	Totally Dependent (0-20)		Severely Dependent (21-61)		Moderately Dependent (62-90)		Slightly Dependent (91-99)		Independent (100)		Total	
	N	%	N	%	N	%	N	%	N	%	N	%
16-30	10	10.4	31	32.3	15	15.6	9	9.4	31	32.3	96	100
31-40	2	1.7	14	11.9	29	24.8	16	13.7	56	47.9	117	100
41-50	8	3.6	9	4.0	71	31.6	35	15.6	102	45.3	225	100
51-60	6	1.8	6	1.8	114	33.9	50	14.9	160	47.6	336	100
61+	2	1.9	6	5.7	35	33.4	12	11.4	50	47.6	105	100

From the data, it appears that age is an important reason for rejection--i.e., a sizable portion of the young are actually rejected for severity while older persons are rejected for other reasons, perhaps because the cannot as readily be trained or placed in jobs as younger persons with similar physical problems.

Of particular concern, however, is the fact that 57 percent of the people under 40 years of age were physically independent or only slightly dependent and still rejected by VR on the basis of severity. In an effort to learn more about these people, we examined responses to questions on motivation and work experience. We also analyzed other factors such as educational background, possible financial disincentives to work, other physical limitations, geographic locale, and other obstacles to working.

Motivation and Work Experience

Young people (16 to 40 years of age) rejected by VR who were independent or only slightly dependent, according to the Barthel Index, were analyzed by work history and motivation to work. Three-quarters were found to have had recent work experience. Ten percent were currently employed, and 65 percent had worked within four years of the time they were rejected by VR (Table 7-14).[8] Many of these people had managed to find jobs on their own despite being disabled, as evidenced by the fact that over half (57 percent) had worked since the onset of their disability.

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[8] Persons over 40 years of age who were functionally independent or nearly so were similar in that almost three-quarters had recent work experience and wanted to work.

Table 7-14

Work Experience & Motivation of Young, Functionally Independent[1] Persons Rejected by VR for Severity

Age	Employed		Recent Work Experience[2]								Students		TOTAL	
			Retired early		Not working but want to work		Not working, do not know if want to work		No recent work experience[3]					
	N	%	N	%	N	%	N	%	N	%	N	%	N	%
16-30	6	15	6	15	15	38	0	0	9	23	3	8	39	100
31-40	5	7	25	34	25	34	2	3	15	20	1	1	73	100
Both age groups	11	10	31	28	40	36	2	2	24	21	4	4	112	100

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1. Individuals scoring above 90 on the Barthel Index.
2. Recent work experience is defined as having worked within 4 years of the time the individual was rejected by VR.
3. Including individuals who have never worked and individuals who last worked more than 4 years before the time of VR rejection.

Persons who stated that they were "not working" rather than "retired early because of disability" were asked whether they wanted to work. Of these 42 persons, 40 stated that they wanted to work, and only two (who had worked recently) were not certain. No one indicated that he or she did not want to work. Hence, poor motivation, as measured by expressed desire to work, does not seem to be a factor in rejection.

In short, almost half (46 percent) of individuals of prime working age who were functionally independent or only slightly dependent and rejected by VR because of severity had either found employment or wanted to work and possessed recent work experience.[9]

Other Characteristics of Young People Rejected by VR

Young people with recent work experience and seemingly good motivation to work were analyzed further, by looking at both their objective and subjective responses to various survey items. After close examination of the data on these individuals, it was found that there was no single reason for rejection due to severity--that anticipated labor market discrimination, psychological problems, disagreement over VR's program, scheduling problems, caseload pressures, and arbitrariness on the part of the VR counselor may contribute as much or more to a definition of closure "by reason of severity" as the physical impairment.

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[9] This is a conservative estimate, since persons indicating they had "retired early because of disability" were not asked whether they wanted to work. These persons comprised 28 percent of this prime working age sample, and almost one of three of such persons had worked since the onset of disability.

With respect to impairment, it was discovered that approximately one-third of these individuals had more extensive physical problems than were evident from the Barthel Index. Physical problems which were not apparent from the Barthel Index include pain, heart problems, and allergic reactions. However, it should be noted that most of these people not only wanted to work but did not feel that their physical problems, even problems like constant or intermittent pain, were significant enough to keep them from working.

Loss of benefits did not seem to be a compelling reason for these persons not to be working. Although almost three-quarters of these persons stated they would lose some benefits; only three percent indicated this as the main reason for not working. This apparent incongruity seems to be due to the fact that most of them receive only bare subsistence levels of benefits, so that working would generally increase their income, and also that most of these individuals disliked being dependent on others, unproductive, and cut off from the activities which they would normally engage in.

Many of these persons also cited employer discrimination when seeking a job. Some employers were simply reticent to hire anyone who was handicapped. Some of those interviewed were fired after having an epileptic seizure or asthma attack, and a number were turned down because the employer claimed that his insurance would not cover them. In many instances, employer discrimination and VR rejection, when the person was physically and mentally able to perform the job, produced almost insuperable barriers to employment.

A glaring example of employer discrimination is the following: a man in his late thirties, a television production specialist (writer) with five years of higher education, stated that "epilepsy is felt as a danger even

Table 7-15

Equipment Usage and Needs
VR Sample[1]

Type of Equipment	Persons who have this equipment[2]		Persons who use this equipment[3]		Persons who still need this equipment[2]	
	N	%	N	%	N	%
Helper for upper limb (e.g., splint, brace)	48	5.4	36	76.6	8	.9
Helper for lower limb	61	6.9	53	88.3	9	1.0
Artificial limbs, hands	21	2.4	19	86.4	5	.6
Back brace	131	14.7	96	74.4	15	1.7
Cane, crutches, or walker	271	30.5	223	82.6	21	2.4
Wheelchair	132	14.8	118	89.4	10	1.1
Motorized wheelchair	15	1.7	12	85.7	17	1.9
Trapeze or bathtub lift	27	3.0	25	92.6	46	5.2
Hospital bed	56	6.3	49	89.1	26	2.9
Specially equipped automobiles or other motorized vehicles	17	1.9	16	94.1	12	1.3
Aids for vision (high magnification lenses, TV monitor)	69	7.8	62	92.5	37	4.2
Seeing eye dog	--	--	--	--	2	.2
Hearing aids	18	2.0	13	72.2	21	2.4
Speech aids (e.g., voice boxes, amplifiers)	4	.4	3	75.0	1	.1
Respiratory aids	31	3.5	31	93.9	20	2.2
Dentures	229	25.8	200	89.3	74	8.3
Other	113	12.7	105	92.9	92	10.3
Don't have any/Don't need any	282	31.7	--	--	564	63.4

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1. Percentage totals exceed 100 percent because clients may have, use, or need more than one kind of equipment.

2. Percentages based on 889 respondents to survey.

3. Percentages based on number of respondents who have this type of equipment.

though three doctors have given certificates that my epilepsy is completely under control." His job was "abolished" after his first seizure, for which he is still fighting Civil Service. He did not know why VR had rejected him. Another indicated the same problems in getting hired because of his record of epileptic seizures, and added that "people don't realize I know when I'm going to have one, and it could be taken care of but they don't help--they hinder me by hauling me off in an ambulance when I could have come out of it alone." He also claimed he would get fired when he had a spell.

Another incident of employer discrimination was related to us by a 34-year-old man with multiple sclerosis, whose only functional limitations were sitting and stooping. He earned one of the highest test scores for a communications job with the city police department but was turned down because he was "too disabled to qualify for the pension fund." When he offered to waive the pension fund, he was told this wasn't allowed.

SERVICES USED AND NEEDED

Having outlined the major socio-demographic, economic, and physical characteristics of the individuals rejected from Vocational Rehabilitation, we now describe the services and service agencies which these persons have utilized as well as their service needs. This section will look at the service agencies contacted, services received from VR and non-VR sources, equipment usage and need, and current service needs. The relationship between dependency, as measured by the Barthel Index, age, and service needs will be explored.

Equipment

The extent to which a severely handicapped individual can leave his home and function independently depends in part on the appropriateness and availability of his equipment. In the survey, information was obtained on the types of equipment owned, usage, sources of payment for this equipment, and additional needs.

Respondents were asked whether they had any special equipment, including such items as braces, wheelchairs, dentures, and aids for vision, hearing or speech. Thirty-two percent of the VR rejects surveyed had no special equipment (Table 7-15). Thirty percent had a "cane, crutch, or walker", 15 percent had a wheelchair, and 2 percent had a motorized wheelchair. These figures are similar to the number of persons with orthopedic impairments (50 percent); the number of persons who were unable to walk 50 yards even with assistance (17 percent), is similar to the number of persons who have wheelchairs. Dentures were common items, probably due to the preponderance of persons over 50 in the survey population (one-fourth of the survey population had dentures).

Respondents were then asked whether they used the equipment, who paid the major share of the cost for the equipment, and what equipment they still needed. Equipment usage varied considerably. Specially equipped automobiles, visual aids, respiratory aids, and trapezes were generally used when available (92 percent to 96 percent of the persons having these items used them). Between 83 and 90 percent of the individuals with lower limb helpers, artificial limbs, wheelchairs (regular and motorized), canes, crutches, or walkers, hospital beds, and dentures used these items. Certain types of equipment, however, were used less frequently. Of those with upper limb helpers (splints, braces), 21 percent did not use them, and 26 percent did not use their back braces. The reasons for failure to use the equipment seem to be a combination of factors. For back braces, upper and lower limb helpers, and artificial limbs, the data regarding ability to put on this equipment suggests that the persons who do not use them may be unable to; 53 persons who had an artificial limb, back brace, or limb helper did not use it, which is identical to the number of people who needed assistance putting on a brace or artificial limb. Other equipment usage, such as with dentures, seemed to be problematical because of the equipment not fitting or working properly. A number of persons reported that they still needed equipment which they had, such as a new set of dentures.

When all types of equipment were combined, it was found that respondents who had some type of equipment averaged 1.9 items of equipment. VR paid for the equipment five percent of the time, public assistance (Medicaid, Medicare, or Welfare) paid 15 percent of the time, and other agencies paid for 17 percent of this equipment. Private insurance handled 13 percent of the bills. But the disabled themselves bore the lion's share (47 percent) of the cost. Respondents tended to pay for certain types of equipment which are not necessarily related to disability or which are relatively inexpensive more frequently than others. Seventy-two percent paid for their dentures, 70 percent for visual aids (usually glasses), 65 percent for canes, crutches or walkers, and 62 percent for specially equipped automobiles.

Two-thirds of the respondents indicated that they did not currently need any further equipment. Persons indicating some need for equipment listed an average of 1.3 types of equipment needed. The most frequently mentioned items were dentures (8 percent), followed by "trapeze or bathtub lift" (5 percent) and "visual aids" (4 percent). The major reason listed for not having the needed equipment was that the cost was prohibitive (51 percent). Other barriers to obtaining the equipment, including "agency won't provide," "equipment not available," and "don't know how to get it," together accounted for 19 percent of the responses. Nineteen percent either "hadn't gotten around to getting the equipment" or stated that their need had developed recently.

Out of 571 persons surveyed who had some type of equipment, 211 (37 percent) indicated that this equipment had needed repair; 84 (40 percent) of those needing equipment repair work had experienced problems in obtaining it. The major obstacle to equipment repair was again the costs--40 percent of the respondents with problems in equipment repair indicated that costs were the major problem.

Service Agencies Contacted

Respondents were asked to indicate the service agencies they had contacted within the last 3 years to apply for benefits for themselves. Since most of the persons surveyed first became disabled during this period, agency contact would be expected to be high during this time.

Ninety-seven percent of the surveyed population had contacted at least one agency (other than Vocational Rehabilitation) during the 3 years prior to the survey (Table 7-16). The most frequently contacted agency was the Social Security Administration (88 percent), followed by food stamps (34 percent) and public welfare other than AFDC (26 percent).

The major type of benefit received from these agencies was "cash income or subsidy." When all types of benefits received from all agencies were totalled, 74 percent of the benefits received were "income", followed by "physician services" (9 percent). This would be expected, given the types of agencies most frequently applied to, since the only possible benefit from most of these agencies is income or income in kind such as low-cost housing and food stamps.

Table 7-16

Agencies Contacted and Benefits Received By VR Sample[1]

	Contacted Agency[2]		Received Benefits[3]	
	N	%	N	%
PUBLIC:				
Social Security Admin. or one of its agencies for DI, OASDI, or SSI	778	87.5	636	81.7
Veterans Admin. or one of its agencies for pension or compensation	170	19.1	127	74.7
Workmen's Compensation for on-the-job injuries	106	11.9	80	75.5
Unemployment Compensation or Total Disability Insurance	75	8.4	51	68.0
Employment and job placement services	67	7.5	8	11.9
Aid to Families with Dependent Children	89	10.0	74	83.1
Any other public welfare or public assistance agency	231	26.0	175	75.6
Low cost or public housing	67	7.5	41	61.2
Food stamps or commodities	307	34.5	209	68.1
Job training programs, e.g., WIN, JOBS, etc	78	8.8	16	20.5
Legal aid societies and programs	19	2.1	11	57.9
State programs for sickness and temporary disability benefits	24	2.7	13	54.2
Railroad Retirement and disability benefits	8	.9	5	62.5
Programs for pensions or disability benefits for government employees	29	3.3	28	96.6
Programs for pensions or disability benefits provided by employers or unions	61	6.9	48	78.7
Bureau of Handicapped Children	11	1.2	4	36.4
Other public agency	34	3.8	21	61.8
PRIVATE:				
Medical agency or hospital	51	5.7	40	78.4
Vocational training agency	76	8.5	20	26.3
Mental health agency (including public)	15	1.7	10	66.7
Employment or job placement agency	9	1.0	1	11.1
Church and synagogue social services	19	2.1	13	68.4
Other private agency	31	3.5	14	45.2
Haven't contacted any	26	2.9		

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1. Percentage totals exceed 100 because clients may have contacted or received benefits from more than one agency.
2. Percentage of total survey population (N=889).
3. Percentage of respondents who contacted the agency that received benefits.

Total Barthel scores were cross-tabulated with service agencies contacted to determine whether dependency, as measured by the Barthel scale, was related to the type of service agency contacted. There was no relationship between dependency and contact with the Social Security Administration. However, the more dependent persons relied more heavily on public welfare (other than AFDC) than the more physically independent persons, and persons who were more physically independent contacted employment-related agencies (agencies which help to train or procure jobs or compensate for loss of employment) more than physically dependent persons.

Services Received from VR and Other Agencies

Almost half of the respondents indicated that they had talked to a counselor at VR. Only 29 percent received any services in addition to counseling. Individuals closed in status 28 or 30 comprise 22 percent of the total survey population and could have received some services; some of those closed in status 08 had also received services. Those who received services from VR beyond vocational counseling averaged 2.1 different services. The services which VR most frequently paid for were "vocational training," "educational costs," "transportation" and "hospitalization"; 6 to 8 percent of all those surveyed reported these services (Table 7-17).

VR paid for surgery for 3.7 percent of the sample, physical therapy for 3.6 percent, "prosthetic devices, braces, wheelchairs, etc." for 3.6 percent and occupational therapy for 3.0 percent. It was extremely rare for VR to pay for certain services. Less than 1 percent of the total survey population received visiting nurse services, homemaker services, special devices for schooling, or home modifications which were paid for by VR. Communication services (for persons with visual, speech, or hearing impairments) were also quite rare, but this is probably due to the small sample size of these disabilities.

Only 60 percent of the sample were aware of the fact that VR had closed their case. Nine percent indicated that VR had referred them to other agencies upon closing their case, and 5 percent had received some kind of assistance from

Table 7-17

Services Received and Needed[1]

	Services Received From VR		Services Received From Other Sources		Services Still Needed	
	N	%	N	%	N	%
Surgery	33	3.7	102	11.5	57	6.4
Hospitalization	52	5.8	149	16.8	50	5.6
Physical Therapy	32	3.6	85	9.6	141	15.9
Occupational Therapy	27	3.0	22	2.5	86	9.7
Speech/Hearing Therapy	8	.9	11	1.2	47	5.3
Other Medical Treatment	45	5.1	148	16.6	84	9.4
Visiting Nurse	4	.4	16	1.8	27	3.0
Homemaker Services	1	.1	6	.7	87	9.8
Prosthetic Devices, Wheelchair, etc.	32	3.6	45	5.1	69	7.8
Vocational Counseling[2]	72	8.1	13	1.5	126	14.2
Vocational Training	68	7.6	12	1.3	183	20.6
Educational Costs	54	6.1	7	.8	111	12.5
Vocational Placement	15	1.7	3	.3	131	14.7
Tools, Equipment, Licenses for Work	12	1.3	--	--	45	5.1
Special Devices for Schooling	8	.9	3	.3	46	5.2
Transportation	53	6.0	32	3.6	162	18.2
Psychological Therapy	19	2.1	27	3.0	52	5.8
Home Modifications	2	.2	7	.8	41	4.6
Deaf Services	2	.2	--	--	6	.7
Reader Services for the Blind	7	.8	5	.6	9	1.0
Orientation Services for the Blind	2	.2	--	--	7	.8
Other	54	6.1	21	2.4	66	7.4
Don't Need Any	--	--	--	--	348	39.1

1. Percentage totals exceed 100 because clients may have received or may still need more than one services.

2. Respondents were asked this question only if they indicated VR had paid for services beyond vocational counseling.

these agencies. However, 31 percent received help from agencies or clinics to which VR did not refer them. Approximately two-thirds of those who received help independent of VR referral went to hospitals or clinics. The major benefits received from agencies for which VR did not pay were hospitalization, surgery, physical therapy, and other medical treatment; between 10 percent and 17 percent of all respondents surveyed had received these services since being rejected by VR (Table 7-7). Services which were received more infrequently included "prosthetic devices, braces, wheelchairs, etc." (5 percent, transportation (3.6 percent), psychological therapy (3 percent), and occupational therapy (2.5 percent).

When all services received from sources other than Vocational Rehabilitation were totaled, 38 percent were paid for by some form of public assistance (Medicaid, Medicare, or Welfare), 36 percent by other agencies, 12 percent by private insurance, 8 percent by the individuals themselves, and 7 percent by unknown sources. "Other agencies" and the individuals themselves paid the bill more frequently for special equipment, psychological therapy, and transportation than for other services. Private insurance paid for hospitalization, surgery, and physical therapy between 17 percent and 19 percent of the time but infrequently paid for other services.

The fact of having received services, however, does not always mean that the services were appropriate, timely, or satisfactory. For example, one individual described his experience as follows:

> [the] Doctor said someone had lied or made a mistake and he would see what he could do. I never heard from him. I was pretty let down. What they [the doctors] had put in the history was a completely different story than what was going on with me--my history at the hospital has disappeared four times. They broke my toe at the hospital and the nail came off two times and it never showed up in the history. They scraped live tissue, and a doctor came in who screamed at the technician who thought it was dead tissue because I couldn't feel anything--I just learn to overlook things because the doctors said if I said it they would deny it. There's nothing I can do.

Current Service Needs

Respondents were asked whether they needed any services which they were not receiving. Thirty-nine percent indicated that they currently did not need any services (Table 7-7) the remaining indicated an average need of three services per person. The services most frequently cited were vocational training (21 percent), transportation (18 percent), physical therapy (16 percent), vocational placement (15 percent), vocational counseling (14 percent) and educational costs (12 percent).

Other service needs mentioned included occupational therapy, homemaker services, other medical treatment, and prosthetic devices, wheelchairs, etc. Six percent felt they needed surgery, hospitalization, and psychological therapy, and 5 percent mentioned "tools, equipment, or licenses for work," special devices for schooling, speech or hearing therapy, and home modifications.

Services Needed by Age Group

The percentage of respondents who needed services was compared by age group to determine whether different groups had different service needs.

There was no clear age pattern for any of the medical services, except for occupational therapy. Proportionately fewer disabled persons over 50 (7 percent) indicated a need for occupational therapy than younger persons (10 to 15 percent).

Vocational service needs (vocational counseling, vocational training, educational costs, vocational placement, and to some extent "receipt of tools, licenses, equipment, etc., for work") showed a clear relationship to age, a larger proportion of the younger persons indicating they needed these services than older persons. For example, 35 percent of those surveyed who were 16-30 years old indicated they needed vocational training, compared with 29 percent of the 31-40 group, 24 percent of the 41-50 group, 16 percent of those in the 51-60 year range, and 11 percent of those over 60. "Special devices for schooling" followed a pattern similar to vocational services, with the young persons needing these most and the older persons least (from 11 percent of the 16-30 age group to 1 percent of those over 60 years indicating a need for this).

Transportation services, which were needed by 18 percent of those surveyed, were more heavily in demand by younger persons, particularly the 16-30 age group. Thirty-two percent in this age group needed transportation services; between 17 and 21 percent of those aged 31-60 and 13 percent of those over 60 needed transportation services. Home modifications were needed somewhat more by respondents under 40 years of age than by those over 40.

The youngest age group seems to have had the greatest need for services of some sort, with only 26 percent indicating that they did not need any services, compared to 40 percent in all other age groups combined who did not need services. This finding is consistent with the low Barthel scores of this group, i.e., the more "dependent" person would be expected to need more services. The total number of services needed (among those who indicated a need for services), also declined with age (an average of 3.7 services per person in the 16-30 age group, 3.2 for 31-40, 33 for 41-50, 2.7 for 51-60, and 1.6 for persons over 60).

Service Needs and Severity

Respondents' perceptions of their service needs were analyzed by the extent of dependency, as measured by the Barthel Index, to see whether severity was related to the type of service needed.

The percentage of individuals who reported no need for services was similar for all Barthel categories except the "severely" dependent; only 10 percent of the severely dependent felt they needed no further services. Among the individuals who felt they needed services, more "dependent" persons indicated a somewhat higher number of services needed: an average of 3.6, 3.8, 3.1, and 2.6 services needed for the totally, severely, moderately, and slightly dependent respectively, and 2.9 for the "independent."

In most instances, service needs clearly differed for individuals with different degrees of dependency. Surgery and hospitalization were needed primarily by persons who were severely and moderately dependent, physical therapy wa needed by 41 percent of the severely dependent, 19 percent of the moderately dependent, 14 percent of the totally dependent, and 11 percent of the slightly dependent and independent. Occupational therapy and "other medical treatment" was needed most by the severely dependent and least by the totally dependent. Homemaker services were needed most heavily by the severely dependent, followed by the moderately dependent.

Visiting nurse services were needed most by the totally and severely dependent, and prosthetic devices, wheelchairs, etc. were needed most by the totally and the severely dependent. To sum up the medical service needs, the severely dependent have the highest proportion of medical needs, often followed by the moderately dependent. The totally dependent, however, need those medical services which would improve functioning without attempting to physically restore the body (visiting nurse services and special equipment).

Vocational counseling was indicated as a service need most frequently by "severely" dependent persons, followed by "independent" persons. Other vocationa services had no clear relationship with dependency, with the exception of "vocational placement"; the only group indicating a sizable need for vocational placement were the respondents who were "independent" on the Barthel scale (20 percent).

Transportation services were most heavily needed by the severely dependent (37 percent), and least needed by those with little or no dependency. Psychological therapy was most needed by those who were quite physically dependent, as were home modifications.

The relationship between age, severity, and service needs is a complex one. However, from the preceding analysis a number of key points can be made. Most medical needs are primarily a function of severity, not age. This is illustrated by the fact that the severely dependent have the heaviest need for restorative medical services, and the totally dependent primarily need equipment and physical assistance.

Vocational service needs, on the other hand, are primarily determined by age, as illustrated by the finding that older persons need proportionately fewer vocational services--particularly those over 50. Vocational placement is needed by those who are younger and more physically able. Transportation services and home modifications are needed most by those who are both young and physically dependent. The findings suggest that the individuals surveyed had a fairly realistic appraisal of their situation and service needs.

SUMMARY AND CONCLUSIONS

The individuals surveyed who were rejected by VR because of severity were older than expected with half over 50 years of age. The majority had not completed high school, a fact which obviously provides some impediment to employment. Most of these people lived with their families, which were their major, and often only, source of social contact. Over one-quarter were beneath the poverty level, even though almost one out of five had household incomes of $10,000 or more.

The most common disabling conditions in this sample were orthopedic impairments, followed by cardiac and circulatory conditions. Unexpectedly, almost half of these people were completely independent in self-care and mobility, as measured by the Barthel Index. Another scale for measuring functional limitations indicated that out of 11 activities, there were only two which the majority of respondents had difficulty doing ("lifting or carrying weights of about 10 pounds" and "stooping, bending or kneeling"). This finding is rather surprising, since all of these people were rejected by reason of severity. It tends to cast doubt on the validity of the use of severity as a reason for closure.

Further investigation revealed that younger VR rejects were more physically dependent than older persons as measured by the Barthel Index. This suggests that older persons may be rejected in part because their age narrows their employment possibilities.

A disturbing finding, however, was that 57 percent of the younger persons (aged 16-40) were physically independent or only slightly dependent. It was not clear why people of prime working age who were fairly physically fit had been rejected because of severity. Further analysis showed that almost one-half of these people had recent work experience and wanted to work. Analysis in more depth revealed that there were many possible reasons for their rejection, bu it could not be said that the overriding reason for rejection of these persons was that they were too physically impaired. It is clear that many of these peopl want work and could manage it currently. Policies which would give persons rejected from VR automatic access to a review board to determine whether rejection was appropriate could help alleviate some of the arbitrariness inherent in human decisionmaking. On the other side, public policies which prohibit employer discrimination against disabled persons and at the same time protect employers by allowing adequate employers' insurance coverage for disabled persons might go a long way toward easing the way for the employment of these persons.

The people rejected by VR in this survey had rather modest equipment needs; if all persons surveyed were supplied every time they felt would be provided. VR rarely paid for equipment (5 percent of the time), and other agencies or insurance failed to provide such equipment about half of the time. The major barrier for these individuals in obtaining equipment was the cost: half the respondents could to afford needed equipment. If VR paid the bill for equipment needed when other agencies would not cover such items, less than one of four VR rejects would need some type of equipment from VR. If, in addition, VR assisted these individuals by directing them to the places which carried the types of equipment needed, the cost to VR for provision of equipment would decrease further.

When respondents were asked about other service needs, 39 percent needed no additional services. For those who needed services, the most sought after were vocational services, transportation, and physical therapy. Vocational services were needed most often by the younger persons surveyed, whereas physical therapy and other medical services were needed most by the more physically dependent. Transportation services were needed most by those who were young and physically dependent. Provision of vocational services, particularly to persons under 45 years of age, should probably be the first line of attack in decreasing their economic and physical dependency. Provision of physical therapy and transportation services might prove useful in reducing the need for attendant or homemaker/housekeeping services for those with more severe physical limitations.

In summary, the contention that these disabled persons received the services they needed from some sources or programs other than VR is not supported by the data. Half of the special equipment which respondents have was paid for by the disabled themselves. Additional service needs were high; 61 percent needed some services, averaging 3 services per person. As noted in other sections of this report, assistance in homemaking activities and attendant services was largely provided by the families of the handicapped, with agencies rarely helping out. The bulk of these service needs fall within the domain of VR, yet VR rarely paid for these services. Greater responsiveness to service needs might improve the vocational potential and enhance the independence of those persons who are currently being rejected from VR.

It is clear that some action needs to be taken to alleviate the plight of these people, many of whom are needlessly sitting at home, often quite isolated socially, and many of whom want to work and are capable of working. Others, who are less physically able, often are even more neglected, in part due to conditions which could be changed with more careful planning for their needs.

The urgent need for more comprehensive services to the severely handicapped can, perhaps, best be concluded by the letter we received from a woman who lives in a nursing home in Maryland.

Dear Sir:

All those things are wonderfull, that you are trying to get for the handycapped, but most of the things, were for those people that are very, very, forchenet to be able to be out on the outside, and someones, that may have money enough to be able to be outside. I can not help much there, for all the time I have been handycapped, I have had to be confined in nursing homes, and hospitals. I do hope that you can get help for all handycapped, most of them deserve all the help they can get. And another thing, I am in the state, and that dose not help you either, and I have a medical card too.

But there is one thing, that I sure am interested in putting in a plug, for all of us younge handycapps, that have to live away frome home. If anyone of them are in my same boat, I am sure they are interested, in this too. Why has someone not gotten to think about the young handycapped, who has to live away frome home? Do people on the outside, have no consideration, for people who are young and handycapped, in every state, set up a place, where us young can be a little free to half way live. Instead of throwing us among the old people. These sad old people, who are just waitting to die, it is not fare at all. Where these old people cannot help the way they are, but that is besides the point.

This is one thing I wish, you would send to Congress, so we could live like other young people, without allways doing things that someone set up for you to do. I hope you will not just put this a side, and for get about it, even one floor, in some hospital, would be better than this, two or three places, in each state, would be great.

Thank you

Chapter 8

ANALYSIS OF INDIVIDUALS MOST SEVERELY HANDICAPPED WHO RECEIVED SERVICES AT COMPREHENSIVE MEDICAL REHABILITATION CENTERS

This chapter addresses the problems, needs, and treatment of those severely handicapped individuals who have received services at comprehensive medical rehabilitation centers (CMRCs). Description of the survey instruments, methodology, and sample is followed by the survey findings, concluding with a comparison of the CMRC and VR populations.

METHODOLOGY

Survey Instruments

Considerable time and effort were employed in the development of the survey instruments. Numerous meetings, discussions, and pretests were held in different locations to develop valid and reliable research instruments. Representatives of rehabilitation medicine and nursing, sociology, psychology, economics and social service, and public policy fields participated in the study design and the formulation of the instruments.

Two of the survey instruments, the Interview Form and the Mail-Out Form, which asked questions about the person's physical condition, income, expenses, services used and needed, and various types of difficulties resulting from their disability, were almost identical to the instruments used in the survey of individuals rejected by VR because of severity. Two additional survey instruments, the Comprehensive Medical Record Review and the Hospital Financial Form, supplemented the data about the individual's current situation, with information about his physical condition on admission and on discharge from the CMRC, together with data on services received at the CMRC and the cost of such services. The survey instruments used in this study are described below.

1. Initial Medical Record Review Form. This form was used for the selection of the subject group through the review of CMRC admission data.
2. Mail-Out Form. This questionnaire requested information about the subject's age, sex, familial status, social activities, membership in organizations, health care received during the past year and the cost of this care, health insurance coverage, and income.
3. Interview Schedule. The interview schedule, similar to the VR interview schedule, sought detailed information on a wide range of topics such as physical functioning, services, and other problems and characteristics of handicapped people.
4. Comprehensive Medical Record Review. This form was used for review of the client's medical record. Information requested included duration of disability prior to entry to the CMRC, diagnosis and complicating factors, evaluation of functional status, communication ability, limitin conditions, and motion of limbs at admission and discharge, length of stay, and medications prescribed.
5. Hospital Financial Form. This form was for review of the patient's hospital account records to ascertain the costs incurred by the client for rehabilitation services at the CMRC.
6. Hospital Profile. This form describes the number, type, and qualifications of the CMRC staff and the CMRC services available and their costs. In addition, patient census data for the past 4 years was collected.

Survey Design

The sample for this study was drawn form former inpatients of 10 CMRCs located across the country. These centers were:

New York University Medical Center
Institute of Rehabilitation
New York, New York

Rancho Los Amigos Hospital
Downey, California

Rehabilitation Institute of Chicago
Chicago, Illinois

Rehabilitation Institute
Detroit, Michigan

Rehabilitation Institute
Tufts-New England Medical Center
Boston, Massachusetts

Spain Rehabilitation Center
Birmingham, Alabama

Texas Institute for Rehabilitation and Research
Texas Medical Center
Houston, Texas

University of Minnesota Hospital
Rehabilitation Center
Minneapolis, Minnesota

University of Washington Hospital
Department of Rehabilitation Medicine
Seattle, Washington

Woodrow Wilson Rehabilitation Center
Fischersville, Virginia

CMRCs offer a full range of rehabilitation services. All 10 CMRCs in this survey provide physical therapy, occupational therapy, speech pathology, prosthetic/orthotic services, social services, psychological services, and vocational rehabilitation, in addition to the usual medical services. Most of these centers also offer therapeutic recreation and pulmonary services.

These centers were selected because of their comprehensive services, the nature of their client population, and their national representativeness. Most of the centers are affiliated with a major university medical school, and seven are SRS Research and Training centers.

CMRC staff were active participants in the study's implementation and sample selection, cooperating in the study by helping to select and schedule persons identified as severely disabled according to specific study criteria. An initial screening of 2,681 former CMRC patients was conducted in order to identify 656 severely disabled persons as potential interview subjects. Two interview teams, one based in Chicago and one in Boston, each composed of a rehabilitation nurse and a rehabilitation social worker, were trained for interviewing and reviewing medical records. Each team visited five CMRCs, interviewed a total of 307 severely disabled, and reviewed the medical and hospital account records for each person interviewed. A consent form was obtained from each subject before the interview and record review.

The selection criteria were applied to each of the records reviewed in order to select those persons most severely disabled and most appropriate for the study. These criteria included:[1]

1. Minimum age of 16 upon admission.
2. First admission to the facility as an inpatient of rehabilitation services.
3. Minimum length of stay at least 14 days.
4. Admission on or after September 1, 1972 and discharge before September 1, 1973.
5. Nonenrollment in Vocational Rehabilitation upon admission to the CMRC.[2]
6. Patient's death is not noted.

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[1] Initially a specific distance from the CMRC was included as a criterion for selection to aid interviewing; however, this criterion was not always applied since it was necessary to draw from a larger geographic area than was first anticipated.

[2] This criterion was waived at two CMRCs (Spain Rehabilitation Center and Woodrow Wilson Rehabilitation Center); many of their patients are enrolled in VR.

7. Record has sufficient information to complete selection.
8. Functional level upon admission as measured by PULSES was 12 or greater.[3]

These criteria were applied to each randomly selected record until at least 60 records were identified that met all of the selection criteria or until all appropriate records had been reviewed. The number of selected cases and the number of records reviewed varied from center to center, owing to large differences in the severity of the population served.

Over 2,000 of the cases reviewed did not meet the study criteria. The reasons why CMRC patients were rejected from the study are presented in Table 8-1. One of the major reasons for rejection was length of inpatient stay being less than two weeks.

Initially, the selected cases were to be weighed in order to obtain a representative sample in each of the disability categories. However, the fact that every case had to be contacted in order to schedule enough interviews made this impossible. The sample therefore overrepresents those persons who were the most severely disabled at the time of their admission to the CMRC. While 30 interviews at each of the 10 centers was the objective of the survey plan, the actual number interviewed at each center varied from 22 to 47. Most of the interviews were carried out in the homes of the severely disabled (69 percent) and 31 percent were interviewed at the CMRC. The severely disabled who were interviewed were paid an honorarium of $10, and transportation costs were covered for those who were interviewed at the CMRC.

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3. The PULSES scale provides a global functional status picture. The PULSES profile includes data on required nursing or medical care, self-care activities dependent mainly upon upper limb function, mobility activities dependent upon mainly lower limb function, sensory components relating to communication and vision, excretory functions, intellectual and emotional adaptability, environmental barriers, financial ability and support from the family unit. Those persons completely independent score a 6; completely dependent persons score a 24.

Table 8-1

Reasons for Individuals Being Rejected from the Sample

CHRC	No. of Records Reviewed	Number of rejected cases (Percent of records Reviewed)		REASONS FOR REJECTION: Age Less than 16		Distance from the CHRC		Outside the Sample Dates		Not a Rehab. Inpatient		Not a First Admission		Less than a 2 Week Stay		Enrolled in VR		Death		Incomplete Record		PULSES Less than 12	
		N	%	N	%	N	%	N	%	N	%	N	%	N	%	N	%	N	%	N	%	N	%
Texas Institute for Rehabilitation & Research	558	503	90	52	10	100	20	37	7	0		246	49	62	12	0		0		1		5	1
Rehabilitation Institute, Detroit	104	43	41	2	5	5	12	9	21	4	9	0		5	12	0		6	14	2	5	10	23
Tufts-NEMCH Rehabilitation Institute	140	76	54	0		0		2	3	11	14	19	25	28	37	4	7	6	8	0		6	8
New York University Hospital	171	90	53	0		20	22	22	24	1	1	4	4	15	17	1	1	4	4	4	4	19	21
Rancho Los Amigos	717	614	86	94	15	17	3	31	5	160	26	0		209	34	0		0		2	*	101	16
Rehabilitation Institute of Chicago	258	142	55	31	22	26	18	29	20	0		0		15	11	0		20	14	5	4	16	11
University of Minnesota Hospital	79	42	53	3	7	18	43	0		0		6	14	2	5	0		4	10	3	7	6	14

CHRC	No. of Records Reviewed	Number of rejected cases (Percent of records Reviewed)		Age Less than 16		Distance from the CHRC		Outside the Sample Dates		Not a Rehab. Inpatient		Not a First Admission		Less than a 2 Week Stay		Enrolled in VR		Death		Incomplete Record		PULSES Less than 12	
		N	%	N	%	N	%	N	%	N	%	N	%	N	%	N	%	N	%	N	%	N	%
Spain Rehabilitation Center	222	152	68	9	6	69	45	5	3	0		18	12	36	24	0		0		1	*	14	9
University of Washington	66	29	44	1	3	1	3	12	41	0		0		7	24	1	3	1	3	5	17	1	3
Woodrow Wilson Rehabilitation Center	366	334	91	8	2	9	3	72	22	7	2	81	24	104	31	0		0		1	*	52	16

*Less than 1 percent.

Major Areas of Analysis

The analysis of the CMRC population covers a wide range of areas. First, the criteria used to identify, describe, and evaluate the most severely handicapped individuals is discussed. Next, the demographic characteristics of the population are described. A discussion of the physical condition of the sample follows, relying heavily on indicators of dependency. The next area describes the services which are utilized by the sample, followed by the current service needs and the environmental problems facing this population. Finally, a comparison of the CMRC and VR populations will be made on a number of key variables.

CRITERIA USED TO DEFINE THE SEVERELY DISABLED

A wide range of criteria may be employed to identify the most severely disabled. Numerous scales, standards, and definitions have been developed by those in rehabilitation medicine and nursing, the social sciences, vocational rehabilitation, and the rehabilitation therapy professions. In general, these criteria for characterizing the severely disabled include either a serious medical condition or critical limitations in physical and social functioning.

In this study, functional performance level was used as the primary indicator of severe disability. Functional performance was measured at three points in time: upon admission to the CMRC, upon discharge from the CMRC, and at the time of interview, approximately 2 years after admission. Two major scales were utilized to measure physical functioning: (1) The PULSES Profile scale, developed by E. Moskowitz and C. McCann[4] and modified by Carl V. Granger, M.D.; and (2) The Barthel Index, developed by F. I. Mahoney and D. W. Barthel[5] and modified by Carl V. Granger, M.D. While the Barthel Index has been generally discussed in

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4. E. Moskowitz and C. McCann, "Classification of Disability in Chronically Ill and Aging," Journal of Chronic Disease, March 1957, p. 342-346.

5. F. S. Mahoney and D. W. Barthel, "Functional Evaluations: Barthel Index," Maryland S[illegible]e Medical Journal, February 1965, pp. 61-65.

other sections of the report, its importance merits a more detailed discussion. Both the PULSES Profile and the Barthel Index evaluate the person's capability to perform specific activities of daily living and his need for professional and nonprofessional assistance.

The PULSES Profile and Barthel Index evaluations for this study were done by two rehabilitation nurses trained in research who also had years of clinical experience. Pretesting of instruments and training of the team nurses were carried out at the Tufts Rehabilitation Institute in Boston under the supervision of Carl V. Granger, M.D. The nurses scored the items on the PULSES and Barthel scales utilizing medical records of a random sample of rehabilitation patients at Tufts Institute. Their independent evaluations were then compared with each other and with independent PULSES and Barthel evaluations routinely done on the patients by the Tufts Institute professional staff. Reliability was at .95 between nurses and between scores gathered from medical records and from in-person interviewing.

The reliability of the Barthel Index itself is currently being tested and analyzed under the direction of Dr. Granger.[6] Preliminary results of this separate study on 100 rehabilitation patients indicate that the modified Barthel Index has high interjudge reliability (an alpha coefficient of .97) when administered at the time of discharge and a high internal consistency reliability (an alpha coefficient of .92). The total score was found to be a discriminating, valid score; and changes over time are a reliable measure of observed functional change.

The PULSES and Barthel evaluations for Time 1 and Time 2 were determined from information available in the person's CMRC medical record. At all centers, specific and often extensive evaluations were done at the time of admission and at the time of discharge. In order to complete the PULSES Profile and the

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[6] Carl Granger, M.D. and Larry Sherwood, "Preliminary Analysis of the Barthel Index and Granger Modifications," unpublished, 1975.

Barthel Index, the team rehabilitation nurse reviewed the record including physician reports and rehabilitation therapy evaluations for the admission and discharge functional status information. The evaluation items were scored on the basis of the individual's level of need for assistance in performing a specific task, such as eating or transferring to a chair. The scoring for each task is clearly defined. The scoring for the task performance was derived from the appropriate rehabilitation therapy evaluation. For example, mobility performance was evaluated from the physical therapy report and self-care capability was determined from the occupational therapy evaluation. The rehabilitation nurse studied the admission and discharge information for approximately 1 hour in order to obtain these data. Infrequently a specific task area was not clearly defined in terms of the level of assistance the individual needed; therefore, the evaluation could not be completed. The same procedure was followed if the task was not discussed in the record. This occurred infrequently because many of the centers in the study used the Weed (1969) problem-oriented medical record system[7] which carefully and accurately records the data needed to complete the PULSES and Barthel scales.

The PULSES Profile and Barthel Index ratings at the time of interview were done by the rehabilitation nurse. Primarily from direct questioning of the person about specific task performance but also through observation of his functional ability, the professional team made an evaluation of the person's capability to perform the tasks and his need for assistance.

The PULSES Profile scale measures the need for professional and nonprofessional assistance in six broad areas:

P - The medical and/or nursing care required for the physical condition.

U - The upper limb functional capability in self-care activities.

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[7] Lawrence Weed, M.D., Medical Records, Medical Education, and Patient Ca The Problem-Oriented Record as a Basic Tool (Cleveland: Press of Case Western Reserve University, 1969).

L - The lower limb functional capability in mobility activities.

S - Sensory functional capability in communication.

E - Excretory function control.

S - Usual role and task performance capability.

Each of these functional areas is scaled with values of one to four. A subscore of three or four indicates assistance from another person is either frequent or necessary on a daily basis. A total score of 21-24 indicates extreme disability (scoring threes or fours in all areas); 16-20 severe disability; 12-15 moderate to severe disability; 8-11 mild to moderate disability; and 6-7 no disability.[8]

The PULSES Profile was used as the principal screening variable for the study. Only those with a score of 12 or higher upon admission to the CMRC were selected for inclusion in the study sample. Of all those selected in this study, 37 percent had a CMRC admission score of 12-15, 49 percent scored 16-20, and 13 percent scored 21-24. The mean score was 16.6 and the median 17.

It is possible to be classified as severely disabled on the PULSES (total score of 12) with only sight impairment (or minimal assistance required) in each of the six areas measured. It is also possible to have a total score of 12 by being totally dependent in two areas and independent in all others. However, a person could be significantly impaired by an emotional disorder and have a total score no higher than 8. Similarly, someone who is blind and deaf but able to manage without assistance in self-care activities would not score the 12 necessary for inclusion in the study. The criterion of a minimum score of 12 therefore requires that the subject be handicapped in more than one area; i.e., minimally in all areas or maximally in two or more areas.

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[8] Carl Granger, M.D., "Scales for Severity in Physically Handicapping Conditions," unpublished, December 1974.

The Barthel Index is divided into two subscales: "self-care" and "mobility." Items which are considered more important, such as ability to eat without assistance, are weighed more heavily than less important items like grooming. A person scoring 100 on the Barthel Index is independent of assistance from others; scores of 91-99 indicate slight dependence; 62-90 moderate dependence; 21-61, severe dependence; and 0-20, total dependence in self-care and mobility. In the Barthel Index the individual who is in a wheelchair and who can perform all activities except walking 50 yards or walking up and down one flight of stairs independently cannot score higher than 80. An individual who can accomplish all of the listed tasks except transferring to a tub or shower will score a 99.[9]

The RT-7 Code of diagnostic categories for clinical disorders or handicapping conditions was utilized in the study for general identification of the disabling condition. This three-digit code was developed by the SRS Research and Training Center at the Rehabilitation Institute of Tufts-New England Medical Center. The code is based primarily on the part of the body affected and is particularly applicable to those types of disorders causing a handicapping condition.

MAJOR CHARACTERISTICS OF INDIVIDUALS SURVEYED IN CMRCs

In this section, the demographic characteristics of the individuals surveyed in the 10 Comprehensive Medical Rehabilitation Centers are discussed. The sample interviewed was distributed in age across the life span, with a disproportionate number in the older age categories; 28 percent of the sample were below the age of 31, and 33 percent were over the age of 60. The largest percentage of patients aged 16-30 (50 percent) were the spinal cord injured followed by those with other neurological disabilities (33 percent). The oldest age

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[9] See discussion of Barthel Index Scoring, in Chapter 27.

group, 61 and over, had disproportionate numbers of persons with cerebral disabilities (42 percent) and amputations (66 percent). Table 8-2 shows age and disability types.

Table 8-2

Age by Disability

Disability	Age											
	16 - 30		31 - 40		41 - 50		51 - 60		61+		Total	
	N	%	N	%	N	%	N	%	N	%	N	%
Cerebral	18	13.6	10	7.5	17	12.8	31	23.4	56	42.4	132	100.0
Spinal Cord	49	50.0	16	16.3	6	4.5	10	1.5	17	17.3	98	100.0
Other Neurological	5	33.3	3	20.0	1	6.6	5	33.3	1	6.6	15	100.0
Musculoskeletal	4	15.3	5	19.2	4	15.3	3	11.5	10	38.4	26	100.0
Amputations	3	10.0	0	0	0	0	7	23.3	20	66.6	30	100.0
Other	3	10.0	0	0	0	0	0	0	0	0	3	100.0
Missing Information												3
TOTAL	82	26.7	34	11.0	28	9.1	56	18.2	104	33.8	307	100.0

The majority (79 percent) of the surveyed popoulation was white. Twenty percent were black, and virtually no other racial groups were represented.

The sex distribution of the sample differed from that of the 1966 Survey of Disabled Adults by the Social Security Administration. In the CMRC survey, males composed 59 percent of the population, and females 41 percent, whereas in the Social Security Administration national sample, a higher percentage of females (7.0 percent) than males (4.7 percent) reported themselves to be severely disabled.

The disability category with the largest number of males (75 percent) was spinal cord injury; females were overrepresented in the "other neurological" category, with 80 percent, and in the "musculoskeletal" category. The sex distribution of the categories of cerebral disability, amputation, and other neurological were similar to that of the total sample.

Almost half of the sample were married, and one-fourth were single. Seventeen percent were separated from their spouses through death, divorce, or separation.

The occupational background of those individuals was diverse, as Table 8-3 illustrates. The majority of the population, however, had a high skill level, as evidenced by the last job at which they were employed (or were presently employed). Professionals, managers, and administrators comprised almost one-quarter of the sample. Sales/clerical workers and skilled craftsmen comprised another sixth. Individuals with less physically taxing jobs are likely to have an easier reorientation process after disability than persons with jobs requiring more physical strength. Those who had been employed as service workers laborers, and private household workers will probably have more employment proble because they generally would not be able to return to physically demanding work. The relatively small percentage of those never employed was composed of housewives and those under 20 years of age who had never been in the labor market prior to the onset of their disability.

An examination of educational background again points out the fact that the persons interviewed were for the most part a highly skilled, highly educated group. This finding highlights the difference between this sample and the 1966 Social Secuirty Administration sample, in which 42 percent had less than 8 years of education.[10] The majority of the CMRC sample (62 percent) had completed 11

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[10] Kathryn H. Allan and Mildred E. Cinsky, General Characteristics of the Disabled Population, Report No. 19, Social Security Survey of the Disabled: 1966, (DHEW, 1972), pp. 1-14.

Table 8-3

Type of Usual Occupation

	Number	Percent
Professional, technical and kindred workers	36	11.7
Managers and administrators	34	11.1
Sales workers	16	5.2
Clerical and kindred workers	32	10.4
Craftsman and kindred workers	39	12.7
Operatives except transport	37	12.2
Transport equipment operatives	4	1.3
Laborers except farm	11	3.6
Farmers and farm managers	4	1.3
Farm Laborers and farm foremen	1	0.3
Service Workers except private household	29	9.4
Private household workers	17	5.5
Never employed	44	14.3
Don't know	3	1.0
TOTAL	307	99.9

or more years of education. However, there was considerable variation between different diagnostic types. Those with "other neurological disabilities" had the highest percentage (93 percent) of individuals who had completed 11 more years of education. Sixty-eight percent of spinal cord injured individuals and 65 percent of those with cerebral disabilities had also completed 11 or more years of education. Only 33 percent of amputees, however, completed a high schoo education. This is probably due in part to their greater age.

Examination of the amount of annual income earned by these persons at their last (or present) positions revealed that 24 percent were earning over $8,000 per year. This finding is compatible with the fact that a large number held managerial positions. While these persons possessed considerable resources, fully 29 percent of the sample earned less than $4,800 per year before their disability.

The present household income is the total annual income that supports the household in which the disabled person resides, whether he lives alone or in a familial setting. At the time of interview, 29 percent reported household incomes of less than $4,801. In other words, almost one-third of the households were at or below the current poverty level.

Table 8-4 presents the different sources of household income. The predomina source of income was Social Security (71 percent) followed by salary and wages at 40 percent. The predominance of individuals receiving Social Security income reflects the age and disability level of the sample. Wages were, for the most part, being contributed by other members of the household, since only 13 percent of the sample were presently employed.

The majority of the survey population (53 percent) were residing in a large city. This factor is probably due to the sample design and to the location of the CMRCs. Forty-five percent of those interviewed lived in a small town or rural area.

Table 8-4

Household Income Sources

Source of Income	Number Receiving Income From Source	Percent Receiving Income From Source[1]	Mean Income for those Receiving From Source
Wages	125	40.7	$10,491
Non-farm self-employment	21	6.8	2,626
Operating a farm	8	2.6	78
Social security	217	70.7	11,309
Dividends and interest	81	26.4	11,393
Public assistance	53	17.3	1,308
Unemployment compensation	50	16.3	3,001
Private pensions, trusts	73	23.8	7,258
Receipts	35	11.4	3,522

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[1] Percentage totals exceed 100 because clients may receive income from several sources.

Most of these people (72 percent) were living with their families. Those who lived in nursing homes comprised almost 11 percent of the sample. Living with one's family does not appear to be determined by disability type.

The family appears to remain intact after one member is disabled. Divorce or separation as a result of disability (3 percent) was not a frequent event in this sample. Changes in relationships with their children were reported by only 12 percent of the respondents. This change was most often negative, such as that children had become disobedient or uncaring, according to respondents. Others have found that impairment is associated with better interpersonal relations only if the condition is obviously apparent.[11]

Employment

The onset of physical disability has serious consequences on employment and generation of income. While 18 percent of the sample was composed of students and people retired because of age, 24 percent had had to retire because of disability, and 43 percent were unemployed. Only 13 percent of the sample were employed at the time of interview.

As Table 8-5 illustrates, of the persons currently employed, 55 percent were physically independent, according to the Barthel Index, with an additional 13 percent being only slightly dependent. In contrast, only 17 percent of the nonworking individuals in the sample had a perfect Barthel score, and 42 percent were either totally or severely dependent, compared to only 3 percent of those who were employed. Clearly, the level of functional capability is related to employment status; the more functionally able, the more likely the person will be employed.

Two-thirds of the working individuals in the sample were below the age of 40, whereas only about half of the nonworking persons were at a comparable age

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[11] Margaret A. Zahn, "Incapacity, Impotence and Invisible Impairment: Their Effects Upon Interpersonal Relations," Journal of Health and Social Behavior, June 1973, pp. 115-123.

Table 8-5

Current Barthel Scores by Employment Status

Scores and Degree of Dependance	Working		Not Working		Other[1]		Total	
	N	%	N	%	N	%	N	%
0 - 20 (Total)	0		14	10.6	7	5.5	21	7.2
21 - 61 (Severe)	1	2.6	40	30.3	35	27.7	76	25.4
62 - 90 (Moderate)	11	28.9	40	30.3	43	34.1	94	32.4
91 - 99 (Slight)	5	13.1	16	12.1	28	22.2	49	16.3
100 (Independent)	21	55.3	22	16.7	13	10.3	56	18.7
Unknown							3	
TOTAL	38	100	132	100	126	100	299	100

[1] Other includes students and those retired because of disability or age.

Table 8-6

Employment Status by Grade of School When Finished or Left School

Status	1-6		7-10		11-12		13-16		17-28		Total	%
	N	%	N	%	N	%	N	%	N	%		
Employed	1	2.6	2	5.1	17	43.6	9	23.1	10	25.6	39	12.9
Not Working	15	11.5	39	29.8	53	40.5	21	16.0	3	2.3	131	43.4
Other[1]	15	11.4	39	29.5	48	36.4	25	18.9	5	3.8	132	43.7
Unknown											5	
TOTAL	31	10.2	80	26.4	118	39.3	55	18.2	18	5.9	302	100

[1] Other includes retired and students.

level. Thus, the older the sample, the greater the percentage who is not working.

Physical and social support at home may be related to employment: Fifty-one percent of those employed were married, while only 39 percent of the non-working individuals were married.

Disability type seems to be related to employment status. For example, 26 percent of those with "other neurological" disabilities were currently employed, almost double the proportion of any other group. Fourteen percent of the sample with cerebral and spinal cord disabilities were currently employed, and no amputees were employed. The latter finding is probably accounted for by the fact that this group is an older population. These results are consistent with the findings relating educational level to disability categories.

Educational level was a major influence on employment status. Of those employed, 92 percent had completed 11 or more years of education, as Table 8-6 illustrates. Only 58 percent of those not working had completed 11 or more years of education. It appears that the higher the educational level, the greater the likelihood of post-disability employment.

Almost 50 percent were employed within the past 5 years; 21 percent had not worked in over 5 years. Thirty-four percent of the sample had worked full time for at least 21 years. This long work history is consistent with the fact that one-third of the sample was over 60 years of age.

Severity of disability was the major reason given for not working. A few listed transportation problems as a hindering factor. The results of the "special conditions needed for working" question seems to indicate that most severely disabled people require, at a minimum, light work and a flexible work environment if they are to be employed.

Those working had fewer impediments than the nonworking in getting to the job. The major needs of those working were centered around transportation, physical accessibility to the work setting, and the need for light work. The needs of those not working were similar but more compelling. Those not working also reported a greater need for personal assistance, such as help from others to get ready for work and need for attendant help at work.

Transportation difficulties, lack of ramps and elevators, rigid work schedules, and inaccessible washrooms were major problems of the sample who conceivably could go to work or school. Over 90 percent of the individuals who could go to school or work needed help in accomplishing these goals. Fifty percent of those who could work were able to do only light work because of their functional limitations.

PHYSICAL CONDITION

This section will describe the physical condition of the sample population. Among the areas which will be analyzed are disability type, Barthel score, PULSES score, and the relationship between disability type, age, and severity.

Disability Categories

Drawing upon the RT-7 code of diagnostic classification, five major categories of disabling conditions were identified and utilized in this study:

1. Neurological Disorder of the Cerebrum, including stroke
2. Neurological Disorder of the Spinal Cord, including paraplegia and quadriplegia.
3. Other Neurological Conditions, including hearing disorders, myopathy, general central nervous system disorder, peripheral nerve disorder, and cerebral disorder (general).
4. Musculoskeletal Disorders, including arthropathy and cardiac disorder.
5. Amputations, including all combinations of limb amputations.

Neurological disorder of the cerebrum (42 percent) and of the spinal cord (32 percent) constituted the largest groups in the sample. Both the musculoskeletal and amputations categories constituted 9.5 percent of the population; other neurological conditions (7 percent) comprised the smallest proportion of the sample population.

The CMRC sample is not representative of national samples of the disabled. In both the Health Interview Survey of 1969-70 and the Social Security Administration Survey of 1966, cardiac and musculoskeletal conditions were the largest categories of disabling conditions, accounting for over half of the disabled in the 1966 survey. All neurological conditions combined accounted for the second largest grouping but at a much lower percentage.[12] The CMRC sample was more severely disabled than the above two samples, which accounts for the high proportion of persons with neurological impairments and low proportion of cardiac patients.

Cause of Disability

The etiology of disability was divided into six major groupings:

1. Self-inflicted accident, which included suicide attempt or a fall with no one else involved.
2. Other-inflicted accident, including vehicular accidents, gunshot wounds from another person, and toxic reactions to drugs.
3. Sudden onset of disease, such as stroke or any disease that resulted in a disabling condition within 1 year.
4. Over-time onset of disease, meaning that the disabling condition did not become evident until 1 year after disease onset. Examples include arthritis and amputation due to diabetes.
5. Birth trauma or congenital condition.

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[12] Charles S. Wilder, "Limitation of Activity Due to Chronic Conditions," Vital and Health Statistics, April 1973; and Allan and Cinsky, General Characteristics.

6. Other or Don't Know. This cateogry was utilized when insufficient medical record information did not provide a clearly defined cause of disability.

Of the interviewed population disability caused by disease was the most prominent, comprising 60 percent of the sample. The accident-disabled (both other - and self-inflicted) constituted 34 percent of the sample. These people primarily suffered spinal cord injury. Individuals with birth traumas were the least represented in the population (4 percent).

Functional Performance

One of the principal rehabilitation goals is to return the disabled person to his optimum possible functional level and to help him maintain that high level of performance. While there is considerable research showing positive changes in functional improvement during hospitalization in a rehabilitation facility, much less is known about the stablity of changes over time. The data permit the study of functional changes over a 2-year period. Functional measures were taken at admission, discharge, and approximately 2 years later, at the time of interview.

A comparison of the PULSES total scores across the three time periods shows substantial functional improvement during the stay in the rehabilitation hospital. A comparison of current and discharge scores reveals that, while a few individuals regressed, most individuals maintained the level of physical functioning that they had achieved by the time of their discharge from the CMRC, and some (9 percent) showed even further functional improvement from discharge to the current time period.

An analysis of the total Barthel scores across the three time periods shows a pattern similar to that observed between the PULSES scores. There was marked functional improvement from admission to discharge and a stabilization or improvement from discharge to the present time. Almost 11 percent made functional gains from discharge to the time of interview. Total PULSES and Barthel scores correlates highly, and overall patterns obtained from these two instruments were very similar. The Barthel Index subscales, measuring self-care and mobility also reveal continued improvement over the three time periods. This evidence seems to indicate that rehabilitation is a long and complex process that takes place over years.

In examining the Barthel Index items for self-care capability over time, several interesting contrasts appear. At time of admission to the CMRC, under 55 percent of the sample could perform such tasks as drinking, eating, and dressing themselves. At time of admission, the population was also a markedly nonmobile group, with less than 7 percent able to either walk 50 yards or climb a flight of stairs. Of those confined to a wheelchair, only 20 percent were able to maneuver it by themselves.

At the time of discharge, a marked improvement was evidenced for all of these categories. Over 75 percent of the sample could drink and eat on their own; the percentage who were independent either in a wheelchair or walking had also markedly increased (36 and 30 percent, respectively). It is important to note that at the time of interviewing, the functional level had not decreased appreciably in any category and had increased in some areas.

The changes in functional level can not be directly attributed to treatment received in the CMRC's, since the level of improvement gained <u>without</u> treatment is not known. In order to make a valid study of the impact of CMRC services, a control group is necessary.

Of equal importance when considering independence of living are those tasks which need to be performed every day in order to maintain a household and to establish social contact. The respondents were asked whether they could perform a number of tasks and, if so, whether performance of the task presented any difficulties. Operating household appliances caused no difficulty for 47 percent of the sample, but 28 percent could not do this at all. Performance of tasks needed to establish social contact, such as using the telephone and admitting visitors to the home, caused no difficulty for about three-fourths of the sample; slightly over 10 percent could not perform these functions at all. Six percent of the sample could not get out of bed alone and another 13 percent could do so only with some difficulty.

For other items such as lifting or carrying weights, stooping, bending or kneeling, reaching with both arms, and using hands and fingers, under 60 percent of the sample could perform these tasks with no difficulty.

Relationships Between Severity, Age and Disability Type

According to our results, age is a major predictor of disability type. Two-thirds (65 percent) of the individuals with cerebral handicapping conditions were 51 years of age and over. Most of this group suffered strokes. Younger individuals were more likely to have experienced a cerebral handicap as a result of a gunshot wound. On the other hand, 50 percent of the spinal cord injured were under 31 years of age, and most of these individuals had experienced serious accidents or gunshot wounds. Almost 40 percent of the persons with musculoskeletal problems were 60 or over. These older individuals had arthritic or cardiac conditions. Two-thirds of the amputees were also over 60; the majority of these persons had limbs amputated as a result of diabetes.

Age and Severity

The age of the sample by severity, as measured by the Barthel Index, is illustrated in Table 8-7. In general, those who were older are more independent, with the exception of the age group of those 41-45. Those in the sample who were under 31 were represented evenly in all Barthel categories, with only slightly

Table 8-7

Age by Dependency as Measured by the Barthel Index

	Total Barthel Score											
	Totally Dependent (0 - 20)		Severely Dependent (21 - 61)		Moderately Dependent (62 - 90)		Slightly Dependent (91 - 99)		Independent (100)		Total	
Age	N	%	N	%	N	%	N	%	N	%	N	%
16 - 30	10	12.6	14	17.7	22	27.8	13	16.4	20	25.3	79	100.0
31 - 40	0		8	24.2	11	33.3	3	9.0	11	33.3	33	100.0
41 - 45	3	23.0	4	30.0	5	38.4	0		1	7.6	13	100.0
46 - 50	1	7.1	3	21.4	4	28.5	2	14.2	4	28.5	14	100.0
51 - 55	1	3.8	4	15.3	9	34.6	5	19.2	7	26.9	26	100.0
56 - 60	1	5.4	9	31.0	9	31.0	5	17.2	5	17.2	29	100.0
61 - 65	1	4.1	6	25.0	6	25.0	7	29.1	4	16.6	24	100.0
66 +	8	10.6	24	32.0	27	36.0	13	17.3	3	4.0	75	100.0
Unknown											14	
TOTAL	25	8.3	72	24.6	93	32.5	48	16.7	55	17.9	307	

fewer in the totally dependent group. In the 31-40 age group, no one was totally dependent, and most were moderately dependent to independent. Persons over 65, on the other hand, were clearly more dependent than independent, with 43 percent being totally or severely dependent.

The excepted group of those aged 41-45 have 53 percent who are totally or severely dependent. Most of the persons in this age group have had strokes.

Disability Type and Severity

The severity of functional limitation at the time of interview as measured by PULSES and Barthel, is considerably more serious for persons with cerebral, spinal cord, and other neurological problems than it is for individuals with musculoskeletal, amputation, and other conditions, as Table 8-8 illustrates. This pattern identifies those individuals who are most severely limited in function over time. It should be noted that every individual who was selected into the study had to have an initial PULSES score of 12 or higher. The data at the time of interview (2 years later) show that 40 percent of the sample fell below the PULSES 12 level, indicating greater functional capacity. These people made and maintained functional improvement 2 years after discharge from the CMRC's.

Table 8-8

Barthel Score at Time of Interview[1] by Disability Category

Category	Total Barthel Score 0 - 20 N	 %	 21 - 61 N	 %	 62 - 90 N	 %	 91 - 99 N	 %	 100 N	 %	 Total N
Cerebral	11	8.6	34	26.6	34	26.6	23	18.0	26	20.3	128
Spinal Cord	8	8.3	30	31.3	37	38.5	11	11.5	10	10.4	96
Other Neurological	1	6.7	5	33.3	3	20.0	0	--	6	40.0	15
Musculoskeletal	1	3.8	2	7.7	8	30.8	8	30.8	7	26.9	26
Amputation	0	--	4	15.4	11	42.3	6	23.1	5	19.2	26
Other	0	--	1	50.0	0	--	0	--	1	50.0	2
TOTAL	21	7.2	76	25.9	93	31.7	48	16.4	55	18.8	293

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[1] Approximately 1 1/2 years after discharge from CMRC.

Persons with musculoskeletal and amputation conditions showed the least functional limitation at the time of interview. The data pattern suggests that these individuals made and maintained marked improvement from time of entry into the rehabilitation facility through followup. Although persons with cerebral and spinal cord handicaps were the most functionally limited, it should be emphasized that one-third had improved their PULSES score (to below 12) at the time of interview. This shows that substantial members of the severely disabled are able to achieve and maintain a moderate degree of functional independence over time.

Functional limitations, defined as the ability to operate applicances, take medicine, get in and out of bed, sit for more than an hour, lift or carry weights, stoop, bend or kneel, reach with both arms, use hands and fingers, use the telephone, operate a TV, radio or stereo and admit visitors to the home, were reported more by older respondents, when interviewed, than younger respondents. The results are consistent with those using PULSES, Barthel, and disability type as indicators of severity. These patterns consistently show that age is strongly related to severity of functional limitation.

Functional Limitations and Severity

Total Barthel scores were highly related to PULSES scores as well as to functional limitations scores, which suggests that all these measures are tapping different aspects of severity. In general, individuals who are more dependent, as measured by the Barthel Index, have more difficulty in performing functional limitation activities. However, even people who scored high on the Barthel had difficulty "lifting or carrying weights," "stooping, bending or kneeling," "reaching with both arms," and "using hands and fingers." These results indicate that individuals who appear to be physically independent on the Barthel scale can experience considerable difficulty performing physically strenuous or dexterous tasks. On the other hand, most individuals who scored low on the Barthel scale were able to use the telephone, operate a television set, radio, or stereo, and sit for more than an hour. Only persons in the totally dependent range on the Barthel scale had difficulty with these activities.

The very severely disabled cannot perform even relatively easy tasks by themselves. For instance, 55 percent of the individuals in the totally dependent range on the Barthel scale could not use the telephone, and another 35 percent had some difficulty in doing so. Some (6 percent) were dependent on others even to use the telephone and operate a radio, television, or stereo set. These individuals required a high level of support. In general, the pattern that emerges indicates that most of the severely disabled (at time of interview) can independently perform tasks of moderate difficulty but that they cannot do well on physically demanding tasks.

Other Factors Affecting Capacity to Function Independently

In roder to assess need for medical attention, respondents were asked how often they saw a doctor, nurse, or physical therapist and how often they took medication. Almost 8 percent saw a doctor, nurse, or therapist at least daily. Over 11 percent visited one of these professionals at least weekly. The largest percentage (41 percent) visited at least once every three months but not as often as once a week. Only 16 percent of the sample did not currently take prescribed medications. Over 80 percent took medication daily.

Level of physical function is very important for independent task performance, but independence in social settings requires that the person be able to communicate well, in addition to being physically independent. Impairments in speech (either in enunciation or content) and listening can all but destroy effective social interaction. An analysis of communication across the three time periods shows that positive gains in listening, speech content, and speech enunciation were made during hospitalization but that little gain or even some reversal of progress was made in the 2 years after discharge. These results might well demonstrate the effects of speech therapy during hospitalization. However, a more detailed analysis of the data is required to test that hypothesis.

Multivariate regression analysis was performed to determine the predictors of change in functional ability. The following variables -- age, sex, race, education, cost of CMRC stay, disability type, and PULSES (admission and discharge) -- failed to explain more than 2 percent of the variance in functional changes over time, as measured by the Barthel Index.

Functional Performance in the Home and Social Environment

Complete rehabilitation implies a resumption of social life. The survey results indicate that 40 percent of the sample who do not reside in nursing homes lead an active social life in their own homes, 40 percent have some visito and 17 percent have almost no social interaction in their homes with friends.

Visiting with friends outside of their residence was a difficult problem for most of the sample population. Transportation problems and physical barrier prevented many of them from going outside easily. Two-thirds of the noninstitutionalized population visited freinds outside their homes less than twice a week. It should be noted that 1 out of 10 persons were completely homebound.

The dependency of the noninstitutionalized sample is also evident in homemaking activities. Sixty-eight percent needed help in preparing meals and washing dishes, 79 percent needed help in housecleaning and gardening, and 16 percen required child care help. This dependency was made even more difficult by the fact that 11 percent of the sample did not have anyone whom they can call upon for help in moments of great need.

The data presented here describe a population that is physically dependent and socially isolated. A superficial reaction would be to paint a bleak picture of a socially isolated, futile existence. However, the facts do not support this view. The severely disabled show marked improvement in physical function, communication, and social competence over time. They do have some degree of functional independence. Much of their isolation and dependence can be attributed to physical barriers and transportation problems in their lives. These are problems with solutions. As barriers are reduced, further functional improvements should be noted.

SERVICES

This section describes the service agencies contacted and the services received from CMRCs, Vocational Rehabilitation agencies, and other service agencies. The sources of payment for these services and the cost of services received at the CMRCs are also included.

CMRC Services

The 10 centers included in the study offer comprehensive rehabilitation programs. All major rehabilitation services are available at these centers, although two secondary therapies are unavailable at a few. The quality of the programs is reflected by the number and qualifications of the staff. With few exceptions, the ratio of core rehabilitation therapy and nursing personnel to patient population is high, and the staff's level of education and accreditation is also high.

Each person interviewed was asked to recall the services he received from the CMRC during the admission under study. Almost all of the sample received physical therapy (96 percent) and occupational therapy (85 percent), most received social services (74 percent), and 72 percent received prosthetic devices or special equipment, such as wheelchairs. Therapeutic recreation, other medical treatment, psychological counseling, and visiting nurse services were received in substantial numbers. The mean number of CMRC services received was 7.2, only

8 percent reporting less than 4 services. Based on this self-report data, we can tentatively conclude that most of the sample received comprehensive services at the CMRC.

Vocational counseling was received by 27 percent of the population, but less than 10 percent received either vocational training or placement, tools for work, special devices for school, or coverage for educational costs. Speech therapy was received by 24 percent of this sample.

Eighty-eight percent of the persons surveyed used various types of equipment. The most common items were wheelchairs (52 percent) and canes, crutches, or walkers (50 percent). Substantial numbers of the sample also had special devices (33 percent), braces, splints, etc. for lower limbs (31 percent), and hospital beds (19 percent). Dentures were also common among this older group, 18 percent having them. Much of this equipment was provided to the individuals during the rehabilitation process at the CMRCs.

Vocational Rehabilitation Services

Thirty-two percent of the persons sampled had applied to a Vocational Rehabilitation agency in the last 3 years. Of those persons, 74 percent were accepted, but a smaller percentage actually received funds for services and/or counseling. The services paid for by VR are shown in Table 8-9. Between 20 and 30 percent of those accepted by VR received the following services: hospitalization, physical therapy, occupational therapy, prosthetic devices or special equipment, vocational counseling, and transportation.

The major reason given for failing to apply to VR was age. Thirty-one percent of those not applying felt they were too old. Fourteen percent had never heard of VR or its services, and 11 percent felt they did not need VR services.

Disability type and, indirectly, age and sex are clearly related to

Table 8 - 9

Services Received From VR

	Number	Percent*
Surgery	11	11.2
Hospitalization	22	22.4
Physical therapy	29	29.6
Occupational therapy	28	28.6
Speech/hearing therapy	4	4.1
Other medical treatment	9	9.2
Visiting nurse	1	1.0
Homemaker services	0	0
Prosthetic devices, braces, wheelchairs, etc.	28	28.6
Vocational counseling	27	27.6
Vocational training	14	14.3
Educational costs	15	15.3
Vocational placement	2	2.0
Receipt of tools, equipment or licenses (for work or training)	3	3.1
Special devices for schooling (e.g. tape recorders, typewriters)	6	6.1
Transportation	20	20.4
Psychological therapy/counseling (individual, family, group)	5	5.1
Home modifications	6	6.1
Interpreter and other communication services	0	0
Reader services, braille instructions, talking books	0	0
Orientation and mobility training/self management services	0	0
Other	21	21.4
Other	4	4.1
Don't Know	4	4.1

* Percentage total may exceed 100 because clients may have received more than one service.

whether or not an individual applies to VR. The disability category with the largest percentage of VR applicants was spinal cord injury (64 percent), followed by those with musculoskeletal disabilities (23 percent). Only 3 percent of amputees applied to VR. Spinal cord injured were much younger than others in the sample, and 75 percent were males. Thus, in the CMRC population surveyed, young, male, spinal cord injured persons were the most likely applicants to VR.

Other Service Agencies Contacted and Benefits Received

Only 10 percent of the severely disabled did not contact any service agencies in the 3 years prior to being interviewed. The Social Security Administration was contacted by the highest number of persons (69 percent); 87 percent of these persons received benefits. Another large group (28 percent) contacted public welfare agencies, about three-quarters of whom received benefits. Many persons (36 percent) sought aid for physician care, physical therapy, or nursing care from private medical agencies and hospitals. Other unspecified private agencies were contacted (24 percent) primarily for receipt of nursing services, and 15 percent sought food stamps.

Most persons received monetary benefits from public service agencies. Physical therapy, nursing services and physician services were obtained from private agencies. Most severely disabled persons had received at least one benefit from service agencies and programs within the last 3 years. The mean number of benefits received was 1.1. Those with spinal cord injury had the highest number of benefits, with 1.4.

By cross-tabulating the service agencies contacted by disability category, we can study the relationship of disability type to the type of agency contacted.[13] Person of all disability types frequently contacted the Social Security Administration. Contact with public welfare and private medical agencies was evenly distributed among all persons. Differences between those with different disabilities were found in only a few areas. The Veterans Administration was contacted most often by those with spinal cord injury (15 percent). Worker's compensation was primarily received by the spinal cord injured and those with musculoskeletal disabilities. Those with cerebral neurological disabilities did not contact food stamp agencies or public housing programs as frequently as others. Persons having musculoskeletal disabilities appeared to contact service programs less than others. Fifteen percent of those with musculoskeletal disabilities, 12 percent of those with cerebral neurological disabilities, 10 percent of the amputees, 6 percent of spinal cord injured, and 5 percent of those with other neurological disabilities did not contact any agency.

Cost of CMRC Care

Rehabilitation is an expensive process. Twenty-eight percent of the sample had inpatient costs over $8,000. The largest single group of people (34 percent) spent between $2,501 and $6,000 on this one rehabilitation hospitalization. Cost of care is also reflected by the length of the CMRC inpatient stay. Thirty-two percent stayed from 31 to 60 days and 34 percent stayed over 60 days.

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13. The small "other" residual category is excluded from this analysis.

Those with spinal cord injury have the most costly rehabilitation stay, followed by those with cerebral neurological disabilities. Persons with musculoskeletal disabilities and amputees have the least expensive rehabilitation stay. These findings are consistent with the length of stay for each disability category.

Over one third of the sample listed private insurance as the major source of payment for this stay. Medicare and Welfare were also frequent sources of payment, particularly for those having amputations and musculoskeletal disabilities. VR paid the costs for 8 percent of those surveyed.

Insurance

Most of the samples are covered in some way by public or private health insurance. This is a reflection of the necessity for coverage when one is disabled, for the cost of the continuous care required is high. In the survey, 53 percent of those interviewed currently had private health insurance coverage. However, private insurance did not always cover the costs of CMRC care, only 38 percent listed this as the major source of payment. The major reason for nonenrollment in a private plan was given as enrollment in a public program, including Medicaid, Medicare, and welfare (38 percent), which provided needed assistance.

CURRENT SERVICE NEEDS

The major service needs of the sample reflect the severity of their functional limitations and dependency. The need for equipment, assistance in homemaking tasks, transportation, changes in architectural barriers, and attendant care is common to many of these individuals. About half of the individuals in the study reported that they needed substantial additional income to live. Additional medical services and physical therapy were also requested as might be expected. However, there was an unanticipated demand

Table 8-10

Rehabilitation Services Perceived as Needed Now Which Are not Being Received

Service Needed	Number	Percent*
Surgery	20	6.5
Hospitalization	18	5.9
Physical therapy	88	28.7
Occupational therapy	48	15.6
Speech therapy	23	7.5
Other medical treatment	49	16.0
Visiting nurse	24	7.8
Homemaker	32	16.9
Prosthetic orthotic devices	36	11.7
Vocational counseling	40	13.0
Vocational training	25	8.1
Educational costs	16	5.2
Vocational placement	31	10.1
Tools, equipment, licenses	11	3.6
Special schooling devices	14	4.6
Transportation	93	30.3
Psychological therapy	47	15.3
Home modifcations	43	11.0
Social services	34	11.1
Therapeutic recreation	78	25.4
Sex therapy	54	17.6
Financial counseling	35	11.4
Other services	10	3.3
Do not need any services	10	21.2

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*Percentages total more than 100 because some clients need more than one service.

for sex therapy, psychological therapy, and organized recreational activities.

Two years after release from the first hospitalization at one of the CMRCs, 80 percent of the sample perceived themselves as needing additional services. Services in greatest demand were transportation, physical therapy, therapeutic recreation, sex therapy, homemaker help, medical treatment, and psychological therapy (Table 8-10). Although financial counseling was specified by only 11 percent, 50 percent of the unemployed persons interviewed did not know how much money they needed to live. These data indicate a need for continued financial counseling.

As noted previously, most respondents (88 percent) had some type of equipment, much of which was provided during the rehabilitation process. Two years later, only 40 percent reported needing additional equipment. The types of equipment in highest demand were specially equipped automobiles and trapezes.

Service Needs and Severity

In order to ascertain the relationship between service need and level of dependence, Barthel scores at the time of interview were cross-tabulated with service need.

The percentage of severely disabled who reported that they did not need further CMRC services varied by Barthel categories. Persons at the two extremes of the index reported the least need for CMRC services. Thirty-two percent of those who were evaluated as independent reported no need, as did 24 percent of those totally dependent.

Vocational counseling and placement were needed primarily by those rated as independent. Persons who were more dependent had a greater need for homemaker and transportation services. Excluding the totally dependent, physical therapy, occupational therapy and home modifications were also needed by persons who were more dependent.[14] In contrast, therapeutic recreation, sex therapy, psychological therapy, and financial counseling tended to be needed by those who were more independent. Although the pattern is inconsistent, it seems that those rated as severely and moderately dependent most often report the greatest need.

Services Needed and Age

Service utilization patterns are a major factor in health services delivery planning. All of the sample interviewed, regardless of age, reported a significant need for physical therapy, occupational therapy, therapeutic recreation, other medical treatment, and transportation!

For those aged 16-30, needs were primarily for vocational, educational, and social activities. Vocational counseling and placement, transportation, sex therapy, and therapeutic recreation were reported as a need by one-fourth of this group. Educational service needs were needed by this group more than any other age group, particularly for school financial aid (16 percent). Financial counseling was needed by 20 percent.

Those age 31-40 reported similar needs for vocational counseling (23 percent), therapeutic recreation (26 percent), financial counseling (18 percent), and special devices for schooling (12 percent). Prosthetic devices and other special equipment were also needed (15 percent).

For those in the 41-50 age category, interest in the vocational area decreased. Major interest areas were centered in the home and social

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[14] This exclusion is due to the fact that the totally dependent are more likely to be institutionalized where they are receiving the required services.

environment. Homemaker services, social services, and sex therapy were needed by 20 percent of the individuals in this age group. Comparing this information with that of age and severity, we see that those aged 41-50 are also the most severely disabled of the sample. This may in part explain why this working age group shifted its interest from the vocational to the social areas.

A similar shift of interest was also found for those over 50. Transportation was needed by 41 percent of those aged 51-65. This high level of need for transportation can be tied into a corresponding need for therapeutic recreation. It should be noted that persons in this age group were not the most physically dependent, but they did have a low rate of employment, which may explain why interest in social activities and social mobility increased. The maintenance of the home was problematic for those persons; over one-fourth reported a need for homemaker service.

Persons aged 61-65 had higher needs than any other age group for physical therapy (54 percent), occupational therapy (33 percent) and special equipment (17 percent), and individuals over 65 showed the same pattern of need for transportation (35 percent), social activities (24 percent), and homemaker services (18 percent).

Homemaking and Attendant Care

Respondents were asked a series of questions relating to assistance needed for preparation of meals, homemaking activities, child care, and shopping.

Of the noninstitutionalized sample, 68 percent could not prepare meals without assistance, and 79 percent needed assistance with housekeeping. (Some of the respondents, generally males, indicated they would not be performing these tasks even if they had been physically able, although this is still a need for the maintenance of their household.) Of those persons needing major assistance, the greatest percentage received help from a family member. Sixty-seven percent received family assistance for meal preparation, 61 percent for housekeeping, 89 percent for child care, and 81 percent for shopping needs. Respondents received paid help most frequently for housekeeping (37 percent of the help received was paid), followed by meal preparation at 26 percent. The largest area where there was still an unmet need was that of housekeeping, with 23 percent of the sample needing more assistance than was presently available.

Respondents paid for this assistance more frequently than did any agency, with welfare payments being the second ranking source.

Respondents who needed assistance in performing ADL tasks were asked who provides this assistance. Although the majority received such assistance from their family or friends, about 20 percent had paid attendants to assist them.

ENVIRONMENTAL BARRIERS

Transportation

Of all the services that the individuals in the sample perceived that they needed, transportation was the most frequently reported. Thirty percent stated that they needed transportation services. Transportation was reported as a major need in order to go to school and to go to work -- 34 percent stated that they needed transportation services in order to go to school, and 45 percent needed transportation services in order to work. For most of these persons, over 60 percent, the needed transportation services were not available.

These people appear to rely heavily on relatives or friends for most of their transportation needs. (See Table 8-11). Seventy-one percent of the sample receive transportation assistance from relatives or friends. Twenty percent drive themselves in either a regular automobile or one with adapted

Table 8-11

Transportation Used, CMRC Sample[1/]

Type	Used		More than Once a Week		Once a Week or Less		Once a Month		Don't Know	
	N	%[2]	N	%[2]	N	%[2]	N	%[2]	N	%[2]
Walk	127	41.4	105	82.7	13	10.2	8	6.3	1	0.7
Wheelchair	91	29.6	59	64.8	17	18.7	14	15.4	2	2.2
Drives self (regular auto)	52	16.9	45	86.5	5	9.6	1	1.9	0	0
Motorized vehicle for disabled	8	2.6	6	75.0	1	12.5	1	12.5	0	0
Relative or friend drives	218	71.0	104	47.7	53	24.3	59	27.1	1	--
Taxi	51	16.6	10	19.6	11	21.6	30	58.8	1	1.9
Adapted bus	5	1.6	1	20	1	20	3	60	0	0
Public transportation	29	9.4	13	44.8	4	13.7	11	37.9	0	0
Rehabilitation agency transportation	30	9.8	5	16.7	4	13.3	21	70	0	0
Drives self (adapted auto)	31	10.1	28	90.3	3	9.7	1	3.2	0	0

[1] For transportation used by the VR sample, see the chapter on transportation.

[2] Percentage totals may exceed 100% because clients may have used more than one service.

controls. Forty-one percent frequently walk to their destinations, and 30 percent use their wheelchairs as a means of transportation. The proportion of persons who used other types of transportation drops sharply, as does the frequency of going outside the home. The relatively low use of these transportation alternatives is not surprising, since access to other types of transportation is clearly limited.

Respondents were asked how often they left their homes. One-third did so less than twice a week and 11 percent of the sample were completely homebound. This immobility is due in large part to the structural problems in getting out of the house and to problems in getting in and out of vehicles. In addition, 57 percent reported physical problems such as fatigue or incontinence as a limitation on travel; 62 percent cited that difficulty in operating vehicles limited their ability to travel.

Architectural Barriers

Architectural barriers in the home caused 22 percent of the population to find a more accessible residence that would allow them to be more independent. Fifty-eight percent of these persons stated that the major benefit in moving to a new residence was that it was on the ground floor and had no stairs. Other reasons given were the presence of wider doorways (47 percent) and elevators (31 percent).

The dependency of the severely disabled is reinforced by architectural barriers. One-third of the persons in the study had made architectural changes in their homes, but another third still need architectural modifications. The major reason why the barriers have not been removed are the high cost of such changes (53 percent), as illustrated by Table 8-12. Transportation and architectural barriers at home, school, work, and in public places continue to be major problems for the disabled.

Table 8-12

Reasons Why Barriers Have Not Been Removed, CMRC Sample[1]

Reasons[2]	Number	%[3]/
Problem developed only recently	0	0
Costs too high	59	53.2
Agency refused to pay for changes	6	5.4
Do not know how or where to get help	10	9.0
Project too large	12	10.8
Haven't gotten around to it	7	6.3
Problems are minor	8	7,2
Other	35	31.5
Don't know	5	4.5

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[1] Categories are not mutually exclusive.

[2] For similar information on the VR sample, see Chapter on Architectural Barriers.

[3] Percentage total exceeds 100 because client cited more than one reason.

Geographic Mobility

Of the individuals in our sample 22 percent had moved to another city or area of the country because of their disability. The most frequently stated reasons for moving were that rehabilitation services and family assistance were more available.

The individuals surveyed were also asked whether they could deal more effectively with their impairment in some other geographic location. Twenty-one percent stated that they thought moving to another city would allow them to live more independently. Forty-three percent of these persons felt that a more suitable climate would be the major benefit in moving.

SUMMARY

The analysis at individuals at 10 Comprehensive Medical Rehabilitation Centers throughout the country provides a wide range of information on an important group of severely handicapped individuals. Only through an understanding of the service needs and environmental problems that severely handicapped individuals face, can intelligent policy options be developed.

The personal physical needs of this group include rehabilitation therapy, attendant care, and equipment, all of which are essential for improvement and maintenance of functional performance. The individuals surveyed had improved in their physical functional capability greatly since first entry into the rehabilitation setting, but it is apparent that physical rehabilitation is a lengthy process which demands continuous and extensive care.

Barriers to mobility were formidable for the disabled. Many could not go to work, school, or to social activities as a result of inaccessible buildings, streets and transportation. Moving to another home or community and remodeling rooms were answers for some. But for most, isolation and increased dependence were the only options. Laws to enforce access, programs designed to remove barriers and to provide accessible transportation services, and funds for immediate implementation of these laws and programs are clearly needed to promote independent action by the disabled.

Social activity -- in particular, outlets for entertainment and the opportunity to visit friends -- was minimal. While much of this was the result of physical inaccessibility, the sample did report a great need for organized therapeutic recreation. They also stressed that counseling was a perceived need. This may be a key to renewed social activity, for many of the disabled reported difficulty in dealing with the changed attitudes of others.

For the severely disabled, returning to work is a difficult, and sometimes impossible, objective. However, many did feel that they could work if they were placed in accessible work settings, with a flexible work schedule, and on a job that was not too physically demanding.

Funding for such specific services in all three areas is necessary for the rehabilitation of the severely disabled. It must be again stressed that rehabilitation is neither short not easy, but indeed possible. Legal, programmatic, and financial support of the rehabilitation process will greatly enhance the independence of the many potentially productive and active disabled.

COMPARISON OF RESULTS OF CMRC AND VR SURVEYS

This part of the analysis compares the persons rejected by VR who were surveyed by The Urban Institute with the sample of severely handicapped individuals surveyed in 10 Comprehensive Medical Rehabilitation Centers throughout the country. The similarities and differences between two types of severely handicapped populations will be explored in a number of areas, including sociodemographic variables, types of services received and needed, physical limitations, and employment situations.

Sociodemographic Characteristics

Previous sections have pointed out that the age of individuals going into the VR system, or perhaps any rehabilitation system, was important implications for physical condition as well as for employment potential. The age distribution of the CMRC and VR populations is illustrated in Table 8-13.

Table 8-13

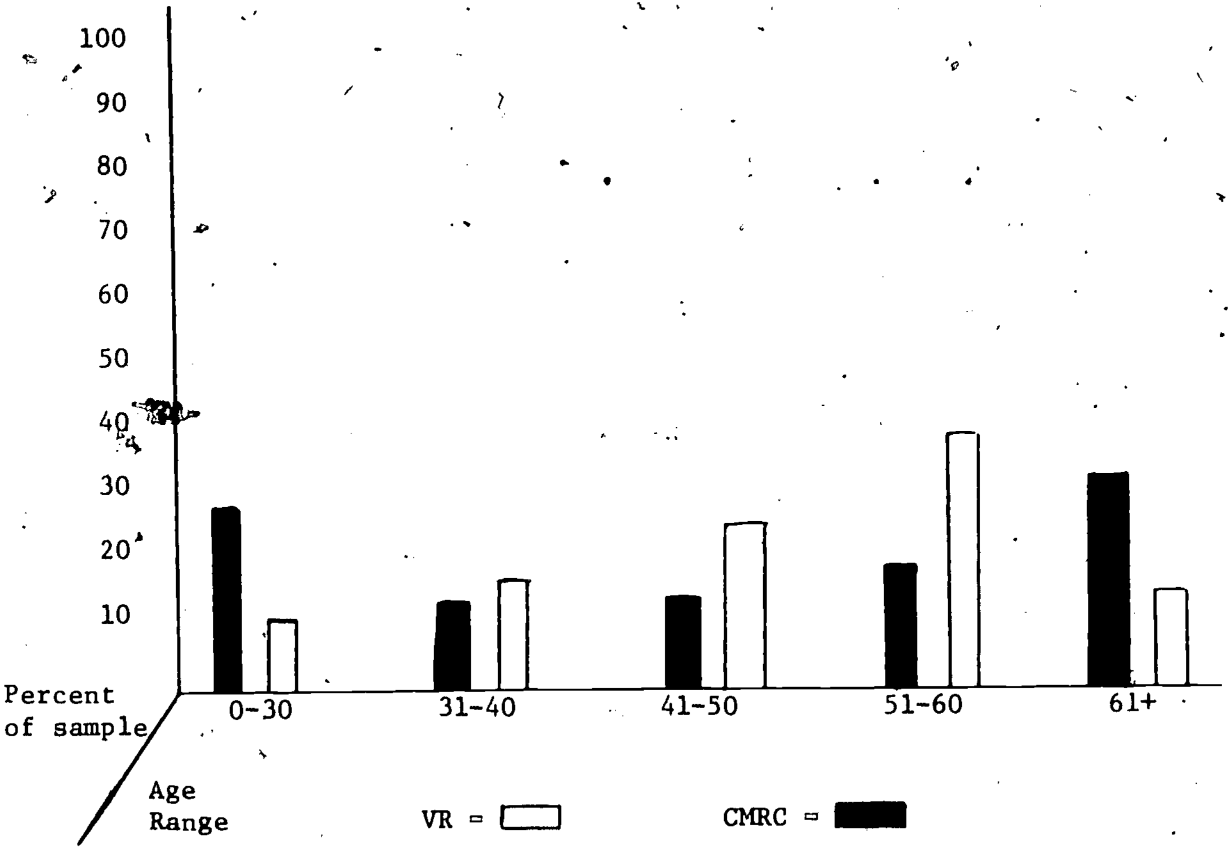
Age Distribution of CMRC and VR Populations

	CMRC		VR	
	N	%	N	%
Age Range				
0-30	85	27.7	81	9.2
31-40	33	10.8	120	13.5
41-50	34	11.1	232	26.1
51-60	54	17.6	351	39.5
61+	100	32.8	104	11.7
Total	306	100.0	888	100.0

The two populations differ considerably in age distribution, the CMRC sample being more concentrated on the extremes. The CMRC population, on a percentage basis, has about three times as many individuals aged 30 and under as well as almost three times as many individuals aged 61 and above. The VR population has over twice as many individuals in the 51-60 age bracket. The differences between the two groups are graphically illustrated in Figure 1.

AGE DISTRIBUTION OF VR AND CMRC POPULATION

Figure 1



While there are important differences in the age ranges of the two groups, an important point to note is that slightly over half of both populations are older than 50. Thus, the VR and CMRC samples have a large number of elderly individuals, and this has important implications for independent living and employment-related policy alternatives.

Other demographic characteristics of the two populations are presented in Table 8-14. As this table illustrates, both populations are largely male, married, white, and living with their families. The CMRC population, however, has a higher percentage of females, more individuals who are widowed or single, and fewer persons who are living with their families. Thus, family support is likely to be more evident with the VR population. The racial composition of the two populations is similar, although there is a slightly higher percentage of blacks in the VR population.

Table 8-14

Sex, Marital Status, Race and Living Situation
of the VR and CMRC Populations

	CMRC		VR	
	N	%	N	%
Sex				
Male	180	58.6	545	61.3
Female	127	41.4	343	38.6
Marital Status				
Single	77	25.1	131	14.7
Married	146	47.6	531	59.7
Separated/divorced	43	14.0	160	18.0
Widowed	40	13.6	66	7.4
Race				
White	228	74.3	636	71.5
Black	62	20.2	225	25.3
Hispanic	11	3.6	18	2.0
American Indian	2	0.7	7	0.8
Other	4	1.3	2	0.2
Living Situation				
Alone	35	11.4	120	13.5
With family	220	71.7	722	81.2
With unrelated people	19	6.2	17	1.9

Both populations are largely urban, although they have a significant rural component. Sixty-six percent of the CMRC population and 58 percent of the VR population live in a large city or suburb of a large city. Both the CMRC and VR populations have slightly more than 10 percent of the sample located in rural areas. Finally, 52 percent of the CMRC population -- either the surveyed individual or his family -- and 54 percent of the VR population own their own homes.

The education level of the two populations differs markedly, with the CMRC population being considerably better educated than the VR population. More than twice as many CMRC patients had attended college or graduate school. (Table 8-15)

In contrast, almost twice as many of the VR population (on a percentage basis) had less than a seventh grade education. While there is a significant difference between the two groups on the extremes, the majority of the individuals in both groups fell within the 7-12 grade level.

Table 8-15
Last Grade in School Completed, CMRC and VR Population

Grade Level	CMRC N	CMRC %	VR N	VR %
0	4	1.3	15	1.7
1-6	31	10.1	163	18.3
7-10	80	26.1	311	35.0
11-12	118	38.4	301	33.9
13-16	55	17.9	81	9.1
17-28	18	5.9	15	1.7
Missing, don't know	1	0.3	3	0.3
TOTAL	307	100.0	889	100.0

Finally, it is important to look at the physical limitations of these two groups. The CMRC population is much more physically dependent, as measured by the Barthel Index. For example, 45 percent of the VR population were completely independent in self-care and mobility compared to only 18 percent of the CMRC group. Only 11 percent of the VR population were found to be severely or totally dependent, whereas almost one-third of the CMRC group were in this category. These differences are primarily due to the differences in sample selection. CMRC patients who failed to reach specified criteria for severity, which included impairment of limbs and need for medical attention, were excluded from the sample, whereas the criteria for inclusion in the VR population was closure by reason of severity. The VR criterion was shown to be inadequate as a means of selecting those with severe physical limitations, since other factors such as age and educational level appeared to play a significant role in their rejection. In addition, almost one-quarter of the CMRC sample was over 65, and these individuals were much more physically dependent than yonnger persons. In the VR sample, however, older persons did not tend to be more physically dependent; it may well be that older persons do not seek vocational services unless they are in fairly good physical condition.

To summarize, both populations are largely male, married, white, and living with family in an urban area in a home they own. However, the CMRC group has slightly more single people and individuals living alone. While there are age differences, both have slightly over half the population over 51 years of age. The CMRC population has a higher percentage of college educated individuals. Finally, the VR population has a significantly higher percentage of physically independent individuals as measured by the Barthel Index, and a much smaller percentage of individuals totally dependent.

Services Received and Needed

This section will compare and contrast the types of service agencies contacted and benefits received by these two populations, followed by the service needs which still exist for these disabled persons in order to function more independently.

Before any new program can be designed for treating severely handicapped individuals, it is important to determine the level of service needs. In order to understand the entire picture, both the services which the severely handicapped have received and the unmet service needs need to be considered.

Service Agencies Contacted and Benefits Received. The agency most frequently contacted in the past 3 years by both groups was the Social Security Administration. Sixty-eight percent of the CMRC population and 87 percent of the VR sample contacted Social Security. When the other agencies which were contacted by at least 10 percent of each population are ranked, there is a reasonably close similarity; for example, the Veterans Administration, Food Stamps, and Public Welfare were among the top five agencies contacted for both populations. It should be noted, however, that the level of agency contact differs, the VR population generally having a higher frequency of agency contact.

The only exception to this general pattern is the fact that the second most frequently contacted agency by the CMRC population -- medical agency or hospital -- is rarely contacted by the VR population. This difference is probably due to the fact that the CMRC population is more physically dependent than the VR sample.

Table 8-16

Frequency of Benefits Received in the Past Three Years, CMRC and VR Populations

Agency	CMRC N	CMRC %	VR N	VR %
Public				
Social Security	182	59.2	636	71.5
Veterans Administration	21	6.8	127	14.2
Workers Compensation	11	3.5	80	8.9
Unemployment Compensation	7	2.3	51	5.7
Employment Service	4	1.3	8	0.8
AFDC	7	2.3	74	8.3
Public Housing	9	2.9	41	4.6
Food Stamps	31	10.0	209	23.5
Public Welfare	66	21.4	175	19.7
Job Training	6	1.9	16	1.8
Legal Aid	1	0.3	11	1.2
State Disability Programs	7	2.2	13	1.4
Railroad Retirement Program	1	0.3	5	0.5
Government Employees Programs	6	1.9	28	3.1
Employer and Union Programs	21	6.8	48	5.3
Bureau of Handicapped Children	3	0.9	4	0.4
Other Public Agency	10	3.2	21	2.3
Private				
Medical Agency	106	34.5	40	4.4
Vocational Training	2	0.6	20	2.2
Mental Health Agency	3	0.3	10	1.1
Employment and Job Placement	--	--	1	0.1
Church and Social Services	13	4.2	13	1.4
Other Private Agency	61	19.9	14	1.5

Given the high percentage of both populations that contacted Social Security, it is not too surprising that both groups -- by a substantial margin -- received Social Security benefits more than any other kind of benefit (See Table 8-16). Close to one-fifth of each population received public welfare.

The VR population generally appears to receive a greater percentage of benefits from the various "public assistance" types of programs than the CMRC population, although they are important sources of benefits for both samples. For example, on a percentage basis, over twice as many persons rejected from VR receive Food Stamps, yet Food Stamps are the third most frequently received benefit received by the CMRC population from a public program. The VR population received public or low cost housing almost twice as often, and AFDC almost four times as frequently than the CMRC clients. The latter finding is probably due to the substantial numbers of persons over 65 in the CMRC sample, most of whom would not have dependent children.

The CMRC population receives considerably more benefits from private agencies, even when private medical agencies or hospitals are excluded, the VR sample rarely received benefits from private agencies. About one-third of the CMRC population received benefits from private medical agencies compared t only 4 percent of the VR population; "other private agencies" were contacted by one-fifth of the CMRC population but by less than 2 percent of the VR respondents.

The VR population, then, generally relies more heavily on publicly funded assistance. Although this is an important source of benefits to the CMRC population, they appear to receive a large percentage of benefits from private agencies. Both groups receive cash or subsidies as their major benefit. However, the CMRC population also received a high percentage of physician,

Table 8-17

Services Perceived as Still Needed, CMRC and VR Population

Service	CMRC[1]		VR[1]	
	N	%	N	%
Surgery	20	6.5	57	6.4
Hospitalization	18	5.9	50	5.6
Physical therapy	88	28.7	141	15.9
Occupational therapy	48	15.6	86	9.7
Speech hearing therapy	23	7.5	47	5.3
Other medical treatment	49	16.0	84	9.4
Visiting nurse	24	7.8	27	3.0
Homemaker services	52	16.9	37	9.8
Prosthetic devices	36	11.9	69	7.8
Vocational counseling	40	13.0	126	14.2
Vocational training	25	8.1	183	20.6
Educational costs	16	5.2	111	12.5
Vocational placement	31	10.1	131	14.7
Tools, equipment, licenses	11	3.6	45	5.1
Special school devices	14	4.6	46	5.2
Transportation	93	30.3	162	18.2
Psychological therapy	47	15.3	52	5.8
Home modifications	43	14.0	41	4.6
Don't need any services	65	21.1	348	39.1

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[1] Percentage totals exceed 100% because clients may need more than one service.

nursing, and physical therapy benefits, which is consistent with the types of agencies they contacted.

Services Needed -- Respondents were asked to indicate the services which they currently needed, over and above services already received.

The pattern of service needs for the CMRC and VR populations, as illustrated in Table 8-18, appears to be quite different. The service needs of the CMRC clients cluster around various physical needs and services that enable individuals to function more efficiently in their home environment. As might be expected, vocational types of services were mentioned frequently by the VR sample. Yet transportation was cited by both populations as one of their major service needs.

The CMRC population most frequently cited physical therapy, other medical treatment, psychological therapy, homemaker services, and home modifications. The VR population, however, frequently listed such things as vocational training, vocational placement, vocational counseling, as well as physical therapy.

The percentage of individuals who stated they did not need any services was almost twice as high in the VR population. This is another indication of the greater independence of this group.

The findings regarding service needs have important policy implications. It may well be that "individuals most severely handicapped" covers a broad spectrum of individuals with very different types of service needs. Some of these individuals need physical types of services in order to function independently in their homes, while others need vocationally related services to enhance their employment opportunities. Thus, alternative policy options may have to be developed to ensure that all severely handicapped are equitably treated.

The availability of the appropriate types of equipment may influence the degree of independence achieved by a disabled person. The surveys indicate a much higher incidence of equipment utilization within the CMRC population for almost all types of equipment. For example, the CMRC patients most frequently used wheelchairs (52 percent), canes (50 percent), and helpers for lower limbs (31 percent). The VR sample most frequently utilized canes (25 percent) and dentures (22 percent). Equipment usage appears to be consistent with the earlier assertion that the CMRC population is more severely disabled than the VR population.

About three-fifths of both populations stated they currently did not need any further equipment. Every category of equipment needed for both populations was cited by less than 10 percent of each group.

Employment

This section will compare the two populations on the types of jobs held prior to disability, the current employment situation, the major reasons for not working, and the kinds of services needed in order to go to work.

The usual occupations for both populations are presented in Table 8-18. In most instances, this represents the type of occupation engaged in prior to disability.

The leading usual occupations for both the CMRC and VR populations are craftsmen and operatives. However, the VR group has a substantially larger percentage of both of these occupational types. The CMRC sample was a more highly skilled group. A substantial percentage -- almost one-quarter -- of its population were in the two most highly trained and paid occupations, "professional" and "managerial", compared to 10 percent of the VR population in these occupations. This finding is consistent with the substantially higher percentage of CMRC clients who have been to college and graduate school.

Table 8-18

Type of Usual Occupation, CMRC and VR Populations

Occupation	CMRC N	CMRC %[1]	VR N	VR %[1]
Professional	36	11.7	50	5.6
Managerial	34	11.1	42	4.7
Sales	16	5.2	34	3.8
Clerical	32	10.4	84	9.4
Craftsmen	39	12.4	165	18.6
Operatives	37	12.1	145	16.3
Transportation operators	4	1.3	51	5.7
Laborers	11	3.6	73	8.2
Farm Managers	4	1.3	8	0.9
Farm Laborers	1	0.3	9	1.0
Service workers	29	9.4	143	16.1
Private household	17	5.5	23	2.7
Missing, no answer, don't know, never employed	47	15.3	62	7.8

[1] Percentage totals exceed 100%.

On the other end of the job skills spectrum, the VR population has a substantially higher percentage of laborers and service workers. Given the physically taxing nature of these jobs, it may be more difficult for severely handicapped individuals who worked in these professions to return to them. A greater investment of resources may be necessary to vocationally rehabilitate the VR population than the CMRC population.

More than twice as many persons in the CMRC sample were employed at the time of interview than in the VR population (13 percent compared to 6 percent). A large percentage in each sample had retired early due to disability. The major reason listed for not working was physical condition for both samples -- 82 percent of the nonworking VR sample and 40 percent of the CMRC sample cited this reason.

Considering the large percentages of unemployed persons in these two samples of severely handicapped persons, it is important for policy purposes to ascertain the kinds of services needed to enhance employment prospects. The needs of these two populations are presented in Table 9-19.

Table 8-19

Types of Assistance Needed To Go To Work, CMRC and VR Populations

	CMRC		VR	
	N	%[1]	N	%[1]
Help from others to get ready	81	26.4	190	21.4
Transportation	139	45.3	363	40.8
Special equipment	59	19.2	173	19.5
Flexible work schedule	99	32.2	356	40.0
Reduced work schedule	97	31.6	422	47.5
Special training or education	86	28.0	350	39.4
Light work only	151	49.2	550	61.9
Ramps or elevators	122	39.7	243	27.3
Accessible washrooms	92	30.0	195	21.9
Regular assistance in work tasks	66	21.5	143	16.1
Attendant help	53	17.3	122	13.7
Anything else	7	2.3	51	5.7
Don't need anything	20	6.5	212	23.8

[1] Percentage total more than 100 because some clients need more than one type of assistance.

The types of assistance most frequently cited by both populations were quite similar. For example, the top five items mentioned by both groups included light work, reduced work schedules, flexible work schedules, and transportation. The only exception was the CMRC population's need for ramps and elevators, and the VR population's need for special training or education.

The major difference in the overall pattern of employment needs was the fact that almost four times as many of the VR population compared to the CMRC population stated they did not need anything to go back to work.

To summarize, the CMRC population has a greater percentage of individuals in white collar jobs and slightly over twice as many individuals employed. The major reason that the majority of both populations are not working relates to physical condition, although the VR population cited physical condition far more frequently. Finally, both groups need similar kinds of services in order to facilitate their going back to work, although the CMRC population has a higher need for services than the VR population.

In developing policy alternatives, important differences between the CMRC and VR populations of severely handicapped should be taken into account. The CMRC population had greater proportions of both younger and older (over 65) persons, was more physically dependent, and consequently needed more services and, in particular, more medical services than the VR population. The VR sample was less educated, less likely to be currently employed, and had previously worked in jobs requiring lower skill levels than the CMRC group. Half were physically independent, and hence their service needs were primarily vocational in nature. Figure 8-2 illustrates some of these differences. In considering the vocational potential of these two groups, it should be noted that a larger portion of the CMRC group was physically unable or too old to

Figure 8-2

Major CMRC and VR Sample Characteristics

	AGE	EDUCATION	BARTHEL	SERVICE NEEDS	CURRENT EMPLOYMENT	TYPES OF EMPLOYMENT
CMRC	More than 50% fifty-one and older	Clustered in 7-12 grade level; 20% college or graduate school	18% totally independent; 63% severely or most severely impaired	Need physical types of services (e.g., medical treatment, physical therapy); 21% don't need any	13% employed	Large number of white collar workers
VR	More than 50% fifty-one and older	Clustered in 7-12 grade level; 10% college or graduate school	45% totally independent; 11% severely or most severely impaired	Need job related services (e.g., vocational training, counseling); 49% don't need any	6% employed	Large number of blue collar workers

work, and that their perceived service needs in order to return to employment were numerous. The VR population was physically more able, but was disadvantaged by lower educational achievement and prior work experience in jobs which often require physical strength or skill. All of these differences should be considered in designing programs for these two groups.

CHAPTER 9

ANALYSIS OF DEPENDENCY

A severe impairment creates adjustment problems for both individuals and their families. The severely impaired must deal with dependency caused by the condition, with impositions by professionals, and general readjustments to school, work, and marital roles. In this section, we will examine empirical studies of dependency, dependency and people rejected by VR, dependency and rehabilitation professionals, dependency and the family, and dependency and long-term care.

Rehabilitation has traditionally been concerned with physical restoration followed by vocational placement. Along with concerned professionals, a number of disabled persons and groups are beginning to demand comprehensive rehabilitation stressing aspects other than vocational. There are several types of dependency that result from a severe disability.

Socially dependent individuals often require assistance in interpersonal relationships for the achievement of their purposes. For example, some persons must have some intermediary to make appointments or to initiate the first contact for services they require. Many of the handicapped become socially dependent because of their feelings of difference from others as well as their feelings of inadequacy relative to the existing norms of competition. They therefore develop their own norms and values and function as a minority group. Although they retreat into their own subcultures, they often seek the interventive help of the non-handicapped society in meeting their needs.

Emotional dependency differs from social dependency in that its goal is the satisfaction of deep emotional needs within the personality. It is often characterized by a constant and inappropriate need for emotional support by one family or group member from another.

The attitudes adopted toward a disabled person's dependent strivings can profoundly influence motivation to work toward self-help in the rehabilitation process. An overprotective spouse or parent can raise a handicapped person's anxiety to the point of being fearful to attempt activities basic to successful rehabilitation. On the other hand, if family members are unable to accept the usual dependent feelings commonly expressed by disabled people, they may adopt a Spartan attitude and push the client physically or emotionally into discouragement and consequent failure.

Psychomedical dependency refers to dependent responses evoked by physical illness or handicap. Such dependency, grounded in the reality of the impairment which requires dependence on those around the severely handicapped individual, is viewed as a natural and symptomatic consequence of severe disability.

Rehabilitation professionals deal with psychomedical dependency in three ways. Some have adopted what might be called a "reality-oriented" attitude based on the feelings that it is important to motivate the handicapped person to achieve his maximum potential. They feel that a certain amount of urging and pressure is acceptable as long as there is no attempt to achieve goals which are so difficult to attain that they arouse anxiety. A second group uses an "acceptance philosophy." Although committed to maximum rehabilitation, they believe they can best meet their client's psychological needs by helping him accept and live within the framework of limitations imposed by the disabling condition. A third group approach the problem with what has been referred to as a Spartan philosophy. The concept is that if rehabilitation goals are set at a high level, the client, if constantly urged, will strive to meet them and will reach a higher level, of rehabilitation than if goals were set completely within his capacity. This group believes that pressure and demands are constructive devices. They minimize the effect of the anxiety that arises over doubts of ability to succeed; as long as adequate counselor support is provided, the proponents of this technique are convinced of its effectiveness.

The question as to whether or not dependency helps the rehabilitation process is an open one; no studies have seriously considered this question. It would seem perhaps that some amount of dependency in the early stages of rehabilitation may be necessary but that it becomes increasingly less important as the process continues. There may be a danger that rehabilitation workers reinforce dependency by doing things for their clients rather than allowing them to do things for themselves.

EMPIRICAL STUDIES OF REACTION TO DISABILITY

People may respond differently to the same health condition. One person may continue to work although he has a severe heart condition; another may not. Therefore, of two people with identical health conditions, only one would be classified as disabled in response to a Census survey on whether the impairment limited work behavior. David Mechanic refers to the concept of "illness behavior."

> Such considerations suggest the importance of the <u>concept of illness behavior</u>, which refers to the ways in which symptoms may be differentially perceived, evaluated, and acted (or not acted) upon by different kinds of persons....Some persons will make light of symptoms, shrug them off, and avoid seeking medical care; others respond to the slightest twinges of pain or discomfort by quickly seeking such medical care as is available. Variables affecting illness behavior come into play prior to medical scrutiny and treatment, but after etiological processes have been initiated. In this sense, illness behavior even determines whether diagnosis and treatment will begin at all.[1]

Illness behavior may not only determine the quality of medical care obtained, it may also determine a person's reaction to a chronic condition once diagnosed.

A number of authors have commented upon the difference between men and women in illness behavior,[2] and this point is worth noting, in view of our finding of higher prevalence of disability among women. One study speculates:

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[1] David Mechanic, "Religion, Religiosity, and Illness Behavior: The Special Case of the Jews," Human Organization, 1963.

[2] The literature on this subject is summarized very well by Phillips and Segal in "Sexual Status and Psychiatric Symptoms," American Sociological Review, February 1969.

> Particularly among men, illness is looked upon as a feminine characteristic to be shunned. The man who publicly announces that he does not know what it means to be sick thereby improves his masculine status. In sum, it seems more acceptable for women to have problems, especially problems of illness ....Women are granted more indulgence...men are subject to different expectations. It is less permissible for them to be sick, emotionally disturbed, or upset, because they are expected to exert more self-control, and, if difficulties do occur, they are expected to bear them with greater equanimity.[3]

Numerous research studies have examined underlying psychological factors which might account for the differences in behavior of disabled persons. The findings of some major areas of interest as listed by B. A. Wright show the following.[4]

There is no substantial indication that physically impaired people differ as a group in their overall adjustment to life. They are neither better nor worse adjusted than the able bodied.

There is also no clear evidence of an association between types of physical disability and particular personality characteristics. Such theories as the deaf being prone to paranoia are not supported by available data.

Although personality patterns have not been found consistently to distinguish disability groups as a whole, certain behavioral traits directly connected with physical limitation have been noted. These are examples of specific behavior in a specific situation, for example, a wheelchair-bound person's reluctance to travel over rough ground.

Such evidence as exists on how people feel about their disabilities suggests that these attitudes vary widely, have little relation to the degree of disability are related to pre-impairment personality, and can accept change through adopting a new value system.

Finally, group trends with respect to personality and adjustment have not been found. However, studies indicate convincingly that physical impairment has a profound effect on the person's life but this effect is neither consistent nor

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[3] Ibid., p. 60. Quotation is from Roger Barker, Adjustment to Physical Handicaps and Illness (New York, Social Science Research Council, 1953), p. 317.

[4] Beatrice A. Wright, "Changes in Attitudes Toward People with Handicaps," Rehabilitation Literature, December 1973.

direct; it shows as many variations as there are disabled individuals.

DEPENDENCY AND PEOPLE REJECTED BY VR

Although the VR survey questionnaire was not designed to record attitudes and emotions in objective form, it did allow respondents to express their feelings through open-ended questions. In their comments, they managed to convey in often powerful terms some of the less tangible effects of a severe disability. The ramifications and consequences of dependency emerged as a devasting problem.

They cited frustration and feelings of helplessness suffered as a result of their disabilities. It is their own powerlessness to improve their position in life that has defeated them. For example, a 29-year-old woman, living with her parents in rural Georgia, made this comment about her life:

> I have always been an ambitious person--wanted to live alone, support myself. That dream has crumbled. I am not a viable person. I feel I am not useful. I am not satisfied. I feel I should be doing something but I don't know what. With a progressive disease you don't know where you're going or what the next day will bring and what you'll be able to do. I would like to feel like a useful member of society but I feel useless. I feel bad because I know my parents feel like they are making sacrifices for me. All I ever wanted was to have a job and be useful.

This comment comes from a man who lives in Baltimore, Maryland. He is a stroke victim and therefore needed an interpreter to speak for him. He was asked whether he agreed with VR's decision to reject him.

> I agree as far as getting into a competitive market, but it should not stop there. The man has potential and potential at any level should not be wasted. Forty-five is too young to be retired to the TV and sofa existence.

It is not surprising to learn that a severe disability causes emotional problems, although it may be easy to underestimate the impact of these problems. But a severe handicap can also affect one's life in unexpected ways. The difficulties cited in the following examples in no way exhaust the possible ramifications of a handicap, but they do give some indication of how diverse the problems are.

A 63-year-old man who lives with his 72-year-old sister-in-law was asked how he felt about VR's decision to reject him. He said:

> I can't do anything for myself and I have no money. I need a new wheelchair; this one is falling apart. I wish they [VR] could help me get my mail. My family asked for help from the post office; I've sent letters all the way to Tennessee to the government. I can't get delivery because I'm off the road and the truck won't come in. It's not but a couple hundred feet but my sister is too old to walk up to the road and I can't, so I have to wait for someone to bring it. In bad weather I just wait and wait. I'd be so happy if the driver would pull in here. Could VR help me get my mail?

This comment comes from a man who lives in a small North Carolina city. He has Parkinson's disease.

> I don't feel like visiting; I have a complex; I am embarrassed. I feel like at times people think I'm an alcoholic because I shake so bad.

Another respondent said that VR would not send her to school partly because the noise of her respirator would be disconcerting in a classroom. And one woman pointed out that the sexual limitation caused by her disability not only meant deprivation for her but made her husband irritable because of his own sexual deprivation.

Perhaps the best indication of how severe the problems are that the handicapped face is the number of people in our survey who have been defeated by them. In nearly 20 percent of our interviews there are comments which give evidence to a state of despair. One can only guess how much higher this percentage might be if the subjects had been asked about their emotional well-being. The following quotes are just a few examples of the hopelessness of many of the severely disabled people we interviewed.

This comment comes from a 46-year-old man in rural Indiana. He suffers from a genitourinary condition. When asked what problems his disability had caused and what plans he had for the future, he responded:

> My disability stopped all activity. My wife has to wait on me all the time and is not able to work. My plans are to go to Farley Funeral Home.

A 52-year-old woman in Flushing, New York made this comment. She has multiple sclerosis and is incontinent as a result.

> Well, I can't go out for too long or go too far because in case I have to go I don't want to be embarrassed. So I just sit here in the chair looking almost like a human being.

The following is an example of a distressingly common reaction among the people interviewed. Some of them have turned away from the agonies of reality and instead fasten their hopes and dreams on a near miracle. This woman has diabetes mellitus. She lives with her 16-year-old son in Baltimore, Maryland. This is what she said when asked about her plans for the future:

> I hope I don't live too long. My son has his own life to live and I don't want to be a burden on him. If I could win the lottery I would like to buy a nice little house somewhere and have someone cook and clean for me.

REHABILITATION PROFESSIONALS AND DEPENDENCY

The central position of the physician and the medical facility in disability is reflected in the research and in the reports of the disabled and their families. While admiration for technical skills is often expressed, dismay at the limitations of medical technology and the ability of physicans to tolerate severely disabled persons and their familites is also frequently noted.

Davis studied 11 polio-stricken children and their families.[5] In all cases the doctors did not give the parents all the information they needed. Family physicians felt uneasy in relating the news to the parents; Davis felt that in many cases, family physicians, knowing that they would have a continuing relationship with the parents, did not want to be the "mean guys" who must tell the parents. Instead, an unknown physician in the hospital broke the news in a very professional and abrupt way. This confrontation was often quite brief, leaving the parents with more questions than answers.

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[5] Davis, Passage Through Crisis (New York: Bobbs Merrill, 1963).

Short addresses the issue of the nature of medical practice.[6] He points out that whereas years ago doctors were concerned with finding cures to diseases, doctors must now turn their attention to the long-term physically handicapped. Developing cures is gratifying in that the doctors are able to see results and can take pride in their work. This feeling is not present when dealing with the long-term physically handicapped. Mellette indicates that medical schools do not even prepare the doctor for this role but rather emphasize the need for curing.[7] When the patient is left with a major impairment, especially one which is visible, it produces a sense of failure in the physician.

For many disabled people, their treatment by professionals, especially medical professionals, is the first step in enforcing dependency and dehumanizing the individual into a "case," a "patient," or "disability." The professional tendency toward labeling, or referring to clients as "CP's," "quads," or "MS's," is tinged with a disregard for individuality. Language generally evolves to express attitudes, whether conscious or unconscious. In this case, the fact that a disabled individual is often referred to as a CP rather than a person with cerebral palsy indicates something about the attitude of the speaker, something that he may not even recognize in himself. DuBrow describes this attitude as "clubhouse disdain of the inferior by members of the 'pro' team; the disabled are seen as different from us normals.[8]

This disease-oriented approach to the disabled may be encouraged by the voluntary organizations which help those with cerebral palsey, multiple sclerosis, etc. These associations may be detrimental to disabled people, at least in the fight against prejudice, since they involve segregation of disabilities rather

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[6] Short, "Care of Children with Long-Term Handicaps," Medical Journal of Australia, September 1969.

[7] J. R. Mellette, "Prevention of Adverse Emotional Attitudes in Families of Chronically Handicapped Children," Southern Medical Journal, March 1964.

[8] Arthur L. DuBrow, "Attitudes Toward Disability," Journal of Rehabilitation, July-August 1965.

than a general effort to come together and work toward common goals. The attitude which results in labeling may even affect the sort of services a client receives. As Salamone points out, many of the rehabilitation services furnished a client are determined by the labels placed upon him.[9] Thus, the mentally retarded get one type of rehabilitation service, while those with cerebral palsy get another. Kirp stated that at least 20 percent of those classified as mentally retarded may not be mentally retarded at all.[10] Because of the effects of labeling and mislabeling, Salamone recommended that we change the work disability to "life modality," which is the configuration of social, vocational, physical, and psychological behavior. We must try to see the whole person, rather than focusing primarily upon the disability.

This tendency to see the disabled in terms of their disability alone has far-reaching ramifications. Seen in this light the disabled become a "minority" and segregation occurs. Segregation requires a majority which evaluates a minority as inferior, and the phenomenon of labeling, for example, suggests that this is the position of the disabled. They are seen as "deviants" who occupy a separate place in society. They are relegated to separate schools and clubs and their activities are covered in separate magazines. This segregation is seen as beneficial by many since it enables the disabled to come into contact with and accept their "own kind." In much the same way as the blacks, the disabled are "ghettoized" in a physical and psychological sense.

There seems to be an unwillingness on the part of some professionals to deal with the needs of their clients on anything but a mechanical level. The literature on rehabilitation includes examples of professionals who not only exhibit this depersonalized view of the client but also recommend it to other

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[9] Paul Salamone, "Disability--A Reconceptualization," Journal of Rehabilitation, August 1970.

[10] D. Kirp, "Student Classification, Public Policy, and the Court," Harvard Educational Review, February 1974.

professionals. In some cases they seem to suggest that the focus of the rehabilitation agency should be on producing a functional rehabilitant, much as a factory produces a commodity.

Nearly as difficult for the clients as the cold depersonalizing attitude is the overprotective, "mother hen" approach adopted by some rehabilitation personnel. Robinault argues that it is time to do away with the accepted "professional role" in which the counselor is too verbal, doesn't provide enough followup, doesn't keep thorough enough records, and is overprotective. What emerges from this description is a picture of the rehabilitation counselor condescending to the client and manipulating rather than assisting him.[11]

Frequently, the rehabilitation process begins in institutions such as general hospitals before the physically disabled individual even encounters the Vocational Rehabilitation counselor. In such institutions, there are negative forces which can create and intensify dependency in the patient. Basically, the patient is always aware that essential needs for food, shelter, clothing, and medical attention will be met.

This situation creates a fertile environment for the growth of dependency. Moreover, there are not infrequent instances in which the patient's efforts to do things for himself are discouraged or blocked because they interfere with institutional routine, inconvenience the staff, or require extra time that staff members are unable to give. The routine of activities acts to stultify independent thinking; the patient who questions the institution's way of doing things is regarded by staff not as an individual fighting dependence but rather as a hindrance to the functioning of the institution.

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[11] Isabel P. Robinault, The Sociology and Social Psychology of Disability and Rehabilitation (New York: Random House, 1970).

Let one severely disabled person speak for himself:

> It's a very unique pleasure for me to stand before a room filled with medical personnel with all my clothes on, because usually I'm in the supine position, under bright lights, with tier upon tier of hostile, white-coated figures staring at me. I think you're all familiar with what I'm talking about; I refer to the unique learning experience known as grand rounds.
>
> You see, as a child, I was "exhibited as a very interesting case." I was often a star performer in the amphitheater. To this day I am convinced that grand rounds were designed to erase the last vestige of dignity in a patient. One is, or at least used to be, laid out stark naked and provided with the equivalent of a 3x3 sterile pad with which to retain some degree of modesty. One is asked the medical top questions like, "What can you do with your frail right arm?" Now if I quipped, "It makes a good paperweight" or something like that, the oracle of Hippocrates would retaliate with something like, "Now if your left shoulder has extremely limited rotation, how does this limit your toileting?" Now that chap knew full well what I thought he meant when he said toileting. My young mind conjured up some strange things, because children are really quite basic. And it never even entered my mind that he meant combing my hair. So my reply usually brought the house down. And he just stood there letting his superiority radiate out to all the worshippers, secure in his knowledge that he had put me down, and that this fresh kid would think twice before he quipped again.
>
> Now, prior to grand rounds, some overworked young intern or fourth-year medical student would be assigned to do a workup on the case, so that the master would have a full set of answers. This conscientious young man would poke, flex, extend, abduct, adduct, poke a flashlight in crevices, grab orifices and skinfolds, and ask 300 questions, then go over my case folder with a fine-toothed comb. To this day, I never volunteered any health information. In all questionnaires for insurance, employment, telephone surveys, the Gallup polls, my only retort to a health question was, "Yes, my health is excellent." Forms requiring information on what shots I have had will automatically be checked off that I had them all. I usually say yes even when asked if I have taken the Pap test....
>
> I'm not trying to put down the medical profession. Many good doctors did share their knowledge with their patients....What I'm saying I guess is that the patient has been neglected and put into the same classification as the tools which are used to treat him. For too long now, a vast segment of the medical profession has maintained a unilateral position, and this is carried over into other fields, especially to the field of rehabilitation. For years the rehabilitation experts felt that their clients all fitted neatly into the stereotyped which they had been taught was the profile of the handicapped. There were certain vocational paths which one could take and others from which one must stay far away.

DEPENDENCY AND THE FAMILY

The research on the disabled and their family relationships can be classified broadly into several general areas. First, there is the disabled child and his or her family situation. The literature on the disabled child includes the stages through which families generally go in adapting to the child's disability, problems which the child faces during various periods of life, adaptations in the family life which may result from disability, responses and coping behaviors of the parents, and the contact which the child and the family may have with institutions, professionals, and society in general.

Second, there is a considerably smaller amount of research on the disabled adult and family relationships. This generally focuses on the family's reactions to the onset of disability in an adult member, changes in family structure and activity, and the effects of disability on adults' performance of common adult roles (or family members' attitudes about the ability of the disabled members to perform those roles) such as breadwinner, homemaker, child raiser, and sexual partner. From these general areas of investigation come numerous discussions and descriptions of family counseling methods as a means to alleviate problems associated with disability of family member, child or adult.

PARENTAL ADJUSTMENT TO DISABILITY

Various articles describe the stages which parents go through in discovering that their child is disabled and in adjusting to this fact. The basic stages are the same for different disabilities, although if the disability is not congenital, there are variations resulting from the specific characteristics of the disability and the period of onset. How the family reacts to this crisis is found to be determined by the way the family deals with crises in general.

Cohen describes four stages which parents go through upon discovering that their child has a disability: grief, then anger, then a dealing with the situation, and finally a readjustment of their lifestyle. The author notes that caseworkers are often too quick to categorize parents as uncooperative and rejecting of aid, when in fact the parents may still be going through states of grief and/or anger.[12]

A book by Davis, A Passage Through Crisis, describes the effects a child with polio has on the family.[13] Davis found that families went through four stages in finding out about the adapting to the fact. At first the child was seen to be sick or believed to be acting as if he were. Responses to this period were seen as affecting later attitudes, for parents who did not take the child seriously often felt guilty later. The second was the warning stage where parents realized that something was wrong. Here doctors were often consulted, and many of the doctors ignored the concern of parents. Again, such feelings often affected later attitudes. The third period was that of impact, when polio was diagnosed and the child was usually hospitalized. Feelings of fear and grief accompanied this period in all families. Most families were told quite abruptly that their child would be disabled, but no details or comfort were offered. In the final stage, parents began to take stock of the situation and look into the future. Davis then goes into the effects of the child's hospitalization and both the positive and negative reactions produced in this period. Physically, all children improved and the fear of death was removed.

All patients clung to the idea of recovery and restoration of physical capabilities. Children who improved physically had a better relationship with their families than those in which no physical improvement was noted. Often physicians tell parents ~~that~~ the physical capabilities which will return will do so within 18 month. As this deadline comes closer, parents become depressed because their hopes are fading. This raises the question of how to change the attitudes of parents (and of society) so that physical improvement is not such a central issue in the parent-child relationship.

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[12] Pauline Cohen, "Impact of the Handicapped Child on the Family," Social Casework, 1960.

[13] Davis, Passage Through Crisis.

Almost all studies found that much time, money, and effort were directed toward having the child walk. What happens to those children who do not eventuall reach this goal? Are they psychologically harmed by this emphasis on walking? Authors agree that children should be pushed to their optimum, but the question is whether walking or looking as "normal" as possible, is indeed the optimum, or whether efforts can sometimes more appropriately be directed at maximizing mobilit and access to contacts with the world. The stress on reaching normality rather than on maximizing independent living abilities is an issue which arose repeatedly yet none of the literature discussed other goals which counselors could present to the family.

FAMILY ADJUSTMENT

Some of the literature discusses concrete changes which a child's disability can make in the family environment. Sometimes there are changes in the physical environment, necessitated by care for the disabled child in the home. For example the child with cystic fibrosis needs a mist tent in the bedroom. The odors and added humidity can alter the home environment for the entire family. There may also be significant change in family activities. Mothers often quit jobs to have more time to visit with the hospitalized child, or to care for the child when in the home. Fathers may also change jobs or get an additional one, partly to ease the increased financial strains on the family.

Due to the needs of attention and care of the disabled child, changes in family relationships may result. For example, siblings may find that more pressure is placed on them to take responsibilities. This can have a positive effect; some siblings of disabled children seem to be more tolerant of people suffering from diseases and of differences among people which result from disabilities. But there are negative effects also. For example, Poznanski, in a discussion of the histories of two families, found that the siblings were more adversely affected by the disability than was the child himself.[14] One reason for this is that paren

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[14] E. Poznanski, "Emotional Issues in Raising Handicapped Children," Rehabilitation Literature, November 1973.

may express their anger and disappointment with the disabled child by taking it out on each other or on the siblings.

DEVELOPMENTAL STAGES

The problems faced by the disabled child and by the family as a whole change at different times in the child's life. The infant will have one set of experiences and problems related to disability and to how disability affects his particular stage of development, and the preschool child, the schoolaged child, and the adolescent will have others.

Infancy and Pre-School Years. -- Battle describes how child-rearing differs when the infant is disabled.[15] For example, feeding a normal infant is often characterized as a pleasurable, gratifying exercise for most parents. Suckling can be beneficial to both child and mother. Yet when the child has a physical disability such as cerebral palsy, feeding is quite difficult, and suckling is almost impossible. What effect this may have on the parent and the child is not known.

Infants, and older children as well, have a need for stimulating contact with their environment. Yet disability can alter the child's ability to obtain this stimulation independently. Where young children learn to roll and move about in their environment, the disabled child may have to depend much more on his parents for movement and stimulation.

Parents can actually unwittingly make it more difficult for the disabled child to obtain stimulation. Several researchers, for instance, found that cerebral palsied infants are not given toys to play with. Either parents don't realize the need for a child to touch and hold objects, or else they place objects too far away from the child in the hope that he will learn to reach. In other words, they see a need for teaching rather than playing with him. Pressure is placed on the disabled child to progress and learn in the same way as a normal child would, but his simple need for stimulation is overlooked.

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[15] C. V. Battle, "Disruption in Socialization of a Severely Handicapped Child," Rehabilitation Literature, May 1974.

The School-Aged Child. -- A major issue for the school-aged disabled child and the entire family is the issue of segregated versus integrated education. The literature on this issue is extensive; some of the main issues will be sketched because this period is so important.

Battle discusses the issue of integrated and segregated schools.[16] He sees a need for both, since segregated classes provide models for the disabled child and enable him to compete proficiently. On the other hand, segregation can give the disabled child an unrealistic environment. Most disabled people, it is assumed, will enter the mainstream of life (although discussion of voluntary separatism is beginning to appear in the literature) and segregation does not prepare them for this entry. The disabled person may have little in common with his nondisabled peers as a result of segregated classrooms. Kirp looked into the legal aspects of segregation and concluded that at the very least the disabled child is entitled to an equal education, which some observers feel is not now being offered.[17]

Recent court decisions say that all children must be educated and that waiting lists for schools are illegal. But the findings of a study by Fleishman indicate that in New York State in 1973 a minimum of 200,000 children with disabilities were receiving no education at all; some 8,400 students were on waiting lists for special education classes.

Children with different kinds of disabilities have different kinds of experiences in terms of peer participation. The disabled child who looks normal may experience more adverse reaction than the visably severely disabled child. For example, while it is apparent that a cerebral palsied child cannot run bases in a ball game, children with cardiac problems often have difficulty explaining why they cannot participate fully.[18]

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[16] Ibid.

[17] Kirp, "Student Classification."

[18] Suzanne A. Kohut, "The Abnormal Child: His Impact on the Family," Journal of American Physical Therapy Association, February 1966.

Adolescence. -- Throughout childhood, the disabled child experiences both overprotection and the effects of pressures to be "normal." Sometimes these two expectations may conflict and confuse him.

In adolescence, the confusion becomes more acute. The adolescent, particularly if disabled, is still treated as dependent by many adults, teachers, and parents. Simultaneously there is pressure from peers and other adults to take responsibilities and adult roles.

Freeman discusses some of the common experiences of the cerebral palsied gathered from his work on the psychological problems of the adolescent.[19] He states that the range of psychiatric problems in the cerebral palsied adolescent is as wide as those found in the nondisabled. These problems are cuased by overprotection, lack of confrontations normal teenagers face, and the imposition of painful or unwelcome physical conditions, in addition to the "unreasonableness of the environment" which is not geared to the disabled child.

Freeman states that there is no general characteristic of the cerebral palsied adolescent. He has to face the deterioration of his physical condition, as well as realize that there is at present no cure. Social activities may be curtailed as peers reach sexual maturity and become more aware of physical abnormailty. Leaving school and changing professional staff may cause insecurity and lead to psychiatric problems. Indeed, psychiatric treatment itself often creates problems. Freeman also points out that for the disabled individual, as for any adolescent, to be bitter and complaining or complacent and passive does not necessarily indicate psychiatric problems.

Often, neither the family nor the school wants to be aware of the sexuality of the disabled adolescent. Freeman gives possible reasons for the prohibition of sexuality: (1) people see the cerebral palsied as sinful and thus undeserving of sex; (2) they feel "if I can't have sex, why should he?"; or (3) they find this normal act inconceivable for the palsied since the dif-

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[19] Freeman, "Psychiatric Problems of Adolescents with Cerebral Palsy," *Developmental Medicine and Child Neurology*, December 1970.

ference between the normal population and the cerebral palsied has been exploited for so long.

Passage Into Adulthood. -- Less literature was available on the adolescent, and no literature was found which dealt with the transition from adolescence to adulthood. Thus we have no information from research on how the disabled adolescent moves into independence or on the implications of remaining as a dependent young adult in the parental household and its effects on the individual and his family.

One important dimension of adolescence often denied disabled youth is introduction to the world of work. Able-bodied youth often are introduced to work by odd jobs such as mowing lawns or volunteer work, or they may help working parents. Disabled adolescents, especially those with sensory deprivation, are generally denied such opportunities. The New Jersey Blind Agency, among others, has developed a program in cooperation with summer resorts to use blind youths as elevator operators and the like. The program is successful in a number of ways, including the number of employers who subsequently rehire the youths without subsidy.

One major problem for disabled children is "modeling." Leech notes that disabled children usually have no one to model themselves after.[20] Parents, teachers, and professionals with whom they come into contact are usually nondisabled and have the notion that to be "normal" is a primary goal. Such attitudes might have serious effects on the disabled child. The only studies done are on the blind and deaf children of similarly handicapped parents and show these children as better adjusted. No studies are available on the implications this may have for the orthopedically disabled. Many parents fear that their child will become too dependent on "gadgets" and prohibit their use. For example, parents sometimes prohibit the use of wheelchairs in the hope of forcing "normal" mobility. This puts great stress on the child and makes socialization difficult.

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[20] Leech, "Raising the Disabled Child," The Independent, Summer 1974.

THE DISABLED ADULT AND THE FAMILY

The literature on family relationships of the disabled adult generally focuses on limits on activities and on social interaction, as well as effects which the disability may have on the roles of the different members of the family. The ability of the disabled person to perform the roles of breadwinner or homemaker, sexual partner, and parent tend to be the object of the literature. There is also discussion of the ways in which other members of the family view the disabled adult. Some practical aspects of disability such as financial problems are touched upon, but generally their effects on the family are not explored.

The Disabled Adult and Spouse. -- Rosenstock did an analytical study on 34 families where one partner had become disabled during the marriage.[21] Interviews were held at two points, one within 2 weeks of the onset of disability, and the other after 2 years had passed. The families saw the disabled member as being more dependent than did the disabled person himself. Since the degree of disability was not discussed there is no objective standard to calibrate the perceptions. One-fourth of the families felt nervous when the disabled member was at home, and one-fifth thought their families had been happier before the onset of disability. It was concluded, "The extent and speed of recovery of independence may be affected by the patient's precrisis perception of his relationship to others."

Indications are that individuals expressing flexibility in sex roles reported fewer problems. Likewise, a higher educational level was associated with fewer reported perceptions of problems. The presence of children contributed to the lessening of the isolation level.

In studying 30 families in which at least one member had developed aphasia, Malone discovered that spouses of the disabled member had guilt feelings, and that all had feelings of rejection toward that person.[22] Some 60 percent believed that

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[21] Florence Rosenstock, Disabling Illness and Family Alienation, Special Report No. 1 (Springfield, Va.: National Technical Information Service, 1968).

[22] Malone, Ptacek and Malone, "Attitudes Expressed by Families of Aphasics," British Journal of Communicable Disorders, Vol. 5. 1970.

"God had done it," and 20 of the 30 were hoping for miracles. Only 20 percent saw the disability as due to a spinal cord injury.

A study by Katz of wives of diabetic men reveals that poor sexual relationships after the onset of disability are seen as a major problem.[23] Dietary requirements also place burdens on the spouse in purchase and preparation of food.

Whereas most pieces of research recommend family counseling as a viable solution, some of the literature warns that not all families are candidates for it. Shellhase points out that some spouses cannot tolerate the increased responsibility placed on them by the disability of the partner.[24] The only answer may be to remove themselves from the relationship. It was felt that in these cases, if in fact they can be identified, it is much more important to worry about the well-being of the disabled person. There are cases in which a rehabilitated disabled member becomes less dependent on the spouse. This may lead to marital problems when the spouse has become committed to the helping role and readjustment is difficult.

Very little was found in the literature about relationships in families where both adults are deaf, orthopedically handicapped, or otherwise disabled, or about the effects on family relationships of acquired deafness in an adult.

Professional recognition of the importance of successful sexual adjustment of the handicapped individual has been developing and expanding in the last several years. To date, however, few formal studies have appeared in print and those that have are primarily directed toward making the professional aware of this area as one of legitimate concern.

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[23] Alma Katz, "Wives of Diabetic Men," Bulletin of the Menninger Clinic, September 1969.

[24] Leslie J. Shellhase and Fern K. Shellhase, Redefinition of Family Style in Response to the Reality of a Handicapped Member (Arlington, Va.: Educational Resource Information Center, 1973).

The existing articles fall into two categories. First, there are those which discuss the physical aspects of sex. For the most part these articles attempt to dispel misconceptions concerning sexual limitations of persons with spinal cord injury. Second, there are a few articles dealing with sexual roles of a psychosocial nature, in particular husband-wife relations.

In 1973 Hohmann published an article which dealt with both categories. The paper provided guidelines as to who should talk about sexuality with spinal cord injured patients and their spouses, what should be told them, what are some of the techniques that can be used by those who lack normal genital functioning, what some of the emotional rewards are which the person achieves from sexual function, and what are the precautions which anyone who counsels the disabled about sexual functioning should keep in mind.

These include the avoidance of offending moral values, forcing the patient to talk about sex, forcing the counselor's own morality on the patient, making sex an all-or-nothing experience, and expecting too much from the sexual partner. The last topic is the most innovative part of the article, since it has previously received little attention.

Indicative of a new, more comprehensive approach is the work of Diamond, who deals with specific problems such as our culture's emphasis on sexual performance, the feelings of guilt that can result from deviance from supposed standards, and the communication of problems. Finally, he makes recommendations on practical matters concerning sexual expression, including use of different types of devices for achieving biological sexual satisfaction and methods of sensory stimulation.

Although the literature occasionally gives details on the special knowledge needed for sex counselors and urges them to be liberal, it does not mention how training or the proper attitude may be acquired. There is little discussion of the organizational limitations of rehabilitation agencies in respect to sexual counseling. Sexual thoughts and conflicts often embarrass not only the client but also the rehabilitation worker.

There is virtually no discussion of the sexual adjustment of women and homosexuals. Only one study was found, published in 1940, concerning sex and the disabled woman, and one article written in 1973 discussed the disabled homosexual. Writings on sexual adjustment, for the most part, have not dealt with psycho-social factors as contributors to maladjustment. Most articles deal with marriage situations; the assumption is that the handicapped individual will have no trouble obtaining partners, while this may in fact be the essential problem.

The Disabled Adult as a Parent. -- Few articles discuss positive aspects a disabled member may bring to a family. It has been hinted that children of families where one of the partners is disabled may have more mature personalities and closer relationships to their parents than other children. It has been established that children are not affected by the presence of a disabled parent as they are by a disabled sibling. No studies are available on this topic and any conclusions must be based on discussion and theory.

There are three articles dealing with the blind mother and her capacities, as judged by a caseworker, a child of a blind mother and a blind mother herself. They conclude that the blind mother is quite able to handle all situations and to be a competent mother. But these are descriptive accounts rather then empirical studies.

DEPENDENCY AND LONG TERM CARE

Very little of the research deals with the issue of whether or not the family provides the best living situation for the disabled individual. Generally it seems to be assumed that relationships should be worked out within the family, which appears at present to be a main resource for care of the handicapped. Yet it may not be best for some disabled to live with families.

We refer to long-term care as care provided the most severely handicapped over a period longer than 6 months, in which some degree of supervision is required. This distinguishes the need for long-term care from chronic illness and severe handicap by virtue of the requirement for supervision. A paraplegic may have long-term medical needs, may require periodic counseling throughout life, or may require periodic assistance in mobility or housing relocation but may not be basically in need of supervision. A severely retarded person, a chronic schizophrenic, a senile elderly person, all may not have physical impairments as extensive as the paraplegic but may require care and supervision.

Most of the institutionalized population, especially those in nursing homes, psychiatric facilities, and retardation institutions are the long-term care targets. Some studies have suggested that many of these persons could be placed in community settings or group care settings with less expensive medical and other specialized components. For the most part, these alternative settings do not exist. Many of the financial incentives for these settings are inferior to the incentives for, say, nursing homes, which are reimbursed under Medicaid. In the long-term care area there is movement to expand home care options as a hoped-for offset to the growing expenditures in long-term care, especially in nursing homes. Our analysis suggests that while such expansion is desirable, it is not likely to bring about savings in public funds.

There are studies which purport to show that many persons in institutions are there "inappropriately," a term which seems to mean that they could be in some other level of care. These studies do not show the extent to which there are persons in the community who need or could use some level of in-home services. Studies conducted by the Urban Institute into the matter indicate that persons in the community now have their care needs met, if at all, solely from informal means, often from non-family members who provide the care, such as it is, without payment.

For the most part, vocational rehabilitation has not had a role in providing for persons in need of long-term care, owing largely to the limited employment potential of those persons. Some studies have, however, suggested that rehabilitation could have a major impact on the population in need of long-term care.

In 1962 the New Jersey Rehabilitation Commission developed a year demonstration project in Essex County providing rehabilitation services to vocationally infeasible clients in two rehabilitation centers and in two nursing homes.[25] The sample included hemiplegics, paraplegics and quadriplegics, amputees, and persons with multiple sclerosis, whose average age was 60.1 years. Of these served, 22 went to Vocational Rehabilitation, 56 achieved independent living status, 11 died, 18 were unable to achieve independent living, and 2 were still in process at the end of the program. A summary of the cases and outcomes is given below.

1. Mrs. R. had been in a nursing home since 1963 with a diagnosis of a fractured hip. In October 1966, the Independent Living Rehabilitation (ILR) Project bought two pairs of shoes with uplifts at a cost of $108. She was moved to a boarding home. This had resulted in a saving to the welfare board of $204 a month. The nursing home records do not record at what point these shoes might have served the same purpose as they are now serving with the resultant savings.

2. Mr. W. a left hemiplegia in a nursing home since 1966, was sent to a rehabilitation center for 6 weeks in February 1967 and discharged from there directly to a boarding home. The cost to the Commission was $1,823. The savings since 1967 are at the rate of $204 a month.

3. Mr. D. had been in a nursing home since March 1965 with diagnosis of cerebral vascular accident. When he was picked up for service, he received 6 weeks of outpatient service in a rehabilitation center, then moved to a boarding home. The total cost to the project was $399, and the savings are at the rate of $204 a month.

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[25] Beatrice Holderman, The Development and Administration of an Independent Living Rehabilitation Program, 1962-1967 (DHEW, 1968).

4. Mrs. R. a 52-year-old woman had been in the City Nursing Home since March 1964 with a diagnosed disability of a bilateral amputation due to diabetic gangrene. Counselor learned that a sister would be able to take her home if she could be independent. Mrs. R. was taught to give herself insulin shots, and a wheelchair was provided. No cost was involved because the wheelchair had been returned to the project due to the death of another client.

Mrs. R. was trained in the nursing home in the use of the wheelchair and was released to her sister's home. She has been there since March 1966. The cost to the project was nil and savings to the welfare board were at the rate of $175 a month.

5. Mr. V., a 40-year-old man was in a nursing home for 6 months in the latter part of 1965 with a bilateral amputation due to frostbite. He was not accepted for VR due to a questionable vocational goal. A prosthesis was provided at a cost of $320, and the man was discharged to a boarding home, with a savings of $175 a month to the welfare board.

A 1975 Massachusetts study of Community-Based Maintenance Care for the Long-Term Care Patient[26] reported on 201 elderly and disabled persons admitted to four cooperating medical institutions. Barthel scores were calculated at admission, discharge, and at two-week followup intervals for three months. The mean age of discharged patients was 70; one-third were married at time of admission. Almost half had neurological impairments. The admission Barthel was a good predictor of discharge status to community or nursing.

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[26] G. Eggert, C. Granger, R. Morris and S. Pendleton, "Tri-State Regional Medical Program," mimeo, January 1975.

The single measure which strongly predicted measure of discharge status was family support, which alone accounted for 65 percent of the variation in discharge status. They used a four-point scale to register family support: Intact, Limited (unwilling to help 24 hours a day), Helper Needed (other than family member required) or Null (family unable to cope or no family).

Self-care ability was the second strongest variable, and financial status was third. Other variables contributed little to the outcome. It is enhancement in self-care status that rehabilitation can most influence both in medical institutions and in the community. Services in this regard are Activities of Daily Living Services or Personal Care Services. These include: help in bathing, dressing, toileting, housekeeping, transportation (escort), shopping and the like. In 64 of 69 cases, the family provided the services, whereas only 11 cases had community agencies and 2 had them provided by non-relatives. The community simply was not providing the services. The reason was probably lack of funding. Over the followup period, about two-thirds of the discharge community patients used the services. Medical/professional services were less used. Household services average 16.8 hours per week for an average cost of care of $72 per week.

The mean time per patient for all personnel--doctors, social workers, etc.--was 6.4 hours and ranged from 0.8 to 28.5 hours. At this average, it seems fewer persons could be sent to nursing homes for about 2 days of homemakers per week and 6 hours of planning at the hospital--if funds and services are available.

One of the primary problems with the allocation of long-term care is the lack of a gate-keeping mechanism other than physician prescription and eligibility for the Medicaid program. Dunlop has estimated that a significant portion of the persons receiving long-term care need to change care settings to match their needs, but few are without need for some level of care.[27] A few in institutions could be at home, and a few at home should be in institutions. Speaking only about the elderly, about 25 percent need some level of long-term care (5 million) but 1.7 million are receiving adequate informal care. Of this 3.3 million, 1.3 million require nursing and other supportive services at home, 1.2 million would be in congregate facilities, about a half-million need nursing care, and 60,000 would require intensive nursing care.

To a large measure, social rather than purely medical needs determine utilization of formal long-term care. In one study, only about one-third of the nursing home population of persons over 80 were admitted for purely medical reasons. One of the key determinants of staying out of an institution is the presence of a family member willing and able to provide care. The bulk of those in nursing homes are without family, and usually without financial resources.

This suggests a role for Vocational Rehabilitation in an independent living program which could be tied to developments in Medicaid or Health Insurance. A rehabilitation role which could be modeled after the SSI and beneficiary programs would permit adequate funding of services to keep persons in the least intensive settings appropriate through rehabilitation services and screening. For the young in such facilities, promise of eventually becoming more self-sufficient could be offered. For the very old, some ability to live in more homelike settings might be possible. If expansion of VR into only one area were to be the effort, this should be a key option.

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[27] B. Dunlop, "Long-Term Care: Need Versus Utilization," Working Paper 975-05, The Urban Institute, Washington, 1975.

Chapter 10

ARCHITECTURAL BARRIERS

One of the greatest concerns of disabled persons is getting from one place to another. Without the ability to get from Point A to Point B, the individual may be left in an unsatisfactory situation, may lack needed assistance, or even be left in danger, which could have been prevented had the barriers not been present. When bathrooms are too narrow for persons in wheelchairs, or flights of steps are not negotiable, or access to public transportation is impossible because of the distance from the ground to the vehicle, the impaired person is faced with humiliation, frustration and, often, reduced opportunities for gainful employment or independent living.

Some barriers faced by the impaired suggest the barriers faced by us all. In testimony before the Senate Committee on Aging, witness after witness pointed out that design features which hamper a person in a wheelchair also hamper children, pregnant women, and persons carrying packages or pushing carriages. Examples of common barriers not obvious to able-bodied adults who can readily negotiate them are drinking fountains and telephones too high for the handicapped to reach, curbs where ramps would do, and steps which limit access to public buildings for many of the handicapped.

In a 1971 conference on the disabled held in Scotland, one British architect and city planner made the observation that virtually every building with a life expectancy of 30 to 40 years will be occupied a considerable portion of the time by a person with a mobility limitation. While this was obvious once said, it brought a shock of recognition to the conference. Most architectural barriers surround our environment because the design professions incorrectly assume that everyone is able-bodied, and that their design criteria suit the bulk of the population.

Types of Barriers

Architectural barriers can be described as those which impede mobility or activity in the residence and living space, the work space, and public places, including recreational areas. Barriers in the home are often severe impediments for the handicapped.

Consider, for example, a newly handicapped paraplegic or a person returning home from a severe coronary episode. Stairs suddenly become an insurmountable problem. The bathroom door is likely to be too narrow to get a wheelchair through. The cherished front porch now needs a ramp. The stove and sink are too high to reach. The remedies will require remodeling of the home or relocation of the family to another setting.

Work place barriers are similar, but the problems are compounded by the effect modifications may have on other workers and the question of who should pay for changes. Public places are often inaccessible to the handicapped because of stairs. Recreational areas are often without guides for the blind or without proper pathways for persons in wheelchairs.

Local governments have made very limited efforts to eliminate architectural barriers in public buildings and facilities. In fact, the great majority of the Nation's cities have not initiated any programs designed to eliminate these barriers to the handicapped. Lack of apparent need is the primary reason given by about 40 percent of the city officials and 30 percent of the county officials for the absence of programs designed to make public buildings accessible to and usable by the physically handicapped.[1] The second most frequently

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[1] M. Baker, M. A. Fischetti, L. A. Williams and E. M. Young, State and Local Efforts to Eliminate Architectural Barriers to the Handicapped, (Washington: National League of Cities, Department of Urban Studies, 1974), p. 2. In response to questionnaires sent to 379 cities and towns and to 272 counties, only 95 cities and 42 counties reported local efforts to eliminate barriers.

given reason is "the absence of a legal requirement."[2] It may be that the majority of the people in this country are *aware of*, but not particularly *concerned about*, the problem of architectural barriers to the handicapped.

Effects of Barriers

Besides being completely barred from many activities they could otherwise engage in, the disabled are constantly frustrated by a myriad of inconveniences: telephones and water fountains that are just out of reach, and too-narrow aisles in theaters, stadiums, restaurants, and other public gathering places. Architectural barriers, then, affect all aspects of living and all ages of the severely handicapped, as the following examples illustrate:[3]

- Kitchen equipment which makes it difficult and sometimes impossible for handicapped persons to carry out their homemaking responsibilities.
- The thoughtlessly designed school and playground which make it necessary for the handicapped young to be educated separately and lose contact with their nonhandicapped friends.
- Steps which prevent the arthritic old woman from going to her church for the spiritual and social satisfaction it gave her when she was able-bodied.

Our survey of individuals rejected from Vocational Rehabilitation because of the severity of their handicap showed that 10.5 percent moved to another house or apartment so that they could get around better. Indeed, architectural barriers can make the severely handicapped prisoners in their own homes. This point is

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[2] *Ibid.*

[3] National Citizens Conference on Rehabilitation of the Disabled and Disadvantaged, U.S. Department of Health, Education, and Welfare, Social and Rehabilitation Service, Washington, D.C.

made clear by Table 10-1, which lists the kinds of things which are difficult or impossible for the severely handicapped individual because of such barriers. One hundred forty-three individuals reported house barriers in the survey. Table 10-1 gives the number and percent of that total with specific house barrier problems.

Table 10-1

Problems Caused by House Barriers, VR Sample[1]

Problem	Number of Responses	Percent
Getting in or out of residence	65	45.4
Moving from room to room	59	41.2
Getting from door to street	66	46.1
Doing homemaking activities	41	28.6
Bathing	45	31.4
Toilet	30	25.8
Grooming	25	17.4
Other	19	13.2

1. Percentage totals exceed 100 percent because clients may deal with more than one barrier.

The first point that Table 10-1 illustrates is the wide range of problems caused by house barriers--from moving between rooms to grooming. The most frequently cited were getting from door to street (46 percent), followed by getting in or out of residence (45 percent), and moving from room to room (41 percent). After these problems, a number of others related to carrying out the activities of daily living (e.g., homemaking, bathing) are closely bunched together.

According to the survey results, 16 percent of the sample currently has difficulty in living in or getting around their residence because of architectural barriers such as stairs and narrow doorways. The reasons these barriers have not been removed are listed in Table 10-2.

Table 10-2

Reasons Why Barriers Were Not Removed, VR Sample[1]

Reason	Number of Responses	Percent 2/
Problem developed only recently	1	0.6
Cost of changes too high	87	60.0
Agency refused to pay for changes	3	2.0
Do not know how or where to get help	11	7.0
Project (changes) too large	36	25.0
Haven't gotten around to it	2	1.3
Problems are minor	14	9.7
Other	38	26.5
Don't know	1	0.6

1. For similar information on the CMRC population, see chapter on that survey.
2. Percentage totals exceed 100 percent because clients may have cited more than one reason.

Other reasons cited which are generally cost-related include "project or changes are too large" (25 percent) and "agency refused to pay for changes" (2 percent). Reasons other than costs included lack of knowledge as to how or where to get help (7 percent), and that the problem was minor (10 percent).

Those individuals who reported moving in order to escape from residential barriers cited several types of facilities in the new residence which reduced barriers.

Table 10-3

Facilities of New Residence Which Removed Barriers, VR Sample Who Moved to Escape Barriers 1/

Facilities	Number of Responses	Percent
Elevators	13	13.9
Ramps	11	11.8
On ground floor, no stairs	71	76.0
Wider doorways	29	31.0
Needed appliances present (washer, dryer, disposal, etc.)	16	17.2
Other	24	25.8

1. Percentage totals may exceed 100 percent because clients' residences may have removed more than one barrier.

As Table 10-3 indicates, 76 percent of those who moved had a new living arrangement which was without stairs or on the ground floor of their new home. This factor was far and away the leading variable. The next most frequent single factor cited was wider doorways (31 percent), followed by appliances (17 percent) and elevators (14 percent).

Our survey of providers of rehabilitation services asked that sample to indicate the extent of their agreement that certain services would effectively assist the severely handicapped in a rehabilitation for independent living program. Almost all of these providers (96 percent) agreed that home modifications would be important. However, only 5 percent of such respondents were actually engaged in providing home modification services. In the same survey, 89 percent of the rehabilitation providers agreed that "lack of barrier-free housing" was a significant problem for the severely handicapped. Only two other problems on the list of potential impediments were agreed to by a higher percentage of providers. Interestingly, both of those were also barrier problems--"lack of barrier-free employment settings" (90 percent) and "lack of usable transportation" (93 percent).

Standards to Eliminate Barriers

In 1958, an ad hoc group of the President's Committee on Employment of the Handicapped (PCEH), with the help of the Veterans Administration, drafted a guide on facilities needed to enable the handicapped to enter and use public buildings. The U.S. Department of Labor printed this guide and sent copies to all State employment agencies. A year later a special Committee of the American National Standards Institute (ANSI), sponsored by the PCEH and the National Easter Seal Society for Crippled Children and Adults, called a national conference of professions, trade associations, and other organizations concerned with the problem to meet with the Federal Government.

As an outcome of this conference and research at the University of Illinois ANSI in 1961 published Making Buildings and Facilities Accessible to and Usable by the Physically Handicapped.[4] This standard specifies the minimum requirements and working details for features such as walkways, parking spaces, ramps, stairs, floor surfacing, mirrors, water fountains, public telephones, control identification, and warning signals.[5]

According to a report by the National Commission on Architectural Barriers to Rehabilitation of the Handicapped (NCAB) to the Secretary of Health, Education and Welfare in 1967, "...the Commission, in common with other authorities who have studied and used the standards, has found that compliance with the standards is neither excessively demanding nor costly."[6]

According to the NCAB, as of 1967 "...44 States have taken some kind of formal or legal action requiring that public buildings (and in a few cases private ones as well) be made accessible to the whole public. Action to eliminate architectural barriers is also reported by 95 cities with population of 50,000 and over and by 42 metropolitan counties."[7]

A 1967 study of architects revealed that 60 percent were familiar with the term "architectural barriers," 65 percent were not familiar with ANSI specifications,

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[4] American National Standards Institute, American National Standad Specifications to Make Buildings and Facilities Accessible to and Usable by the Physically Handicapped (New York: The Institute, 1961).

[5] A broad updated review on the subject of removing architectural barriers, including 40 selected bibliographies, is one prepared by R. Lauder, The Goal is Mobility (DHEW, 1969). The Department of Housing and Urban Development also has studied the subject and provided guidelines using many of the same criteria as the ANSI for design of barrier-free housing and rehabilitation facilities. For example, Housing for the Physically Impaired: A Guide for Planning and Design, (DHUD, 1968); and T. K. FitzPatrick, Selected Rehabilitation Facilities in the United States (DHEW, 1971).

[6] Design for All Americans, a report of the National Commission on Architectural Barriers to Rehabilitation of the Handicapped (DHEW, 1968), p.9.

[7] Ibid., p. 5.

and 66 percent were not aware of the legal requirements of their State and local governments to provide accessibility to the handicapped.[8]

As of 1967, 3 percent of 278 cities and 4 percent of 124 counties surveyed in the United States had adopted or developed building codes to meet the requirements for a barrier-free environment.[9]

The NCAB found that even at the Federal level, where requirements are specified and construction grants for making buildings accessible for all people exist, "...new buildings continue to be constructed with unnecessary barriers, and too many renovations of existing buildings leave many barriers untouched." Out of 5,000 buildings owned by the Federal Government, only 71 were free of barriers in the period January 1966 to June 1967.[10]

Laws Against Barriers

Even though, as of 1967, almost all States had passed laws or taken official action with respect to removal of barriers, the Commission found their action to be "both vague and weak." Only six States specified what they meant by accessibility, and only nine had enforcement provisions. In three States the law applied only to State-owned buildings, and in almost all cases the law applied only to new publicly owned structures. Only in three States did the law apply to those privately constructed.[11]

Public Law 90-480, the Architectural Barriers Act of 1968, requires that all Federal structures as well as those financially assisted with Federal funds be made accessible to the handicapped. The law also stipulates that when public structures undergo extensive alterations, the elimination of barriers shall

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[8] *Ibid.*, p. 40.
[9] *Ibid.*
[10] *Ibid.*, p. 9.
[11] *Ibid.*, p. 9.

be included as part of the work. Among the barriers to be modified are stairs, elevator buttons, narrow doorways, revolving doors, inadequate restroom facilities, and location of telephones and water fountains.

The provisions of P.L. 90-480 as amended by P.L. 91-205, appear to be weakly enforced partly because some of its language permits large loopholes. In addition, the law is primarily relevant to Federal buildings, while the bulk of public buildings are State and local structures. However, it is now generally recognized that the biggest problem area with respect to architectural barrier laws is that of compliance.

Section 502 of the Rehabilitation Act of 1973 created the Architectural and Transportation Barriers Compliance Board. A major purpose of the Board is to ensure compliance with Public Laws mandating accessibility and usability of the man-made environment by the handicapped and elderly. Many of the handicapped look to the Board with great expectation that its potential for enforcement of compliance requirements will be fulfilled. As of this writing it is difficult to measure the impact of the Board in preventing barriers, given its lack of sanctioning authority, and funding and staff limitations.

In the early 1960s, HEW funded two surveys to determine the degree to which public buildings are accessible and usable. The first project was undertaken by the Minnesota Society for Crippled Children and Adults, which surveyed 483 public buildings of a number of types to ascertain the incidence of various kinds of architectural barriers. The National Society then applied for and received a grant to conduct a similar survey on a national scale, which ultimately covered 5,010 buildings falling into 14 categories.[12] The Minnesota study concludes

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[12] Governmental, office, industrial, restaurant, travel facility, merchandising, service, hotel and motel, apartment, religious, educational, health and medicine, cultural, and recreational and sports.

that architectural barriers are so self-evident that statistical documentation of the problem is for the most part superfluous.[13]

To our knowledge there has only been one study in which recently constructed buildings were actually surveyed to determine how well they complied with applicable architectural barrier laws. This study, titled Accessibility -- The Law and The Reality,[14] was conducted as a joint venture by the Easter Seal Society for Crippled Children and Adults of Iowa, the Iowa Governor's Committee on Employment, and the Iowa Chapter of the American Institute of Architects. Teams consisting of an architect, a person in a wheelchair, and a recorder surveyed 34 buildings built since 1968 which were financed at least in part with Federal funds and thus were covered by the provisions of P.L. 90-480.

The survey found that while some of the standards (such as the one setting minimum door widths) were virtually always complied with, there was a substantial degree of noncompliance with others; more than a third of the buildings surveyed did not have accessible drinking fountains, for example. In summary, "although there have been great improvements made as a result of the law, too many deficiencies were noted to judge the majority of projects built under the law fully accessible."[15]

Need to Improve Standards

The Iowa study found that the fact that many of the buildings surveyed were not fully accessible was due not only to noncompliance with the standards of accessibility but also to inadequacies in the ANSI standards themselves

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[13] A survey is now being conducted by the Center for Handicapped Children and the Public Interest Research Group in the District of Columbia to determine which public buildings may present architectural barriers to handicapped visitors during the Bicentennial events of 1976.

[14] Accessibility--The Law and the Reality (The Easter Seal Society for Crippled Children and Adults of Iowa, Inc., The Iowa Governor's Committee on Employment, and The Iowa Chapter of the American Institute of Architects, 1974).

[15] Ibid., p. 15.

The Federal standards under discussion are virtually identical to the American National Standards Specifications for Making Buildings and Facilities Accessible to, and Usable by, the Physically Handicapped, so this finding is of profound significance in view of the enormous weight given to these specifications in the architectural barrier field. Some of the omissions and deficiencies reported in the Iowa study are the following:

- The section on doors does not set a limit on the force required to open a door (the phrase "operable by a single effort" is used, but what this means is unclear), nor does it set minimums for clearances between doors that are in series, as in the entrance to a restroom.
- The standards relating to elevators are vague and ambiguous; minimum platform dimensions are not set forth (except perhaps inferentially); and no mention is made of the location of controls.
- The toilet room specifications are inadequate in several respects.
- No mention is made of measures to accommodate wheelchairs in places of assembly.
- Discussion of wheelchair curb ramps is relegated to a rather hard-to-understand footnote.

A more fundamental criticism is leveled at the American Standard Specifications by Selwyn Goldsmith, who contends that they are oriented primarily to the needs of independent wheelchair users, sometimes to the disadvantage of those who need assistance. He suggests that this is related to the fact that independent wheelchair users are more likely to be able to contribute materially to society.

What appears called for, however, is a thorough reevaluation and revision of the American Standard Specifications. Such a project, funded by the Department of Housing and Urban Development, is presently under way at Syracuse University under the direction of Dr. Edward Steinfeld.

Costs of Removing Barriers

While there may be some question as to the need for further evidence of the extent of the architectural barrier problem, there can be little doubt of the need for information about the costs of remedying the problem, particularly in view of the widespread misconception that the elimination of architectural barriers adds substantially to a building's cost. One of the few sources of such information is an unpublished report, "Preparing Higher Education Facilities for Handicapped Students,"[16] which gives is an account of the establishment of the University of Missouri as a regional university facility for the handicapped.

This process included the modification of administrative procedures and the establishment of several special services, but most relevant to our purpose here is the section describing the comprehensive program of structural modifications undertaken to make the campus and its buildings accessible. Many of these modifications--including curb cuts, ramps, elevators, and modifications of doorways, restrooms, and drinking fountains--are discussed in detail, with cost figures given. With few exceptions,[17] the cost of these modifications is shown to be comparatively insignificant.

As we shall discuss in detail in the chapter reporting results of the survey of rehabilitation service providers, some agencies already are offering services to assist individuals with correctives to barriers in their homes and in their work place. The Massachusetts State VR agency is also performing in an advocacy role in working with housing authorities and has supported State legislation for barrier free housing. The agency is represented on the State

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16. Produced under a grant from the U.S. Office of Education.

17. The exceptions were situations necessitating substantial changes in levels, and thus requiring an elevator or a very long ramp, either of which--an elevator especially--entails considerable expense.

Architectural Barriers Board and seeks to strengthen enforcement for all new construction. Through its own requirement that any facility leased by VR or utilizing VR funds must be barrier-free, some further gains are made. It is largely undocumented, but there are stories of VR agencies in buildings inaccessible to those in wheelchairs.

It would be of help to many severely disabled individuals to have a local program giving information on how modifications could be made and on types of devices which assist in performing various household functions. Such a program could include assistance in finding barrier-free housing. Since the bulk of the costs of architectural modifications is now absorbed by individuals or famililies, many in the low income brackets, some sort of financial assistance should also be considered.

On the broader level, greater enforcement of existing standards for a barrier free environment would do much to assist the most severely handicapped. Without accessible homes, offices, and public buildings and areas, the probability of entry to the programs of rehabilitation envisioned in Section 130 will be low.

Chapter 11

GEOGRAPHIC MOBILITY OF THE HANDICAPPED

Geographic mobility, the ability to move one's place of residence to somewhere beyond a given labor market, is often necessary to gain access to specialized jobs and educational opportunities, to escape labor surplus areas, to move along the career ladders of large organizations, or to meet a variety of personal and family needs. Inability to move, especially at the age of career development and family formation, can drastically restrict one's life opportunities. Thus there is an increasing recognition of the social value of relocation assistance. The United States is now the only major Western nation that does not use some form of relocation assistance to alleviate regional unemployment.[1]

Many individuals who are most severely handicapped have additional reasons to move. They may require or might benefit from conditions which exist in only a few locations, such as special medical, therapeutic, or educational services, sheltered workshops, and jobs or schools suited to their individual qualifications and disabilities. They may seek a supportive social situation and a safer, more accessible physical environment with such aids to independent living as are being created by and for the physically handicapped in cities such as Berkeley, California.

The success of such efforts has depended in part upon the relocation of handicapped people into the area, spontaneously or with the assistance of university services and private organizations. Success also requires building a critical mass to support the emergence of leadership, the demonstration of new approaches, and the building of public acceptance of the severely handicapped in daily life.

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[1] Peter A. Morrison et al., Review of Federal Programs to Alleviate Rural Deprivation, RAND Publication No. R-1651-CF (RAND, 1974), p. 32.

Of the individuals in our survey of persons rejected by the VR program, 7.8 percent had moved to another area because of family assistance services available there, or because they felt they could live there more independently than at home. The main reasons why these individuals moved are listed in Table 11-1.

Table 11-1

Reason for Moving, VR Sample

Reason	Number	Percent
Rehabilitation service more available	13	18.5
Transportation system more accessible	2	2.9
Subsidies and benefits better	2	2.9
Climate more suitable	5	7.1
Jobs more available	6	8.5
Family assistance available	24	34.3
Desire to be away from family	2	2.9
Other	16	22.9
Total	70	100.0

As Table 11-1 indicates, the major reason for moving, cited by a third of the sample, was assistance from family members, such as parents, adult children, and other relatives. Another principal reason, cited by nearly one-fifth of the sample, was the availability of rehabilitation services. A number of other reasons are closely bunched at the lower end of the spectrum.

Sampled individuals who had not moved were also asked whether they could deal more effectively with their handicap in some other geographic location. To that question, 13.2 percent responded affirmately. The major benefit they anticipated was a more suitable climate (e.g., one easing their disability), and better transportation and rehabilitation services. Although they realized the benefits they would gain from such a move, they had not moved for a variety of reasons, which can be found in Table 11-2.

Table 11-2

Reasons for Not Moving, VR Sample

Reason	Number	Percent
Needed physical assistance to relocate	1	.8
Cost of moving too high	46	36.8
Cost of living too high in new location	14	11.2
Too difficult to make arrangements for moving, jobs, etc.	12	9.6
Don't know people in new location	6	4.8
Good job in present location	3	2.4
Other	41	32.8
Don't know	2	1.6
TOTAL	125	100.0

The most frequently mentioned reason for not moving, cited by more than a third of those who would like to move, was the cost involved. Other important reasons frequently cited were the cost of living in the new area (11.2 percent) and difficulty in making housing and job arrangements (9.6 percent).

One probable result of increased mobility by the severely handicapped would be to increase their number in a few densely populated areas. Such relocation could permit economies of scale in providing services to groups of the handicapped. Theoretically, the unit costs of urban services are expected to rise at very small scales of operation, where the minimum viable facilities and staff are not fully utilized, and at very large scales, where internal coordination becomes more costly. Most empirical studies have confirmed the existence of diseconomies at very small scale, the minimum efficient size varying widely by type of service, but some have found nearly constant costs in the higher scale services.[2]

Another kind of scale economy must also be considered in cases of this kind: the economies are related to the size and complexity of the city or

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[2] Werner Z. Hirsch, "The Supply of Urban Public Services," in Harvey S. Perloff and Lowden Wingo, Jr., <u>Issues in Urban Economics</u> (John's Hopkins Press, 1968), pp. 477-525.

metropolitan area in which the service operates. Berkeley's Center for Independent Living (CIL)[3] for example, which operates as a sheltered workshop and referral center in the San Francisco-Oakland metropolitan area, benefits strongly from the existence of such services as Neighborhood Legal Assistance, the manufacture, sales, and repair of orthopedic supplies, a pool of potential attendants and readers, a university, and the regional headquarters of various agencies and service organizations where client requests are presented.

In a smaller or regionally less significant metropolitan area, many of these features would have to be provided internally at considerable cost or would simply be unavailable. The availability of these types of external economies is reasonably well assured in the Nation's six metropolitan areas with 3 million or more population (the size of the San Francisco-Oakland area in which CIL is located), plus a half dozen or so which are somewhat smaller but regionally important enough to support such organizations with some nonlocal assistance.

Only 25 percent of the noninstitutional disabled population aged 16-64 live in these six areas at present, slightly less than the areas' share of total population.[4] It might well prove possible to provide similar services economically in smaller areas, but we have no evidence one way or the other.

Mobility of the Severely Handicapped

Relatively little is known about the specific patterns of mobility behavior of the severely handicapped, although it can be inferred from our survey that

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[3] The Center for Independent Living (CIL) in Berkeley, California presently operates at a level of about $300,000 per year, serving about 1,000 clients out of an estimate 30,000 disabled or blind in its target area; CIL has limited its target area to a compact area containing only about one-tenth of the Bay Area population, because of its desire to retain close personal contacts and user control of its services (The Independent, 2:1, p.3). CIL is large enough to support a number of specialties.

[4] Transportation System Center, The Handicapped Elderly Market for Urban Mass Transit: Technical Report, report to the U.S. Department of Transportation Urban Mass Transit Administration (1973), p. 23.

their residential mobility is considerably less than that of the general population. Low mobility may be inferred, a priori, from the deterrents to mobility inherent in their demographic characteristics and particular handicaps.

Geographic mobility is very unevenly distributed in the general American population. The 1-year rate of migration between counties stays between 6-1/2 and 7 percent of the total population year after year, but age-specific rates peak sharply (near 20 percent at age 22), with small rises in early childhood and at retirement age. The well-educated, the affluent, and those with few or no family ties are much more mobile than others.[5]

Individuals who are severely handicapped by virtue of also being typically old, poor, and dependent are predisposed to low average mobility. Also, the handicapped persons interviewed stressed the homebound lives led by most of the severely handicapped and the many social and physical deterrents to relocation they have faced.

Some information on the mobility of the disabled has been gained from a related study by The Urban Institute concerning the outmigration[6] of heads of families containing disabled individuals aged 18 to 64.[7] Of this population, 5.1 percent of the heads of families containing disabled individuals outmigrated, as opposed to an 8.4 percent rate for the general population of family heads. Other findings from the study indicated that the probability that the head of a family with a disabled member will migrate decreases as his age increases; that

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[5] Edgar Rust, Metropolitan Areas Without Growth, a report to the U.S. Dept. of Health, Education, and Welfare, Population Research Center (DHEW, 1974).

[6] Outmigration refers to the gross geographic movement out of specific States. An "outmigrant" from a State is a person who resided in that State in 1965 and in a different State in 1970.

[7] Not all individuals in the study were family members. Those who were not--unrelated individuals or individuals in group quarters--were considered to be family heads even though the family consisted of only one person. The disabled population in this study consisted of persons who reported a partial or complete work disability and who had been disabled for five years.

women are less likely to migrate than men; and that blacks are less likely to migrate than nonblacks. In addition, it was found that the probability of outmigration increases with the educational level of the family head, most dramatically when the head has completed some post-graduate education. Other findings indicated that those who own their own homes are less likely to outmigrate than nonowners with the same sociodemographic characteristics. The presence of school-aged children was found to be negatively associated with outmigration. Also, it was found that being in the most highly skilled occupations had a positive effect on outmigration and that those who were self-employed were less likely to migrate than those who were not.

The foregoing observations imply that any efforts to enhance the mobility of the most severely handicapped are likely to appeal most to certain subgroups: the better educated, especially those in their early twenties and those without (or willing to leave) family ties, those of retirement age with substantial assets or pensions, and young children who are themselves severely handicapped or are dependents of handicapped persons. These subgroups are the ones who would be most likely to move spontaneously if they were not handicapped.[8]

If the severely handicapped of each age group were to move at the average rate for that age, about 266,000 or roughly 2.6 percent of the noninstitutionalized severely disabled would move between counties each year.[9] The present

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8. Rust, Metropolitan Areas.

9. Age-specific mobility rates estimated by Long (Larry H. Long, "New Estimates of Migration: Expectancies in the United States," Journal of American Statistics Association, March 1973) were applied to the age distribution of the noninstitutional severely disabled as estimated by Lawrence D. Haber and Philip Frohlich, The Severely Disabled in the Institutionalized and Noninstitutionalized Population, 1966, Report No. 14, Social Security Survey of the Disabled: 1966 (DHEW, 1970). Haber and Frohlich provided data only for persons aged 18-64. Estimates of the severely disabled population 17 and under (100,000) and 65 and over (3 million) are from Todd H. Everett and Frederick Collignon, Cost and Policy Considerations in Improving the Capacity for Independent Living of the Most Severely Handicapped (Berkeley Planning Associates, 1975), Table A, p. 5.

mobility of the severely handicapped is not likely to exceed half that rate.[10] Thus, the potential for additional migration resulting from mobility norms will be on the order of 1.3 percent of the target handicapped population in the area, or 133,000 per year nationally.

Relocation Assistance

Hansen has reviewed the experience of relocation assistance programs.[11] One of the more relevant programs for the severely handicapped was operated by the Travelers Aid Association, a private organization which provided, on a contract basis, counseling and screening services to some of the Manpower Development and Training Act (MDTA) projects of the U.S. Department of Labor.

Hansen found that hiring interviews by recruiters from private firms at destination were the most effective inducement to move. He states, however, that the following additional services were needed:

- -- prelocation counseling
- -- assistance in obtaining housing
- -- orientation at destination
- -- health aid
- -- financial counseling
- -- help in obtaining transportation, clothing, furniture
- -- help in preparing applications for employment, school, public assistance, etc.

Hansen contrasted the American MDTA "demonstrations" with the extensive labor relocation program in Sweden, which provides for the following:

- -- travel and moving expense and packing

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[10] Analysis of special Census tabulations of 1965-1970 migration of handicapped persons, when available, may considerably refine these estimates.

[11] Niles B. Hansen, Urban and Regional Dimensions of Manpower Policy (U.S. Department of Labor, Manpower Administration, 1969), pp. 398-424.

-- family allowances

-- starting allowances

-- second household cost

-- special payments for leaving lagging region

-- aid to visit destination area, find job and housing, return for family.

A most striking feature of prior programs has been their political unpopularity. MDTA funded a number of "experimental" relocation assistance programs for unemployed workers in 18 States during the period 1965-67, none of which were funded again. As Mangum points out, legislators have been exceedingly "reluctant to authorize public spending to move their constituents to other districts," and responses of the sending communities, employers, and even Community Action Program agencies were downright hostile.[12]

Services to Assist in Relocation

Many of these observations from prior experiences of other groups and programs apply to the severely handicapped who are potentially mobile. Like other potential movers, they are unlikely to be aware of many potential destinations, and having learned of one that is satisfactory, most may be uninterested in further search. Information is likely to be sought from credible firsthand sources rather than from published material. Prearrangement of a job or other income source will be important. Their special disabilities may prevent them from driving a personal car, which will be a substantial barrier both to exploring possible destinations and executing the move unless special assistance can be arranged. Short moves will probably be the most numerous.

In making a major geographic relocation, severely handicapped persons may require assistance in order to:

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[12] Garth L. Mangum, "Moving Workers to Jobs: An Evaluation of the Worker Mobility Demonstration Program," Poverty and Human Resources Abstracts, Trend Supplement, December 1969, p. 12.

1. Learn of one or more possible destinations.
2. Gather the following general information on the destination and establish feasibility:
   - -- sources of income
   - -- suitable housing
   - -- attendant, guide, or interpreter services
   - -- medical and health services
   - -- equipment supply and maintenance
   - -- specific friends
   - -- other people with similar handicap
   - -- community acceptance of the handicapped
   - -- advocacy organizations
   - -- recreation
   - -- local mobility (see transportation chapter)
   - -- climate
3. Make one or more exploratory visits.
4. Gather the following information on the moving process:
   - -- disposal of present housing if owned or leased
   - -- transportation of belongings
   - -- access to terminals and transfer between modes of travel (physical or operational barriers may exist)
   - -- acceptance by carriers (some are reluctant to transport the severely handicapped)
   - -- length of trip, physical comfort
   - -- services en route if needed
   - -- provision for emergency care
   - -- schedule
   - -- cost

5. Arrange financing and make specific arrangements for the move (disposing of present housing, acquiring new housing, travel reservations, etc.). Note that in many cases attendants, emergency care, and housing absolutely must be arranged in advance of move.

6. Execute move (attendant, guide or interpreter may be needed en route).

7. Obtain orientation in new area. (In many cases help will be needed for physical pathfinding, establishing sources of daily needs, and making social contacts.)

8. Furnish and equip new residence.

Costs of Providing Relocation Assistance

A model could be designed to provide information on possible destinations, the moving process, financing and moving arrangements, and other aspects of settling in the new area. Locating such a service in a rehabilitation agency would essentially add some staff costs for dissemination and collection of data on units. If State agencies were the focus of these services, interstate exchange of data could be arranged. Depending on the scope of information collected and demand for use, such a model might cost from $2 to 5 million.

A direct service model could operate where there are a large number of the severely handicapped who would like to relocate or where there is a capacity to provide the wide variety of services desired by these individuals. A hypothetical program would consist of a staff of four to six individuals. The program would be designed to handle several thousand inquiries for relocation, of which 1,000 households would eventually move to the new destination. Flexible combinations of the following services would be offered, depending upon the specific needs and capabilities of individual users:

1. Counseling prospective movers in selecting destination areas, estimating moving costs, etc. (travel agency type of services).

2. Assisting in prearrangements as needed: jobs or other income sources, housing transactions, medical and health services, attendants, guides, interpreters, sources of special equipment, drugs, referrals to sources of aid.

3. Exploratory visits to nearby potential destination areas (in groups where possible; user would provide own meals and 20 percent of fare).
4. Moving allowances for 50 percent of direct costs, such as fares or moving van.
5. Provision as needed of attendant, guide, or interpreter en route, and for emergency medical arrangements.
6. Advocacy of clients' interests with carriers and regulatory agencies.
7. Services after move: assistance as needed in orientation and establishing daily routine.
8. Followup: evaluation of success of relocation or reasons for failure, return, or dropout; identification of difficulties; economic, geographical, and demographic analysis of demand patterns; revision of services provided.

The annual cost of a program with an administrator, three counseling staff, two clerks, moving costs, attendant care, overhead, and the like would run about $700,000.

These costs are comparable with other relocation programs. Mangum[13] gives an average total cost of $700 to $800 per relocation for the 3,800 workers moved under MDTA in 1967. About half was for relocation allowances and half for counseling and administration. The Minneapolis experiment with 80 "hardcore" unemployed achieved 46 stable relocations at a cost of $127,478, or $2,771 per relocatee, although some benefits also went to the 34 nonmovers.[14]

If half the estimated number of severely handicapped needing relocation assistance needed direct services as well as information, the above program could serve an area of about 3 million people. On the same assumption, a national program would handle about 67,000 cases per year at a cost of $46 million.

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[13] Ibid., p. 14.

[14] Jack L. Nichols and Harvey Abrams, The Relocation of the Hard Core Unemployed (Minneapolis Rehabilitation Center, 1968).

Policy Options

One method of improving the geographic mobility of the most severely handicapped would be to establish major pilot projects incorporating both information and direct services. Such projects would contribute in the following ways to any long-term mobility strategy subsequently adopted:

1. They would generate information on patterns of demand, including the aggregate density of response from a pilot area, and the composition of demands for different kinds of services by different users.

2. They would permit the working out of cost-effective methods and procedures suitable for replication and the elimination of costly or unacceptable features.

3. They would generate more accurate cost data.

4. They would generate a trained, experienced group of potential program administrators.

Another option is to extend research into the actual mobility patterns and mobility needs of the severely handicapped. Also needed is a geographic analysis of the accessibility of present and projected services to the national severely handicapped population. Finally, survey information on mobility and locational preferences of the handicapped is needed. This information, when combined with ongoing experience of the pilot program, should provide material for a reasonable legislative debate.

Chapter 12

TRANSPORTATION

As our survey data have shown dramatically, transportation is a vital element in the independence of the severely handicapped. The ability of most severely handicapped persons to get medical care, rehabilitation and other services, education, employment, and recreation depends upon their ability to get from their homes to other places. When, because of their own limitations or obstacles in the transportation environment, they cannot reach those places, their potential for improved functioning is reduced or eliminated. Access to the public transportation systems for those severely handicapped who are mobile has long been denied, more because of the nature of those systems than to the nature of the individual's handicap. Congress recognized the need to improve the mobility of those with limitations when it enacted the Urban Mass Transportation Act, which stated that "...handicapped persons have the same right as other persons to utilize mass transportation facilities and services..."

The transportation problems facing the severely handicapped are extensive, and many remedies go beyond the confines of an individual-oriented service program such as vocational rehabilitation. But because this is one of the basic problem areas, we feel it is important to describe it in some depth and discuss some remedies, even though they may be outside the scope of VR. We will then point out what VR can do.

Definition of Problem

There are several dimensions to defining the transportation needs of the handicapped. The first is the mobility of the individual with respect to being able to move about anywhere. If he or she is mobile enough to leave home, the problem then becomes one of accessibility to transportation facilities. The last dimension of the problem is the ability to negotiate a system for a round trip.

Persons restricted to bed or wheelchair often have no capacity for transportation in the usual sense, other than by ambulance. At one time many persons were in this category. Technological developments that made wheelchairs lighter and more easily operated, followed by the invention of the electric wheelchair, have begun to alter this situation radically. These breakthroughs have changed the nature of who is homebound and has led to new problems of transportation. However, such everyday items as curbs and stairs still are humiliating and often insurmountable obstacles for people in wheelchairs.

Because of physical strength and stamina requirements, persons who use manual wheelchairs are usually limited to short distance travel. Power wheelchairs, while more expensive and requiring more maintenance, can be used for travel of up to several miles. So far as we can estimate, less than 10 percent of the persons using wheelchairs use the powered type. Individuals in manual wheelchairs include people who have no use of their lower extremities, as well as the elderly and others who could use walkers or leg braces but have elected to use wheelchairs because of the lower physical demands, greater functionally utility, and higher comfort.

With the growing number of severely impaired persons now able to leave their homes, the pressure of such barriers as steps to transit stations, gaps between vehicle and platform, narrow doors, and the like have become serious. When there were few persons out in wheelchairs there were, in effect, few problems. Many persons in manual chairs can transfer to an automobile--say, a taxi--collapse the chair and get about, albeit at greater expense than if the local bus were accessible. Persons in power chairs cannot be transported by car or taxi, but only by vans. The price of the power chair is high, often two or three thousand dollars, and is rarely paid for by VR, Medicaid, or any other public program.

As more severely impaired persons get jobs and succeed, they must travel distances. Bus or air lines which refuse to let such persons ride unless attended cause problems of cost and inconvenience. Thus, the nature of the transportation handicap lies in the interaction between the individual and his transportation opportunity. The flat sprawl of Southern California presents quite different transportation requirements for, say, a person with hemiparesis than do the hills of San Francisco or the snow-covered streets of Duluth, even with the disability held constant. Individuals' income, the availability of friends and family members, and relationship to various social programs which provide transportation as part of their services largely determine the degree to which transportation is a problem.

It is important too to point out that, for the severely handicapped, transportation is a problem not just for the concept of a "trip" out of town or across town. It is also a problem in terms that the able-bodied do not even consider--how to get to the corner grocery, and if there, how to get through the narrow aisles, and if through the aisles, how to get home with the bag.

One wonders, too, why we still hail as an innovation the news that some project or locality has figured out a way to get services to the impaired rather than getting the impaired to the services. For the most part, our history of service provision has been sedentary. The providers (with some exceptions, of course) sit in some building waiting for the citizens to come to them. Often, due to shifting residential patterns, movement of the organizations themselves or other community changes, the services and the potential service users are not in proximity.

Thus, the problems of connecting the provider and the demander exist. There are three logical alternatives: to get the client to the service, or the service to the client, or to meet at some third place. The problem of connecting the two is usually thought of as more acute in rural areas, but anyone who has tried to negotiate the public transit systems of most suburbs and central cities will not underestimate the seriousness of the problems of these systems as well. If getting to services is difficult for the able-bodied, it is far more serious for the impaired.

Specific Problems

Any discussion of transportation problems of the severely handicapped must include an understanding of how the problems vary by type of handicapping condition. For example, there are certain physical functioning requirements for some basic transportation functions. Inability to perform these requirements because of a disability make for some sort of transportation problem, as indicated in the following chart:

Functional requirement	Transportation problem if unable to perform
Walk more than one block	Long walk from entrance to boarding platform
Sit down, get up	Sit/rise from seat in vehicle
Stoop, kneel, crouch	Retrieve dropped fare, pick up packages
Reach, handle	Buy fare, operate turnstile mechanism, hold overhead grip, use exit turnstile
Move in crowds	Crowded platform and vehicles conditions
Identify visual and audio cues	Read direction signs, see arriving train, locate platform edge, hear announcements and warnings
Wait standing	Wait on platform, stand in ticket line

Psychological as well as physical factors affect transit use by handicapped persons. According to a study by Abt Associates, Inc., 16 percent of the handicapped are sufficiently fearful or embarrassed by crowds to avoid using public transportation.[1] Other concerns are feelings about being segregated from the nonhandicapped and fears of injury, of assault, or of getting lost. These factors interrelate with other changeable factors. For example, smooth and physically accessible passenger flow systems may decrease the threat and the fear of unpleasant crowd experience.

Income is another important determinant of transportation use among the handicapped, as it is with the general population. Income data indicate that at lower levels of income the handicapped travel less frequently. Beyond consideration of the cost of any particular transportation mode is the issue of the portion of the family or individual budget which goes to transportation. A pivotal question is whether handicapped individuals below a certain income, when given increased purchasing power, will purchase transportation and, if so, how—on more trips, or trips by different, more convenient, or more expensive modes?

Lastly, the performance of the transportation system is an important determinant of the extent of its utilization by the handicapped. A rich literature exists on the importance of various factors affecting transportation use by the general public.[2] The most important factors include: reliability,

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[1] Abt Associates, Inc., Travel Barriers, Transportation Needs of the Handicapped, prepared for the U.S. Department of Transportation (DOT, 1969), p. 99.

[2] Edmund J. Can[illegible]illi, Programming Environmental Improvements in Public Transportation (Lexington, Mass.: Lexington Books, 1974).

convenience, comfort, time, cost, fatigue, safety, and sense of freedom. Further, these factors have been found to shift in importance depending on whether the purpose of travel is work or entertainment.[3]

Reliability includes the ability to engage in a form of transportation and to arrive at a destination on schedule and without mechanical failure. In one survey, the mentally disabled respondents advocated schedule maintenance as the primary improvement which can be made for their transportation.[4] Availability concerns where and when services are provided, distance to the bus, and system adjustment to peak hours. Dial-a-ride systems often operate without arranging specific peak times because elderly riders do not like taking trips which demand precise punctuality.[5] Comprehensiveness deals with the style of service: door-to-door, station-to-station, and transfers required. The time required to engage and complete a transportation act is an important factor, as are safety and comfort. Fifty-three percent of the National Urban League handicapped sample responded that they would use the bus more if there were shelters at the bus stop.[6]

SPECIFIC PROBLEMS OF PARTICULAR GROUPS

It is important to understand the particular transportation problems of different groups of the transportation handicapped, since solutions to problems faced by various groups will differ.

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[3] G. A. Brunner, et al., User Determined Attributes of Ideal Transportation Systems: An Empirical Study, (College Park, Md.: University of Maryland, 1966).

[4] Center for Transportation Studies (CTS), Transportation for the Handicapped, (New Brunswick: Eagleton Institute of Politics, Rutgers University, 1969), p. 53.

[5] Diogo Teixorra, An Analysis of Massachusetts Council on Aging Dial-a-Ride Systems, (Boston: Project Links, THEM, Inc., 1974).

[6] National Urban League and Mark Battle and Associates, Transportation for the Elderly and Handicapped, prepared for the U.S. Department of Transportation, (DOT, 1973), p. 151.

The physically handicapped--i.e., those people in wheelchairs and those using canes and other special equipment--face a series of architectural and attitudinal barriers that make transportation on existing systems very difficult or impossible. Steps, narrow doorways, and inaccessible facilities and vehicles are all fairly well-known transportation problems. Significant but less well known problems include discriminatory practices by insurance companies with regard to disabled drivers. Many instances are reported of these drivers being placed in an assigned risk category (where they pay higher rates) when there is no empirical evidence that they are poorer risks. In fact, the available evidence suggests the opposite.[7] Considerable press attention has focused on discrimination by airlines in refusing to fly disabled passengers without a medical certificate or attendant. Some disabled drivers report waits of 6 months or more before some Vocational Rehabilitation agencies can complete the work that will allow for the installation of hand control devices and/or other special equipment on their automobiles.

Other barriers prevent people who are physically disabled from using transit systems that have been thought to be well suited to their needs, such as BART, the Bay Area Rapid Transit System in San Francisco. Problems that the handicapped face on BART include: difficulties in using the telephones needed to gain access to the elevators at the stations; lack of secure, out-of-the-way places where people in wheelchairs can wait; and gaps between the loading platforms and passenger cars that can entrap a cane, crutch, or wheelchair tire.[8] These situations are not as obvious as the presence of steps or narrow doors but

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[7] Research Utilization Branch, Division of Research and Demonstration, Office of Research and Demonstration, SRS, Research and Demonstration, Vol. IV, No. 8, (DHEW, 1971).

[8] Hale Zukas, "Why Aren't the Disabled Using BART: An Analysis," paper prepared for BART, January 1974.

can present as much difficulty to many of the transportation-handicapped. The more subtle aspects of transportation handicaps go beyond the system itself. One reason for less than the anticipated use of BART is not BART per se, but the fact that there are curbs a block away from a stop.

Attitudinal barriers cause transportation handicaps for others besides those with obvious disabilities. Some epileptics experiencing petit mal seizures on buses and trains, for example, have reported that they have been treated with understanding by bus drivers and other transit personnel. For those who have not received such treatment, however, riding mass transit facilities can cause emotional difficulties. It can also be expensive if the epileptic is forced to leave the scene of the seizure in an ambulance and be charged $50 for the trip.

The deaf, blind, and mentally retarded constitute a large percentage of the transportation handicapped, and each group has unique problems. The deaf cannot hear arrival and departure announcements at airports and train or bus stations. The boarding of trains can also be a difficult process for the deaf, since there are often no signs directing people to the appropriate cars. Possible solutions for this group, then, include large and more numerous video screens at mass transit facilities giving current information on arrivals, departures, and delays.

The blind have almost the opposite problem in using mass transit facilities. The blind need frequent travel and departure announcements at each facility. Blind passengers would benefit from announcements given <u>during</u> trips on buses and trains identifying particular streets and stations. The blind and partially sighted waiting at bus stops would also benefit from announcements from the driver giving route designation and destination. Route timetables in braille and relief maps in stations would greatly assist the blind in using mass transit facilities.

The mentally retarded have special problems in using mass transit facilities. Complicated routes and schedules often are beyond their comprehension. In addition to travel training, the retarded could use color-coded bus identification markers and simplified route schedules showing principal routes.

The effects of medication contribute to the travel difficulties of some handicapped persons. For example, patients receiving kidney dialysis also take medication which often has the side effect of making them dizzy. Although their mobility may be rated as high, they cannot drive because of the dizziness. Furthermore, many cannot stand in line for any period of time. This makes use of public transportation very difficult, since most bus stops do not have seating facilities and most buses do not have reserved seating arrangements. This group, then, may require special transportation arrangements, such as dial-a-ride vans or taxis, that can reduce their waiting time.

MODAL CHOICE AND TRAVEL REQUIREMENTS

Available data on how the transportation handicapped travel are limited to those derived from several studies of relatively small samples in a few areas of the country.[9,10,11] These data indicate that the mode-choice decisions of the handicapped appear to be more complicated than those of the nonhandicapped.[12] If they have access to an automobile as a driver or passenger, then

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[9] Abt Associates, Inc., Travel Barriers.

[10] Arthur D. Little, Inc., Employment, Transportation and the Handicapped, prepared for the U.S. Dept. of H.E.W., (DHEW, 1968).

[11] National Urban League, Transportation for the Elderly and Handicapped.

[12] Abt Associates, Inc., Travel Barriers.

they prefer it [redacted]ot, then they must make a choice between more comfortable high-cost service and a barrier-ridden low-cost mode. If public transit is truly inaccessible, then the necessity of making the trip must be weighed against its high cost by taxi, specialized van service, or ambulance.

The data also suggest that the handicapped, like the able-bodied, travel primarily by automobile. The handicapped, however, are much more likely to travel as passengers.

The greatest difference between handicapped and nonhandicapped modal choices, as shown by the studies, appears in the use of taxis. The handicapped in the Abt study took almost 14 percent of their trips by taxi, while the nonhandicapped took fewer than 2 percent by this mode. Although the handicapped are less able than other people to afford the use of taxis, they are found to trade off more reasonable cost for a mode which accommodates their physical limitations.

The handicapped studied by Arthur D. Little preferred for the work trip, in order, walking, bus, regular auto, and a specially equipped auto.[14] The handicapped are both more willing than the general population to use public transportation (when accessible) and more dependent on it. However, this may also be a function of their relatively lower income, making their choices more like those of other poor people. Most studies did not control for this effect.

Data from the studies mentioned above indicate that there are significant differences between the handicapped and nonhandicapped in the purposes of travel. For example, the handicapped in the Abt study took an average of .24 social and recreational trips per person per day, compared with .67 for a sample of

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13. Abt, Travel Barriers, p. 6.
14. A. D. Little, Employment, Transportation, p. 27.

nonhandicapped drawn from the same area. Only one-third as many work trips were taken by the handicapped as by the nonhandicapped.[15]

The National Urban League study ranked shopping (26.7 percent), then medical (23.5 percent) trips as the major purposes of handicapped transit use. More handicapped (16.3 percent) use the bus to go to work than do elderly people (6.7 percent). When asked where they would travel if they were better able to use the bus, large differences from present behavior occurred in "to see friends" (10.1 to 27.7 percent) and "visit family" (5.0 to 18.4 percent).[16]

FINDINGS OF URBAN INSTITUTE SURVEY

A number of findings relating to transportation problems and patterns resulted from our survey of persons closed by VR for severity. The most significant finding was that transportation was second only to vocational placement in terms of perceived need. Transportation service was indicated as a need by 18.2 percent of the sample. This general need for transportation services was consistent with the survey of our 1,000 providers of rehabilitation services to the handicapped, as well as with two other sections of the client survey related to services that individuals perceived they would need in order to go to school and work. The provider survey results indicated that 87 percent of those sampled felt that the lack of affordable transportation was a major impediment to serving the severely handicapped. In particular, the lack of affordable transportation was the most frequently cited difficulty in finding job placements for those who were the most severely handicapped.

Almost 41 percent of the VR sample felt that they would need transportation services to go to work, and 22.3 percent indicated they would need

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15. Abt, Travel Barriers, p. 5.
16. NUL, Transportation for the Elderly and Handicapped, p. 163.

transportation in order to go to school. Transportation services ranked first in perceived service need to go back to school. The results indicated that for most of these people the services were not readily available.

Besides these general findings of services needed, data were collected on the types of transportation used as well as the frequency of use.

Table 12-1

Transportation Used by the Severely Handicapped, VR Sample[1]

Transportation Type	Total Used %	N	More than Once a Week %	N	Once a Week or Less %	N	Once a Month or Less %	N	Don't Know %
Walk	42.1	374	32.6	290	6.7	60	2.6	23	.22
Wheelchair	10.7	95	5.3	47	2.6	23	2.5	22	.22
Drive Self-Regular Auto	41.8	372	33.3	296	5.7	51	2.2	20	.65
Adapted Auto	24	27	22	25	2	.2	--	--	--
Motorized Vehicle for Disabled	0.4	4	0.2	2	--	--	0.2	2	--
Relative or Friend Drives	59.7	531	29.2	260	17.3	154	12.7	113	.44
Taxi	18.3	163	2.0	18	4.6	41	11.0	98	.76
Adapted Buses Minibus for Disabled	1.9	17	0.7	6	0.3	3	0.9	8	--
Normal Public Transportation	19.0	169	4.9	44	5.6	50	18.7	77	--
Transportation Arranged by Rehabilitation or Similar Agency	3.8	34	1.2	11	0.8	7	1.5	13	.33

1. For similar data on patients of comprehensive medical rehabilitation centers, see Section III, chapter 8.

Table 12-1 indicates that the handicapped appear to rely heavily on relatives, friends, or themselves for most of their transportation needs. Almost 60 percent of the sample used relatives or friends as their transportation mode, and over 40 percent walked or drove themselves. These three modes accounted for the highest frequency of going outside the home.

After these transportation modes, the percentage which used other types of transportation dropped off sharply, as did the frequency of going outside the home. Specially adapted automobiles for the disabled were used by 2.7 percent of the sample. The lack of adapted buses and special transportation services for the handicapped in most areas of the country may explain the low use (1.9 percent of sample) of this transportation alternative. The utilization of taxis by our sample was 18 percent. This high figure is consistent with the findings of other studies. The frequency of going outside the home can be gathered from breakdowns in Table 12-2.

Table 12-2

Number of Times a Week the Severely Handicapped Are Out of the Home, VR Sample

Times per Week	Number	Percent
0	73	8.2
1	189	21.2
2-3	273	30.7
4-5	123	13.8
6-8	179	20.1
9-15	34	3.8
16+	9	1.0
Total	880	100.0

About 8 percent of the population does not go outside the home in a typical week. Almost 30 percent of the sample goes outside the home once a week or less. Finally, 60 percent go out of the home not more than three times a week.

Thus, our severely handicapped sample appear to be limited to their homes except for special circumstances such as appointments.

A number of reasons can be cited for this relative immobility. Table 12-3 lists the major reported problems which prevent our sample from traveling.

Table 12-3

Deterrents to Travel Reported by the Handicapped, VR Sample[1]

Deterrent	Number	Percent
Problems in getting out of home	188	21.3
Problems in getting into or out of vehicles	285	32.1
Problems in operating vehicles	351	39.5
Physical problems	464	52.2
Other	154	17.3

1. Percentage totals exceed 100 percent because clients may have more than one problem.

While some problems are directly related to the physical structure of transportation systems, such as getting in and out of vehicles, other factors are also important. For example, architectural barriers in the home appears to limit travel for 21.3 percent of the handicapped population. Over half the population surveyed have physical problems (e.g., extreme fatigue, poor bladder control). In designing transportation alternatives these factors, which will have a critical effect on demand for transportation services, should be considered.

To summarize, transportation is an important service need of individuals with severe handicaps, whether vocationally rehabilitated or not. A significant percentage of the sample indicated that they needed transportation services in patterns similar to those described in other studies of the handicapped. Most of the transportation requirements of this group are met by friends or family, with a good percentage driving themselves when necessary. However, the most striking finding is that almost one-third of the individuals are homebound (go outside once a week or less).

ALTERNATIVE SOLUTIONS TO THE TRANSPORTATION PROBLEMS OF THE SEVERELY HANDICAPPED

A wide range of alternative solutions is available, from inexpensive capital-intensive modifications of existing transportation systems to the development of wholly new transportation systems to accommodate the severely handicapped. These alternatives are briefly described below.

Service System Adjustments

All systems, especially VR, should have obligations for outreach, which includes getting services to the client when the client has trouble getting to the services. This is especially true in rural areas or in certain cities with poor bus or taxi systems. Other problems of connecting services to the citizens occur when the service resource is rare or specialized. Take the example of persons with Hansen's disease (leprosy). The leprosy center in Carville, Louisiana is an excellent resource which can serve the disabled effectively. Since there are only an estimated 3,000 persons with this disease in the U.S. and the Territories, the number is too small to set up comparable centers in many places. Many persons who could benefit from the care apparently cannot afford the costs of getting to it. Certainly in such cases the organization should have authority and funds for transportation.

Regional spinal cord centers are another example, but with a different problem involved. If a person is injured in an auto wreck, the service is quick—by helicopter in many instances. Usually such service is provided by the State. But if the individual has to pay for it, the cost can be catastrophic.

The Veterans Administration now can provide vans and hand-controlled cars for many disabled veterans. If VR were to provide this benefit to persons with or without vocational potential, it would permit many of the severely handicapped to expand their mobility.

Mobility Training

Traditionally, mobility training has provided assistance to handicapped individuals in learning how to use mobility aids and in finding their way in new localities. Training is of different value to individuals of different disabilities. It has been long administered to the younger blind with "VR potential." The report of the President's Committee on Mental Retardation states that, as regards mobility, "...the problem is one of training the mentally retarded individual, rather than seriously modifying equipment."[17] One program for the mentally retarded found transportation training successful for individuals aged 17 to 40.[18]

Direct Subsidies

Another approach is to give direct subsidies to handicapped individuals for transportation expenditures. Such a program can favor one mode or apply to all modes.

Income tax credits for transportation is one method.[19] Provision of transit stamps or coupons to those below a certain income and with certain characteristics for purchase of taxi, transit service, or gasoline is another. Various public programs, such as Medicaid and Vocational Rehabilitation, provide some direct assistance for essential trips, often subsidizing the purchase of wheelchairs and other mobility aids and occasionally subsidizing the modification of personal vehicles or the purchase of those already modified.

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[17] The President's Committee on Mental Retardation, Transportation and the Mentally Retarded (The Committee, 1972).

[18] Arnold Cortazzo and Robert Sansone, Travel Training (Miami: Sunland Training Center).

[19] Musicians and construction workers are the only individuals who can presently deduct local transportation expenses. Federal Tax Guide (Englewood Cliffs, N.J.: Prentice Hall, 1973), p. 11.

Program practices vary tremendously from State to State and within any one State. Various proposals have been advanced by HEW and the Treasury to subsidize extraordinary transportation costs for the employed handicapped.

Approaches can be made specific, focusing on particular transportation modes and specific target groups. One widely implemented special service is reduced bus or subway fares. So far, however, these programs have been restricted to the elderly.

Mode-specific programs have the advantage of channeling increased ridership into a given way to get around and thus allowing economies of scale to develop. They do, however, unlike programs applicable to any mode of transportation, interfere with the mix of types of existing transportation.

Modifying Support System

A full discussion of mobility must include aspects of the environment outside of formal transportation systems. First, short-distance mobility itself is important as a mode of travel. Thirty-eight percent of the respondents in the Arthur D. Little study replied that they walk to work.[20] Secondly, short-distance mobility can be a factor in gaining access to other transportation forms.

The mobility of many individuals stops at the first curb. Curbs are an insurmountable barrier to people who use wheelchairs, walkers, and other special aids or have other mobility limitations. In some areas this barrier is being eliminated by ramps or curb cuts. Where extensive curb cutting has been undertaken, usually all curbs have been modified in heavily travelled areas and certain curbs have been changed in other areas, based on individual needs. All new curbs in these sites have been built with cuts.

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[20] A.D. Little, Employment, Transportation, p. 27.

In some cities curb modification has been delayed at the urging of the blind. Changes in level are important indicators for the blind, and curb cuts, if done in a certain way, can obscure the distinction between street and sidewalk to a blind person, thus creating a safety hazard. But proper design and location of curb cuts can eliminate the hazard to the blind. Comparable changes of the environment for other disability groups are street identification by touch signs and traffic light identification by sound signals.

Automobile Modifications

Although personal vehicles offer the greatest mobility, it appears that in most cases adequate mobility can be provided much less expensively. However, personal vehicles may be the best solution, particularly when public transportation is inadequate or nonexistent and where there is insufficient demand to justify a demand-responsive system.

For the handicapped who are confined to wheelchairs and unable to drive, an attendant-operated van can be modified by installing a power lift and mechanical wheelchair tiedowns and making minor floor and roof modifications. Owing to the high cost of automobiles and vans, attempts have been made to develop smaller vehicles which retain the advantages of the large vehicles. Thus far these attempts have not been very successful.

Alteration of Transit Systems

There are, finally, the alternatives which alter the transit system itself. Some address existing system characteristics, both physical and operational. Others address new systems or new services. For a transit system to be accessible, both the stationary facilities and the vehicles must be easy to reach. The makeup of the system can be changed as equipment is replaced, thereby phasing in improvements. Or it can be improved by retrofitting; that is, making currently inaccessible facilities accessible.

A bus or surface rail system could be made accessible immediately by retrofitting the vehicles with a ramp or power lift. In most cases a lift would be needed, since the incline which can be negotiated by many of the handicapped requires a prohibitively long ramp. Retrofitting a subway system requires installation of elevators, elimination of the gap between the platform and the cars through use of an automatic plate that bridges the gap as the doors open, and minor modification of cars. The problem of seating space on railroad cars and buses could be alleviated somewhat by reserving a section of seats, some folding, near the entrance. To reduce the effect of acceleration, these seats could be designed to provide extra support and stability, and tiedowns for wheelchairs could be provided.

The alternative to retrofitting a bus system is to phase in a completely redesigned, barrier-free bus. Under the "transbus" operation, the U.S. Department of Transportation is encouraging the development of such a vehicle. It will feature interior modifications such as wheelchair tiedowns, a power lift, or perhaps a low-slope ramp. Buses manufactured by General Motors, American Motors, and Rohr are being tested in regular city use, and production models may be available in the near future.

Some cities have attacked these problems by structuring and expanding their service, and bus stop shelters are gradually becoming more common. Attempts at detailed planning in routing and scheduling for the handicapped have been made, using geographic and travel data acquired from special surveys.[21]

Another set of options is based on the hypothesis that for many handicapped the transportation problem is one of attitudes on the part of operators, whether management or drivers. Bus and taxi operators, for example, may harbor

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[21] CTS, Transportation for the Handicapped.

the same fears, resentments, and misconceptions about the handicapped that other people do. Driver training includes nothing to sensitize these persons to the needs of the transportation handicapped. Thus, a driver may well refuse passage to a blind or cerebral-palsied person or an epileptic in the midst of a petit mal episode. Some remedies may include little more than convincing a transit authority to provide a special attendant for the handicapped at key stations. Special training may be a viable alternative for improving the system. With this kind of training, special seating could be arranged for the blind or any other handicapped person to assure driver attention. Teaching taxi drivers how to handle a paraplegic could also be helpful. Just plain exposure to and explanation of those who are mobility-limited may advance accessibility into many systems, such as airlines.

Demand-Responsive Systems

Some systems, such as taxicabs, "handicabs," and dial-a-ride, provide on-call and usually door-to-door service. Such systems can establish door-to-door service for those able to use, but unable to get to, public transit. Regardless of the modifications made to fixed-route transit systems, there will always be some handicapped persons who require door-to-door service. Door-to-door systems can offer many of the same advantages as personal vehicles; they reduce walking distances, exposure to weather and crowded conditions, and problems of routing or complexity.

Most handicapped persons, except many of those confined to wheelchairs, can be transported in taxicabs. The fare, of course, is significantly higher than the fare for public transit. A "handicab" is usually equipped to handle all handicapped persons, including those in wheelchairs, but the fare is high: $10 minimum for the first 30 blocks, which would cost $1.70 in the typical cab. A typical flat rate for a dial-a-ride service is $.50. If the modified vans in taxicab systems were operated on a shared-ride basis, the fare could be reduced to the dial-a-ride level.

Handicabs usually offer door-to-door service, and drivers will assist individuals into and out of buildings. This is an important service for the severely handicapped who need service but have no attendant available. Most taxicab systems do not permit their drivers to go into homes or otherwise assist individuals.

In some communities, door-to-door service is provided by local service organizations and private interest groups such as the American Cancer Society, the Easter Seal Society, community hospitals, convalescent hospitals, or senior citizen groups. However, these services are usually available only for emergencies and certain other essential trips. Also, most of the services cater to specific types of disabilities and have strict eligibility requirements.

CONCLUSION

Clearly, there are both economic and noneconomic benefits in improved mobility. Many handicapped persons would be newly able to work, study, and participate in recreational activities. Other benefits include the reduced burden of the handicapped on friends and relatives and the increased contribution to the community though the activities of many talented and well-educated handicapped persons. Also of benefit would be the reduction of emotional burdens of physical problems on individuals and the entire community, which are often debilitating and inhibit productivity.

The psychological benefits to the handicapped individual are also important to consider. The opportunity for increased mobility, if utilized, necessarily increases the amount and variety of social contacts, and these contacts are likely to improve performance in various roles and to enhance self-concept.

The transportation needs of the severely handicapped are an important element in any program which seeks to make this group more independent and productive. Yet finding solutions to their transportation problems is a complex undertaking, since different types of severely handicapped individuals require different of transportation. It is important, then, that a wide range of solutions be explored and evaluated so that the most effective national program options are developed.

Chapter 13

EMPLOYMENT AND LABOR FORCE PARTICIPATION OF THE SEVERELY DISABLED

Ours is an economy which creates jobs and allocates people to them largely by market mechanisms emphasizing productivity. While some humanitarian concerns often mitigate concerns for pure efficiency, we as a society do not generally argue for creation of a job for anyone who wants it. This being the case, it is necessary to accept the bitter concomitant--that there are many who could contribute something to social productivity whose offer is rejected. We simply do not want everyone who could work at some level to do so.

An example may be useful. We came across an experience in Czechoslovakia where three persons impaired by polio quadriplegia and severe respiratory failure will most likely never function away from the hospital in which they are placed. They were trained to be the hospital's telephone operators.

On reflecting, one wonders whether such an effort would be made in this country. The Czech operators displaced at the hospital switchboard by the three severely disabled persons would be placed in other jobs. In the United States we do not so allocate people and positions. Without full employment, our people are reluctant to join the ranks of the unemployed to make way for the most severely handicapped.

As one of our literature reviews from the Center for Independent Living observed, it is probably technically possible to teach anyone who is reasonably alert and has some movement to work. The problem is the jobs.

Thus a knowledge of the labor market and employment experience of the severely disabled and the barriers they face in engaging in labor market activity is essential to an intelligent assessment of alternative policies designed to enhance their employment opportunities. In this section we review the existing literature on employment, summarize its findings, analyze its limitations, and point to possible future areas of fruitful research effort. We also present preliminary statistics on labor market activity of the severely disabled derived from the Urban Institute survey of VR rejectees. In addition, we discuss the implications of alternative policies designed to increase employment and the quality of work for the disabled.

Because many studies deal with the disabled in general or categorize the population on some basis other than severity of disability, it has not been possible to focus exclusively on the severely handicapped. Instead, the total disabled group and various specific subgroups are considered. Wherever possible, inferences are drawn about those who would be considered most severely disabled by various definitions. While this approach provides the strongest possible foundation for meaningful analysis, more definitive statements about the most severely handicapped must await future research efforts.

We begin with a description of the labor market status of the disabled. We then turn to studies related to employment barriers for the disabled. We then discuss employment related programs for the severely disabled and conclude with a discussion of policy options.

It should not be assumed that the severely disabled do not have some productive capacities either in the competitive economy or in a sheltered situation. Even though some severely disabled may not be able to work in traditional occupations or in sheltered positions, many of them may be capable of performing gainful work--producing goods or services that have economic value--even though these goods are not produced at competitive prices and this labor is not compensated (e.g., volunteer activities). Some of the demonstration programs cited later in this analysis suggest that some severely disabled individuals may have productive potential through proper counseling, training, and job restructuring.

Besides the limitations placed on the severely disabled by their impairments and their socioeconomic characteristics, other factors affect their level of participation. Among these factors are inadequate aggregate demand, capital disincentives, employer lack of awareness of the capabilities of the handicapped, and possibly discrimination.

The paucity of studies on the labor market activity of the severely handicapped or even on the handicapped as a whole precludes determining with any reliability how many would be able to enter into different kinds of work situations, what would be the most productive use of their capabilities, and what would be the magnitude of the tangible and intangible benefits produced as a result of their work. This analysis, therefore, only suggests what might be possible and describes some preliminary programs that might be expanded as warranted by experience to meet demand. Estimates are provided where possible of what it might cost to meet some of the employment service needs of the severely handicapped. Benefits are discussed in the most general terms with some crude estimates of probable values.

LABOR MARKET EXPERIENCE OF THE DISABLED

One of the problems with investigating labor market characteristics from survey data is the tautological nature of most of the data available. Most data files define disability in terms of the ability to perform on a job. Severely disabled individuals are people who cannot work at all. Thus, the severely disabled are not well represented in the labor market. Given this definition, one is not surprised to find that the disabled work less than other people and have lower earnings. One is also not surprised to find that the severely disabled work even less and earn even less than the partially disabled.

Disability and Labor Supply

Several studies have been undertaken to estimate the relationship between disability and labor supply.[1] They found that disability consistently reduces labor supply, regardless of the measure used to estimate either labor supply or disability. Disabled persons have labor force participation rates that are 5 to 25 percentage points lower than rates for comparable nondisabled persons. Moreover, disabled persons tend to work 4 to 8 fewer weeks per year and are more likely to be part-time workers (i.e., working less than 35 hours per week). The magnitude of these effects on labor supply varies with race, sex, and severity of disability.

For example, one study found that the effect of disability on the labor force participation of non-white males was notably larger than the effect for other sex-race groups.[2] Nonwhite disabled males had participation rates that were 25 percentage points lower than those of comparable nonwhite nondisabled males, whereas disabled persons in the other age-sex groups had participation rates that were 16 to 19 percentage points lower than those of comparable nondisabled persons in these age-sex groups.

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[1] Monroe Berkowitz and William G. Johnson, "Health and Labor Force Participation," Journal of Human Resources, Winter 1974; William G. Bowen and T. Aldrich Finegan, The Economics of Labor Force Participation, (Princeton University Press, 1969); Fechter et al., "Disability and Labor Supply," Working Paper 963-32, The Urban Institute, Washington, September 1973; Belton M. Fleisher, "The Economics of Labor Force Participation: A Review Article," Journal of Human Resources, Spring 1971; Harold S. Luft, "The Impact of Poor Health on Earnings," The Review of Economics and Statistics, February 1975; and Richard M. Scheffler and George Iden, "The Effect of Disability on Labor Supply," Industrial and Labor Relations Review, October 1974.

[2] Luft, "Impact of Poor Health."

Another study, using the same data base, estimated that participation rates were 5 percentage points lower for black males, age 25-64, and 10 percentage points lower for white males, age 25-64.[3] It also found a larger impact for older males (55-64 years old); 9 percentage points for white males and 23 percent for black males. Differences between the two studies in their findings reflect differences in age composition of their samples, differences in control variables, and differences in the way disability was assumed to impact on labor markets.

Only two studies were found that tried to estimate the effect of severity of disability on labor supply. Berkowitz and Johnson employed the Social Security Survey of Disabled Adults to examine the effect of an index of severity on employment rates of disabled males.[4] Their index was a combination of functional limitations and mental and neurological conditions. They found that employment rates were significantly lower for males of both races with mental and neurological conditions and for white males with limitations in their ability to lift. They also found that there was no significant difference in employment rates among older males (55-64) classified by their index of severity. Fechter et al. employed the Survey of Economic Opportunity to assess the effect of severity on labor force participation and found that a smaller fraction of the severely disabled participated in the labor force in 1966.[5] The effect of severity on labor force participation was found to be considerably smaller for white females than for other age-sex groups. White females who were severely disabled had participation rates that were 3 to 14 percentage points lower than those of comparable partially disabled white females; in contrast, severely disabled

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[3] Scheffler and Iden, "The Effect of Disability."

[4] Berkowitz and Johnson, "Health and Labor Force Participation."

[5] Fechter et al., "Disability and Labor Supply."

persons in the other age-sex groups had participation rates that were 40 to 50 percentage points lower than those of comparable partially disabled persons in the other age-sex groups.

Given labor force participation, the studies found that disabled workers tend to work 3 to 8 fewer weeks per year than do comparable nondisabled workers.[6] One study investigated differences between partially disabled and severely disabled workers in the number of weeks worked per year and found that the severely disabled worked 1 to 5 weeks less per year than did comparable partially disabled workers. It also found that severity had a larger impact on men than on women in weeks worked per year. The differential was 8 weeks for males of both races, 1 week for white females, and 5 weeks for nonwhite females.

Disability and Labor Demand

Decisions to look for work are made by suppliers of labor; hiring and employment decisions are made by demanders of labor, usually employers. These demand decisions reflect employer perceptions of costs, labor productivity, and the demand for the product being produced and are manifest in employment and earnings patterns. A number of studies have examined the impact of disability on employment and earnings.[7] Not surprisingly, they find that disabled workers have lower annual earnings because they work fewer weeks and have lower weekly earnings. The lower weekly earnings, in turn, reflect a greater tendency on the part of disabled workers to work part-time.

Luft[8] found that the disabled earned $500-$1,400 less per year than comparable nondisabled persons, that weekly earnings of the disabled were anywhere from

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[6] Ibid., Table 3.5; and Scheffler and Iden, "The Effect of Disability."

[7] Fechter et al., "Disability and Labor Supply."

[8] Joseph M. Davis, "Impact of Health on Earnings and Labor Market Activity," Monthly Labor Review, October 1972; Fechter et al., "Disability and Labor Supply"; Robert E. Hall, "Wages, Income, and Hours of Work in the U.S. Labor Force," in Glen G. Cain and Harold W. Watts, eds., Income Maintenance and Labor Supply (Chicago: Rand McNally College Publishing Company, 1973); Luft, "The Impact of Poor Health."

$13 to $18 less per week than weekly earnings of comparable nondisabled persons, and that hourly earnings of the disabled range from 6 to 38 cents less than hourly earnings for comparable nondisabled workers. He also found that disabled workers work 4 to 8 weeks less per year than comparable nondisabled workers.

Fechter[9] found that full-time disabled workers had wage rates that were 7 to 42 cents per hour less than those of comparable nondisabled workers in 1966. They also found that the differential tended to be larger for men than for women and larger for whites than for nonwhites.

Davis,[10] using a longitudinal survey of males aged 45-54, found that disabled men earn $700-$1,500 less per year than nondisabled men with comparable educations. He also found that disabled men have hourly earnings that range from equal to or as much as 51 cents lower than nondisabled men with comparable educations. In addition, disabled men work 42 to 208 hours per year less than nondisabled men with comparable educations.

Hall,[11] using the 1967 Survey of Economic Opportunity, found that workers with disabling conditions earned an hourly wage that was 5 to 10 percentage points lower than that of comparable workers with no disabling conditions. The differential was larger for males than for females and was statistically significant only for males.

The employment experience of those who are less severely handicapped provides an indication of what the employment prospects are likely to be for the most severely handicapped. Generally, the handicapped are members of the secondary labor market, employed part-time in low-skilled occupations as operatives or laborers. The Social Security Survey of Disabled Adults estimated that 19.7 percent

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[9] Fechter et al., "Disability and Labor Supply."
[10] Davis, "Impact of Health."
[11] Hall, "Wages, Income, and Hours of Work."

of the employed disabled population in 1966 were in professional and managerial occupations. Of the employed severely disabled, only 14.1 percent were in these occupations. Working in clerical and sales occupations were 17.9 percent of the employed disabled; only 11.5 percent of the employed severely disabled worked in such occupations. In each instance this is a lower proportion than for the nondisabled. Of the employed disabled, 29.2 percent were craftsmen and operatives, while 15.5 percent of employed severely disabled worked in these occupations. Working as farmers, farm managers, farm foremen, and farm laborers were 11.8 percent of the employed disabled (a much higher percentage than in the employed general population), with an even higher percentage (22 percent of the employed severely disabled) working in these occupations. Of the employed disabled, 2.4 percent worked as service and private household workers and laborers, compared to 37.0 percent of the severely disabled employed. The percent for the severely disabled is higher than in the general working population.[12]

It is generally assumed that local and national labor market conditions will have a profound effect on employment of the handicapped, since the disabled are often last hired and first fired. A significantly higher involuntary termination rate among the 11,000 disabled workers than among the nondisabled controls in a national study conducted by the Bureau of Labor Statistics in 1948[13] tends to support this belief. The authors attributed the high rate of firing of disabled workers to the postwar influx of nondisabled returning veterans. They also found a tendency among many of the 109 manufacturing plants surveyed to reinstate policies against the hiring of disabled workers after having relaxed

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[12] Gertrude L. Stanley, Work and Earnings of the Disabled, Report No. 17, Social Security Survey of the Disabled: 1966 (DHEW, 1971).

[13] The Performance of Physically Impaired Workers in Manufacturing Industries, Labor Statistics Bulletin No. 923, 1948.

such policies during the war years. Certainly things are different today, but unfortunately there appears to be no more recent national survey providing comparable kinds of information. The entire question of differential treatment of the handicapped requires further research.

In 1966, when unemployment was at one of the lowest points in the decade, employment prospects for the severely disabled should have been quite promising. But 15 percent of those severely disabled who were looking for work were unable to find it. In less prosperous times, the handicapped (who are members of the secondary labor force) may be among the first to be fired and must compete against a pool of better-trained, more experienced individuals for the limited supply of available positions. Thus, inadequate aggregate demand should seriously limit the employment prospects for the handicapped and particularly for the severely handicapped.

Two unpublished studies have analyzed national data on employment characteristics of the disabled with the purpose of determining whether or not the demand for disabled workers differs in any significant way from the demand for other workers.[14] Both studies concluded that it does differ and that disabled workers generally belong to the secondary labor market, which is "characterized by lower wages, lower skill levels, fewer opportunities for advancement, and more frequently part-time and part-year work than the primary labor market."

The purpose of the 1973 paper by Wolkowitz is to determine whether the demand for the labor of disabled workers differs in any significant way from the demand for the labor of nondisabled workers, and, if so, how and why, with a view to enabling the making of intelligent policy aimed at integrating disabled

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[14] David Tausig, "The Participation by the Disabled in the Secondary Labor Markets," unpublished student paper in connection with the Institute for Urban and Regional Planning, U.C. Berkeley, 1972; Benjamin Wolkowitz, "Characteristics of the Demand for Disabled Workers," Working Paper, The Urban Institute, Washington, 1973.

workers into the general work force. Using aggregate data on (a) disabled workers in the Survey of Economic Opportunity Sample and (b) nondisabled workers in the same occupation/industry categories from the same sample, he found that disabled and nondisabled labor were not substitutes for one another. A difference in hourly wage (nondisabled $2.91, disabled $2.63) was found, but it was determined to be nonsignificant.

Disabled workers were found to be older, less well-educated, more commonly white, and more commonly male than their nondisabled counterparts. The results imply that the nonsubstitutability of the two groups may result from age and/or education as well as impairment. It was also found that disabled workers were more often employed part-year or part-time than nondisabled workers. This was taken as evidence of disabled workers' belonging to the secondary rather than the primary labor force.

By disaggregating the labor inputs into occupational and industrial categories the author found that disabled workers have a disproportionately large representation in the operative occupations, which are relatively unskilled and poorly paid jobs. And even within the operative occupations there was found to be a very low level of substitutability of disabled and other workers.

The Tausig study used the 1966 Social Security Survey of Disabled Adults for basic data. Consistently lower rates of labor force participation, median earnings, occupational status, and industry status, and consistently higher rates of unemployment and part-time work were found among the disabled more than among the general population. Also it was consistently found that in each of these categories, disabled females were in an even worse position relative to all working females than disabled males were in comparison to all working males. And a comparison between the severely disabled and the general population revealed that the employment status of the severely disabled was even worse relative to the population in general than was that of disabled females relative to females in general.

However, the author found that within occupational categories, wage rates for the disabled were not significantly different from those for the non-disabled. (This is consistent with the Wolkowitz findings.)

Tausig also examined the labor market status of 1970 rehabilitants, using Rehabilitation Services Administration data. He found that 18.1 percent of rehabilitants were placed as homemakers, unpaid household workers, or sheltered workshop employees--occupations generally even below the secondary labor market in terms of wages, opportunities for training and advancement, etc. (One might call this the "tertiary labor market".) Among the rest of the rehabilitants, 51.6 percent were in the four lowest paying occupations, compared to 22.0 percent of the general working population (more than twice as high a proportion). Among rehabilitants 48.8 percent earned less than $3,500, compared to 39.6 percent of the general working population.

The author concludes that not only disabled people in general but also rehabilitants are by and large trapped in the secondary labor market. He argues that movement out of the secondary into the primary market is difficult because of heavy restrictions on entry into the latter. He also argues that national macroeconomic policies aimed at increasing the demand for labor do not have a great effect on the secondary market. He further points out that education and formal training are irrelevant to most secondary labor market jobs.

The Wolkowitz and Tausig studies present convincing evidence that the demand for disabled workers is less than the demand for workers in general and that disabled workers are part of a secondary labor force which does not share the relatively high wages, job security, and full-time employment of the greater part of the labor force in this country.

However, these studies do not offer reasonable evidence on the possible causes for the difference in demand. Wolkowitz's finding of little substitutability between disabled and nondisabled workers is weakened by the fact that he found no difference in observed wages between disabled and nondisabled workers after they had been standardized for social and demographic characteristics. Thus, the observed lack of substitution may more realistically reflect lack of observed incentive to substitute rather than unwillingness or inability to substitute.

The differences in labor demand discussed above may reflect differences in the cost of having disabled workers or prejudice against them, or some combination of these factors. They may also reflect supply factors. We try to evaluate these factors in sections below on demand and supply barriers. It is clear, however, that more research on the causes of these differences in demand will be needed before rational policy can be formulated.

Evidence from Urban Institute Survey

The Urban Institute survey of individuals rejected from the Vocational Rehabilitation program focused on a number of employment-related questions: What was the predisability employment status of this group? How many severely handicapped are employed? What kinds of services do they need to enter the labor market? Are these services currently available?

Prior to their being disabled, the sample population worked in a wide range of professions, as illustrated in Table 13-1.

Table 13-1

Usual Job Prior to Disability, VR Sample

Job	Number	Percent
Professional	50	5.6
Managerial	42	4.7
Sales	34	3.8
Clerical	84	9.4
Craftsmen	165	18.6
Operatives	145	16.3
Transportation operators	51	5.7
Laborers	73	8.3
Farm managers	8	0.9
Farm laborers	9	1.0
Service workers	143	16.1
Private household	23	2.7
Missing - no answer	62	7.8
Total	889	100.0

A number of observations can be made from Table 13-1. First, almost the entire sample had some usual occupation. Second, professionals and managers--generally considered higher-income people--comprised 10.3 percent of the sample. This is a bit lower than the 14.1 percent found in the Social Security Survey of Disabled Adults in 1966. Third, craftsmen, operatives, and service workers are the leading occupations on a percentage basis by a wide margin, and the three occupations comprised 51 percent of the sample, which compares to 52 percent from the Social Security Survey.

Of the sample population who worked prior to disability, the survey indicates that this was a rather industrious group. For example, 67 percent of the entire sample worked full-time for at least 11 years. Furthermore, 48.5 percent worked full-time for at least 20 years. This long work history is consistent with the fact that 51 percent of the sample is 51 years old and above, giving them ample opportunity to have a long work history.

Other indications of the commitment of the sample population to work are number of hours usually worked in a week and the number of weeks usually worked in a year. In their usual jobs, approximately 75 percent of the sample worked at least 40 weeks and 84 percent worked at least 33 hours a week.

The earning power of the sample at their usual job prior to their disability is illustrated in Table 13-2.

Table 13-2

Last Yearly Income from Usual Job

Yearly Income Range	Number	Percent
$ 1- 2400	102	11.5
2401- 4800	215	24.2
4801- 8000	257	28.9
8001-10000	81	9.1
10000+	91	10.2
Missing - No answer	143	16.1
Total	889	100.0

From Table 13-2 we can make the following observations. Although they were working prior to disability, 11.5 percent of the sample made incomes of $2,500 or less and 35.7 percent made incomes of $4,800 or less. Thus, over half are in income ranges below the current poverty level. On the other hand, 10.2 percent made $10,000 or more. In addition, 19.3 percent of the sample earned $8,000 or more. Finally, the highest proportion of the sample (28.9 percent) were in the $4,801-$8,000 income range. Considering that this reflected earnings for time periods prior to 1973, these could be considered "average" incomes when inflation is taken into account.

Thus the sample population was employed prior to their disability. They were hard-working, and many were earning an average income. The majority of this population were not working at time of interview. In Table 13-3 the reasons for their not working are cited.

As Table 13-3 reveals, 82.5 percent of the sample cited their "physical condition" as the main reason for not working. All the other major reasons cited for not working were not significant compared to this.

Secondary reasons for not working which are of significance covered a wide range. The most frequently mentioned reason is that employers would not hire them, followed by the problems of finding work near the level of the individual's ability. Other important factors included transportation problems and finding jobs with part-time or flexible work schedules.

While most of the severely disabled rejected from Vocational Rehabilitation are not working in 1975, a part of the sample have jobs now or have worked within a year of the time they were interviewed. Table 13-4 gives the percentage of disabled who are working now as well as how long ago other individuals in the sample last worked.

Table 13-3

Reasons for Not Working, VR Sample

Reason for not working	Main Reason		Second Reason	
	N	%	N	%
Income from working wouldn't cover loss of medical and/or cash benefits	13	1.5	32	3.6
Transportation costs or difficulties	5	0.6	64	7.2
Other costs too high (child care, wear and tear on prosthetic)	3	0.3	5	0.6
Disability/health too severe or impaired	733	82.5	20	2.2
Couldn't find job with part-time or flexible schedule	7	0.8	63	7.1
Union policies do not allow flexibility	--	--	6	0.7
Employer will not hire	23	2.6	100	11.2
Couldn't find work near level of ability	17	1.9	80	9.0
Fellow workers would discriminate	1	0.1	1	0.1
Needed at home	4	0.4	17	1.9
Waiting to go to work	2	0.2	7	0.8
Don't want to work	2	0.2	4	0.4
Need attendant to work	--	--	8	0.9
None	--	--	334	37.6
Don't know	--	--	38	4.3
No answer	68	7.6	75	8.4
Other	11	1.0	32	3.6
Total	889	100.0	889	100.0

Table 13-4

Current Employment Status, VR Sample

Status	Number	Percent
Currently employed	55	6.2
Worked less than 5 months ago	14	1.6
Worked 6 months to 1 year ago	35	3.9
Worked 2 years ago	104	11.7
Worked 3-5 years ago	390	43.9
Worked 6-10 years ago	156	17.5
Worked 11-20 years ago	54	6.1
Worked 21-87 years ago	18	2.0
Other	51	5.7
Missing	12	1.3
Total	889	100.0

Table 13-4 is quite revealing. Despite the fact that the sample consists of individuals rejected by Vocational Rehabilitation as too severely disabled to rehabilitate, 11.7 percent of the sample had worked within a year of the date they were interviewed. At the time of interview, 6.2 percent of the sample were employed. Although most of the persons rejected by VR are not currently working, the fact that this percentage could find employment seems to suggest some small slippage in VR procedures.

Of the severely handicapped who are currently working, approximately 71 percent have perfect Barthel Index scores,[15] which indicates that they have few problems in carrying out the activities of daily living (ADL). Furthermore, an additional 13 percent had Barthel scores in the 91-99 range, which means they have only slight problems in carrying out ADL. In contrast to these

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[15] The higher the Barthel score, the less limitation or severity. A 100 score shows little severity. A detailed discussion of the Barthel Index as well as the distribution of the scores for the entire sample can be found in Section VIII, Chapter 28, Financial Options.

nearly perfect Barthel scores are the scores for those not now employed, only 43.3 percent of whom have perfect Barthel scores.

Other comparisons between those currently employed and those not working can also be made. Those employed are disproportionately female; 53 percent of those employed are female, when only 38.6 percent of the sample are women. This is in contrast to the "not working" group, which is 63 percent male.

In terms of age, race, sex, education, and geographical location the currently employed and not working are roughly comparable on a percentage basis in the various categories which are compared. Thus, perfect Barthel scores and sex appear to be the characteristics which differentiate the currently employed from the "not working."

Having looked at the characteristics of those currently employed, the next section will focus on the characteristics of those currently employed together, with those who were working within a year of the time they were interviewed. The Barthel scores for this population are given in Table 13-5.

Table 13-5

Barthel Scores for Currently
and Recently Employed, VR Sample

Score	Number	Percent
0 - 20	1	1.0
21 - 61	2	1.9
62 - 90	19	18.3
91 - 99	10	9.6
100	72	69.2
Total	104	100.0

As Table 13-5 indicates, 69.2 percent of this particular group have perfect Barthel scores and 78.8 percent have a score of at least 91. Finally, only

1 percent (one individual) has a Barthel score in the 0-20 range. Again, there appears to be some relationship between a high Barthel score and employment.

In terms of age, 40.3 percent of this particular population is 51 and above. Females comprise 51.9 percent and male 48.1 percent. Other key characteristics of the currently and recently employed can be found in Table 13-6.

Table 13-6

Characteristics of Currently and Recently Employed, VR Sample

Race	Number	Percent
White	72	69.2
Black	26	25.0
Hispanic	3	2.9
Unknown	3	2.9
Total	104	100.0
Education		
1 - 6 grades	10	9.6
7 - 10	40	38.5
11 - 12	42	40.4
13 - 16	11	10.6
Unknown	1	1.0
Total	104	100.0
Marital Status		
Single	17	16.3
Married	62	59.6
Separated/divorced	19	18.3
Widowed	6	5.8
Total	104	100.0
Geographical Location		
Large city	52	50.0
Suburb of large city	10	9.6
Small city	17	16.3
Suburb of small city	1	1.0
Small town	14	13.5
Rural	10	9.6
Total	104	100.0

As with the general VR population, the currently and recently employed are mostly white, married, and residents of urban areas. In terms of education, the currently and recently employed have more education than the general sample. For example, 52 percent have completed at least the eleventh grade, while only 43 percent of the general sample has that much education. The same general relationship holds for the currently and recently employed, who have more formal education than the general sample. Finally, 28.8 percent of the currently and recently employed have incomes of $9,000 and above.

While a significant percentage of the sample are and have been employed, most rejects from Vocational Rehabilitation program are not working. As a consequence, it is important to determine the types of help the handicapped need in order to go to work. Table 13-7 delineates the types of services that the severely handicapped perceived they need in order to go to work.

Table 13-7 may be a useful aid in designing a special work program for the severely handicapped. The services most frequently cited by the severely handicapped seem to be divided into two categories, one related to the intensity and duration of work and the other to pre-work activities. The first category includes the need for light work only (61.9 percent), reduced work schedule (47.5 percent), and flexible work schedule (40.0 percent). The prework needs most frequently cited were transportation and special training or education.

Other services, cited less frequently but still important, include such things as help from others to get ready for work (21.4 percent), ramps and/or elevators (27.3 percent), and accessible washrooms (21.9 percent). Thus, in designing a program or programs for facilitating the employment of the severely handicapped, it is clear that a number of variables must be considered such as the intensity and duration of work, prework services (e.g., transportation, special training) and architectural and physical barriers like ramps and elevators.

The results also indicated that these kinds of services are not currently available for the individuals rejected from the VR program.

Table 13-7

Services and Conditions Needed to Go to Work, VR Sample

Service/Condition Needed	Number	Percent	No Answer
Help from others to get ready	190	21.4	699
Transportation	363	40.8	526
Special equipment	173	19.5	716
Flexible work schedule	356	40.0	533
Reduced work schedule	422	47.5	467
Special training or education	350	39.4	539
Light work only	550	61.9	339
Ramps or elevators	243	27.3	646
Accessible washrooms	195	21.9	694
Regular assistance in work tasks	143	16.1	746
Attendant help	122	13.7	767
Other	51	5.7	838
Don't need anything	212	23.8	677

The survey results on employment are quite revealing. First, prior to their disability the rejects were employed in a wide range of occupations and most worked on a full-year, full-time basis. Second, a meaningful percentage (11.7 percent) fall into the currently and recently employed group. This fact is extremely important, since they were rejected from the VR program as being too severely handicapped to have a reasonable chance of becoming employed. Most of those currently and recently employed have perfect Barthel Index scores, indicating that they can perform the activities of daily living with little difficulty. Finally, the services which individuals perceived they needed in order to work related to the intensity and duration of the work.

After reviewing these results, one might interpret our finding that over 11 percent of the rejectees are working as an indication that some of these rejectees are really employable even without having had the benefit of VR services and are erroneously being turned away as too severely disabled for successful rehabilitation. Another reason they were turned away as too severely disabled is the possibility that they were misclassified. Rather than being too severely disabled, they may really have been rejected because they did not have a sufficiently severe handicapping condition to be acceptable to the VR program. Recall that almost all of these currently and recently employed rejectees had almost perfect Barthel scores.

An alternative hypothesis for the finding is that rejections are really based only on judgments about employability. Our finding of an 11.7 percent employment rate among our entire sample of rejected persons is consistent with this hypothesis. Of course, the sample is disproportionately weighted toward older persons, who typically are more difficult to place in jobs, regardless of disability status (51 percent of our sample was over the age of 50). Thus, the observed employment rate of our sample should be compared with the employment rate of a control population with similar social and demographic characteristics before strong inferences are drawn. In addition, findings reported in earlier chapters of this study are consistent with this hypothesis.

Recall that young persons in our sample (age 16-30) had lower Barthel scores than older persons. If younger workers are more easily placed on jobs than older workers, this evidence can be used to support the hypothesis that a larger proportion of the young rejectees are truly severely disabled than is the case with older workers and that the real reason for the rejection of older workers is that they are less easily employed.

These hypotheses have important implications for policy. The second hypothesis discussed above suggests that for the younger group of rejectees some type of special methods may have to be developed to enhance their employment or independent living situation. For the older population, however, some type of sheltered workshop program which reduces the duration and intensity of work may be most appropriate. Further research will be necessary to investigate the validity of these hypotheses before such policies can be assessed.

Demand Barriers to Employment

A large number of studies of employer attitudes on hiring the disabled workers are reported in the literature. Twelve have been reviewed for this study, and a number of others have been cited from review articles. The main problem with analyzing and comparing these studies is that methods, sampling populations, and disabled groups vary so much among the studies that comparisons and generalizations are necessarily on shaky ground. In addition to employer attitude studies, a very few studies (one primarily) have examined employer policies and practices and attempted to determine the relationship of attitudes to practices.

The only study found which reports nearly universally favorable attitudes toward hiring the disabled among any employer group is National Committee for Careers in Medical Technology,[16] in which 1,984 hospitals throughout the country were surveyed to inquire into employment of disabled workers in medical laboratories. Of hospitals reporting having no such workers, almost all expressed a willingness to hire qualified disabled workers for medical lab positions.

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[16] National Committee for Careers in Medical Technology, Careers for the Handicapped in Medical Laboratories (1969).

Williams[17] reports on a mailed questionnaire survey of 108 Minnesota employers (not necessarily a representative sample). Results indicated that most employers believed that higher costs are associated with hiring people with most kinds of disability; that most employers would not consider people with most kinds of disability for production and sales jobs, but would for clerical and, to a lesser extent, managerial jobs; that over 50 percent of employers would never consider hiring a blind or mentally retarded person for any type of job; and that over 50 percent of employers would not usually consider epileptics and persons with serious heart conditions for production, managerial, or sales jobs. Economic factors such as added costs incurred in hiring, training, placing, and providing special physical arrangements, as well as the potential costs arising from absenteeism, low productivity, and limited flexibility in job assignments, workers' compensation and insurance claims, were often viewed as deterrents to hiring handicapped persons.

Those factors most often viewed as deterrents were: (1) the hiring cost of a physical exam; (2) flexibility in job assignment (i.e., lack of flexibility for handicapped workers); (3) medical insurance; (4) paid sick leave; (5) promotionality; (6) absenteeism; and (7) disability income insurance. Those factors which were least often viewed as deterrents were: (1) the hiring cost of testing; (2) pension plan cost; (3) unemployment insurance; (4) hiring cost of interviewing; (5) quantity and quality of work; and (6) turnover. One interesting conclusion is that relatively few employers (21.4 percent) view productivity (quantity and quality of work, or lack thereof) as an extra cost of hiring disabled workers, while relatively many (62.2 percent) regard job flexibility as an extra cost. Workers' compensation was viewed

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[17] C. Arthur Williams, Jr., "Is Hiring the Handicapped Good Business?" Journal of Rehabilitation, March-April, 1972.

by an intermediate proportion of employers as an extra cost. The author concludes that employers do not view hiring the handicapped as good business.

The Federation Employment Study[18] includes information on employer attitudes gathered in a study of policies and practices conducted among New York City firms. Two-thirds of the employers stated that added costs were associated with hiring the disabled. Leading the list of extra costs was Workers' Compensation and other statutory benefits, followed by non-statutory benefits (e.g., health insurance) and absenteeism. Note that those findings are inconsistent with Williams' findings with respect to Workers' Compensation costs. The Federation Employment study also found that only 15 percent of the firms reported being opposed to hiring the disabled because of lack of job flexibility. This finding also appears to be at variance with Williams' findings, but the explanation may lie in the different methods used; the Federal Employment and Guidance Service asked about actual experiences, while Williams asked about attitudes only. One-third of the respondents believed that impaired employees are "better" workers; half believed that they are more conscientious; and 60 percent believed that the impaired are less likely to quit. More than one-third believed that the disabled tended to abuse sick leave less. A significantly larger proportion of large firms (1/2) than small firms (1/3) viewed hiring disabled workers favorably. The Federation Employment Study found that employers who had employed disabled workers in the past were much more likely to view hiring them favorably. Whether the differing results from the Williams and Federation Employment studies are attributable to differences in questions asked, sampling method, region of the country, or some other factor or combination of factors is unclear.

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[18] Federation Employment and Guidance Service, Survey of Employers' Practices and Policies in Hiring of Physically Impaired Workers (1957).

A number of authors argue that increased costs believed by many employers to be associated with employment of the disabled are not real.[19] Also, studies of performance records of disabled workers indicate that at least performance-related costs (absenteeism, rate of productivity, on-the-job injury, etc.) should not be higher for disabled than for nondisabled workers.[20]

Nagi[21] cites two articles supporting the view that employers frequently underestimate the capabilities of disabled workers.

Data on cost of modifications to work place are virtually nonexistent. Several recent studies cite costs of making universities accessible (see chapter on Architectural Barriers), but the comparison to work place is probably inappropriate.

Employer Preferences

One of the most innovative and interesting studies of employer attitudes is by Colbert.[22] Fifty-four Los Angeles area firms were surveyed. A stratified random sample, composed of firms of different size and in different industries was used. The authors probed the attitudes of employers by asking them to rank various groups in terms of which ones they believed "most employers" would be more likely to hire. (This was done with both a straight ranking schedule and a matched pair schedule to allow comparison for reliability.) Groups about whom the questions were asked include five physically disabled groups: "cripples," heart disease patients, the deaf, cancer patients, and

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[19] E. F. Cheit, Injury and Recovery in the Course of Employment (New York: 1961) cited in Saad Z. Nagi, William M. Broom, and John Collette, "Work, Employment, and the Disabled," American Journal of Economics and Sociology, January 1972; and Leonard Mastbaum, "Medical vs. Economic Progress for Diabetics," Minnesota Medicine, March 1974.

[20] The Performance of Physically Impaired Workers.

[21] Nagi et al., "Work, Employment, and the Disabled."

[22] James A. Colbert, Richard A. Kalisk, and Potter Chang, "Two Psychological Portals of Entry for Disadvantaged Groups," Rehabilitation Literature, July 1973.

the blind. Mentally and behaviorally disabled groups included were the mentally retarded, alcoholics, the mentally ill, and drug addicts. Minority groups (Orientals, Mexicans, and blacks) were also included, as were "controversial" groups (student militants, policemen, prison parolees), old people, and "neutral" groups (Canadians, whites, social workers).

The results indicated a significant and consistent ranking of those with physical disabilities in the order listed above. More interesting, however, was the finding that physical disability groups were clustered together and ranked lower than all minority groups and old people and higher than all behavioral disabilities and mentally disabled groups. In other words, employers were most open to hiring radical and ethnic minority group members, followed by physical disability group members, followed by behaviorally and mentally disabled group members. Very little variation in these patterns was found when the sample was subdivided into different sizes of firms or types of industry. The only significant variation was found among manufacturing firms, where small firms were found to be more likely to hire old people than were large firms, and medium-sized firms were less likely to hire blind people than were small and large firms. The implications of the finding that disabled groups are consistently ranked below minority group members and old people are not entirely clear. However, they may suggest the effectiveness of antidiscrimination laws, affirmative action programs, and strong general public interest in ending discrimination in hiring against the latter groups. With affirmative action now extended to the disabled, employer preferences may shift.

A variety of other studies have looked into occupational characteristics and labor force status of various groups within the disabled population. Of particular interest are those which have focused on minority groups and groups of the severely disabled. Unfortunately, no comprehensive national study has been found in either area. These studies tend to show that the effects of discrimination by the labor market with respect to race and to disability are cumulative.

Bowe[23] presents information gathered from a number of previous studies on the nonwhite deaf. The following conclusions were presented: (1) twice as high a proportion of deaf nonwhites reported 8 years of less or school; (2) one in five white deaf who work hold a professional or technical position, while only one in 50 black deaf who work do. Half of white deaf women (who work) hold clerical or sales jobs while the corresponding ratio for nonwhite deaf is one in 25. Only 5.5 percent of nonwhite deaf males are in the professional categories. There are virtually no black deaf professionals except teachers. Median earnings of nonwhite deaf males are $2,611 compared to $6,473 for white deaf males. Corresponding figures for females are $990 and $3,547. The author points to a general paucity of research in the area and to the fact that many of the studies do not have representative samples. Nevertheless, the results strongly indicate that among the disabled population, which is as a whole economically disadvantaged, nonwhites are in a worse relative position than whites. There is definitely a need for more research in this area.

In a study of Workers' Compensation recipients in the New York metropolitan area, Jaffe[24] found that those who had "very poor" or no jobs at the time of the survey tended to be older, less well-educated, unskilled or semi-skilled, and black or Puerto Rican. Unemployment was also much more common among those who had several injuries than among those who had one. These findings are consistent with Rowe's findings regarding the relatively worse position

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[23] Frank G. Bowe, Jr., "Non-White Deaf Persons: Educational, Psychological, and Occupational Considerations," <u>American Annals of the Deaf</u>, 116(3), 1971.

[24] A. J. Jaffe, Lincoln H. Day, and Walter Adams, "Disabled Workers in the Labor Market," <u>Rehabilitation Literature</u>, May 1964.

of the nonwhite disabled in comparison to the white disabled and also underscores the relationship of age, education, skills, and severity of disability to unemployment and underemployment.

No study was found which adequately investigates employment characteristics and labor force participation of groups of the severely disabled. Dvouch, Rusk et al.[25] and Felton[26] are two studies which look at employment characteristics of paraplegics and quadriplegics. In neither study are the samples representative enough to yield generalizable results, however. The Dvouch study concerns 55 persons who had been employed after medical rehabilitation. Among these, there was a preponderance of professional, clerical, and skilled workers, indicating that a high level of training and education yields greater employment prospects for paraplegics and quadriplegics. Those who were employed were also found to be significantly younger than those who were not.

The Felton study was a mailed questionnaire survey of 222 paraplegics and quadriplegics. The authors report that of the 23 percent of the sample who were quadriplegics, 48 percent were employed and half of these were in the highest income category. Sixty percent of paraplegics were reported employed. Those who were self-employed were in the lowest income category. The authors note that there was probably a substantial self-selection factor in returning the questionnaire. In addition, a very high proportion of the sample--85 percent--were veterans. This also indicates an important bias, in that disabled veterans receive special employment-related services not available to other disabled persons.

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[25] Patricia Dvouch, Lawrence Kaplan, Howard Rusk, and Bruce B. Grynbaum, "Vocational Findings in Postdisability of Patients with Spinal Cord Dysfunction," Archives of Physical Medicine and Rehabilitation, November 1965.

[26] Jean Spencer Felton and Myra Litman, "Study of Employment of 222 Men with Spinal Cord Injury," Archives of Physical Medicine and Rehabilitation, December 1965.

A third study of paraplegics and quadriplegics, and the only one which does not appear to have a heavily biased sample, is by Heitzman.[27] This study reports on 77 paraplegics and quadriplegics who were rehabilitated at the University of Mississippi Medical Center. Of the 47 who were alive at the time of the study (the death rate was extraordinarily high), only 4 percent (two) were employed. The authors estimate the 46 percent were employable. They blame inadequate medical followup and rehabilitation for the extremely low employment rate.

Performance of Disabled Workers

Although it is ancient by social research standards, by far the best and the only national comprehensive study of job performance of disabled workers is the U.S. Department of Labor's The Performance of Physically Impaired Workers in Manufacturing Industries (1948).[28] In this study, Department staff examined the employment records of 11,000 impaired and 18,000 carefully matched unimpaired workers in manufacturing plants throughout the country. Data on productivity, absenteeism, nondisabling injuries, disabling injuries and quits were abstracted. (The data on quits were collected at a later date than the other data.) The methods used allowed very little margin for error. Company records rather than supervisors' impressions were the data source. For each impaired worker, one to three unimpaired workers were matched, not only for sex, age, and occupation but also for plant, shift, and particular job within the same plant and shift. (Where more than one unimpaired worker was found for an impaired worker, appropriate computational adjustments, of course, were made.) The most important finding was that differences between impaired and unimpaired workers in any of the performance categories measured were slight. Impaired

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[27] Harry B. Heitzman and Robert D. Currier, "The Prognosis of Paraplegia in Mississippi: A Follow-Up of University Hospital Patients," Southern Medical Journal, April 1970.

[28] The Performance of Physically Impaired Workers.

workers had slightly (1.0 percent) higher productivity rates and fewer disabling injuries (8.9 injuries per million exposure hours compared to 9.5). The two groups had identical nondisabling injury rates. Impaired workers had slightly higher absenteeism rates (3.8 days per 100 scheduled workdays compared to 3.4), and somewhat higher voluntary quit rates (3.6 per 100 employees, compared to 2.6). Impaired workers had significantly higher involuntary termination (firing) rates. The authors attribute this to postwar practice of firing disabled workers to hire returning (able-bodied) war veterans. Results were also tabulated according to disabling conditions. Orthopedically impaired workers had a substantially lower disabling injury rate but a substantially higher quit rate than their controls. Multiply impaired workers had a somewhat lower disabling injury rate than their controls. One of the conclusions that the authors draw is that the physically impaired worker is not necessarily a handicapped worker. The results of this major study are strong evidence that employers' fears of low performance rates among disabled workers are unjustified.

As mentioned above, no study comparable to the 1948 Department of Labor study seems to have been done since. What evidence has been presented more recently on performance rates of disabled workers has generally been consistent with the findings of that study. Mastbaum[29] reviews a number of studies reporting absenteeism among diabetics and finds inconclusive and conflicting results. Dvouch, Rusk, et al.[30] refer to a study of 100 employees indicating that handicapped workers' performance is equal to or better than that of non-handicapped workers.

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[29] Mastbaum, "Medical v. Economic Progress."
[30] Dvouch et al., "Vocational Findings in Postdisability."

It is sometimes argued that performance of disabled workers is irrelevant or meaningless because of the selection process inherent in hiring. The argument is that obviously only qualified disabled workers are hired and therefore there is no reason that their performance should be different. Yet the value of performance studies lies exactly in that they give empirical evidence to support (as it turns out) this assumption. Many employers apparently do not believe that disabled workers have the same performance rates as others, even though it may be obvious to the social scientist that, given hiring selection, they should.

Hanman[31] argues convincingly that efforts to determine work capacities of groups with various physical limitations and match them with physical requirements for job categories are misdirected and will always lead to a large proportion of incorrect assessments. For this he gives two reasons. First, even workers within a narrowly defined disability category (e.g., those who have had one arm amputated) vary greatly in their abilities to perform many tasks. Even if an accurate estimate of the physical capacities of the average one arm amputee can be developed, there will be many who cannot meet the average and many who can exceed it. (The same principle of course applies to quadriplegics, the blind, etc.) Second, even occupations narrowly described or defined vary greatly from one plant or office to another and may vary greatly within the same plant or office. Hanman gives the example of arc welders in a particular shipyard. Arc welders working in one shop can perform their jobs adequately if they are deaf, missing one arm, in a wheelchair, have back injuries, have a heart condition, have a shoulder disability, are missing fingers, or have a nervous condition, while arc welders working in

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[31] Bert Hanman, Physical Capacities and Job Placement (Sweden: Nordisk Rotogravga, 1951).

another part of the same shipyard cannot have any of the above impairments. The central point is that physical impairments do often limit capacity to perform jobs, but the relationship between the two is nearly impossible to systematize and generalize in the process of job placement. Attempts to do so are likely to lead to the exclusion of some disabled workers from jobs which they can perform and perhaps also to hiring of some disabled workers for jobs which they cannot perform. The author recommends taking an individual approach to assessing the capacities of each worker and the requirements for each job.

Felton[32] reports on a survey of 101 Los Angeles area employers to probe their attitudes toward and experiences with hiring paraplegics. Irrespective of experience with disabled workers, employers were found to believe that paraplegics were best suited for nonprofessional jobs and jobs requiring a minimum of public contact. (Ironically, paraplegics were found to be employed most frequently as professionals, then, in order of frequency, as semi-professionals, skilled, unskilled and clerical workers). Most employers reported that they expected performance of impaired workers to be the same as or better than that of non-impaired. The study also found that many employers feared the negative effects of "reactions of others to the disability."

England[33] reports on a national survey of employers. The most important finding from this study is that although most personnel managers and supervisors surveyed indicated openness to hiring impaired workers, their answers to other questions, such as opportunities for advancement and actual employment practices indicated that they were less open in practice than in theory.

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[32] Felton and Litman, "222 Men with Spinal Cord Injury."

[33] George W. England et al., Attitudinal Barriers to Employment, Minnesota Studies in Vocational Rehabilitation, Bulletin 32 (1961).

Bauman[34] reports on a survey of employers of blind workers. Of these employers, 88 percent rated their employees as "superior or completely satisfactory," and 76 percent would favor hiring other blind workers in the future. Other ratings for blind workers were also high. The authors hasten to point out that these results are not conclusive, since the employers surveyed were referred to the authors by a rehabilitation agency and were not necessarily representative of employers of blind workers in general.

In "Employer Prejudice Against the Mentally Restored-Fact or Fancy," Olshanky[35] makes reference to an earlier study in which he found that employers have varying degrees of prejudice against the mentally ill and that the larger the firm, the less likely it is to be open to hiring them.[36] However, he also presents new evidence to show that those ex-mental patients who want to work are able to find jobs without much trouble (mostly by concealing their mental illness history or "passing"). He suggests that unemployed ex-mental patients are not unemployed because of employer prejudice but either by their own choice or because they are unemployable. He urges rehabilitation professionals to stop paying so much attention to employer attitudes and to focus attention instead on such issues as how best to provide services to ex-mental patients while they are employed and how to serve those who are unemployed in the best ways.

A great deal of effort has been put into campaigns such as "Hire the Handicapped Week" in the United States, and some writers claim that such campaigns have been successful. Yet, so far as we know, no evidence has been produced that they have had any success at all.

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[34] Mary K. Bauman and Norman M. Yoder, Placing the Blind and Visually Handicapped in Clerical, Industrial, and Service Fields (Vocational Rehabilitation Administration, 1965).

[35] Simon Olshandsky and Hilma Unterberger, "Employer Prejudice Against the Mentally Restored--Fact or Fancy?" Journal of Rehabilitation, Nov.-Dec. 1973.

[36] Simon Olshansky, Employer Receptivity in Rehabilitation for the Mentally Ill (Washington: American Association for the Advancement of Science, 1959).

A number of studies have reported on projects to <u>change</u> employers' attitudes toward hiring disabled groups.[37] None have been successful. A particularly well-planned, intensive, and multi-faceted effort to change employer attitudes is reported in Sands in examining an experimental project to measure and attempt to change employer attitudes toward hiring of epileptics in a city with a very low unemployment rate. A second city, with a comparably tight labor market, was used as a control. It was found that even with an unusually high demand for labor, only 25 percent of the employers surveyed expressed openness to hiring epileptics. An intensive, year-long educational and public relations campaign was undertaken to change attitudes of employers in the experimental city. The campaign included opening a downtown office, making radio announcements, printing newspaper articles, showing a feature movie on epilepsy at a downtown theatre, sending letters and brochures, and approaching employers through church and civic organizations. At the end of the year, the questionnaire was again administered in the two cities, and no significant changes in attitudes were found.

Another project to change employer attitudes reported that the only effect of an educational campaign was to make some employers even <u>more</u> adverse than they had been at the start of the project toward hiring epileptics.[38] In the survey of 50 employers in Baltimore, Maryland and Tacoma, Washington, Greenleigh Associates[39] reported that those few employers who recommended public

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37. Kevin C. Baack, Michael Conn, and Merle Miller, "Demonstrating How a Rehabilitation Center Can Reduce Community Barriers to the Employment of Epileptics," NTIS Microfiche; Joan Fell Murray, "An Experiment in Changing the Attitudes of Employers Toward Mental Illness," <u>Mental Hygiene</u>, July 1958; and H. Sands and S. S. Zalkind, "Effects of an Educational Campaign to Change Employer Attitudes Toward Epileptics, <u>Epilepsia</u> (Amsterdam), January 1972.

38. Baack et al., "Demonstrating How a Rehabilitation Center Can Reduce Community Barriers."

39. Greenleigh Associates, Inc., <u>A Study to Develop a Model for Employment Services for the Handicapped</u> (New York: The Associates, 1969).

education campaigns as an effective means of securing employment for the handicapped were among those who hired no handicapped workers.

Virtually all the studies on employer attitudes have found that large proportions of employers disfavor hiring disabled people. There are strong indications that these attitudes are in large part based on nonrational, negative feelings--prejudice, in other words--rather than on realistic fears of low productivity, high absenteeism, high insurance rates.

There are also indications that certain groups of the disabled, particularly those with mental and behavioral disabilities and those with severe or aggravatable physical disabilities, are more disfavored by employers than others, though the evidence on this question is not entirely consistent. There is conflicting evidence about whether employers vary in their attitudes toward hiring the disabled according to size of firm or type of industry, and also about what factors employers fear most in hiring the disabled. The available evidence seems overwhelmingly against educational and public relations campaigns as effective means of increasing or bettering employment for disabled people.

Labor Union and Co-Worker Attitudes and Policies

No study has been found dealing with this issue. In an opinion article, Kwapp[40] suggests that labor union policies are a significant deterrent to employment of disabled workers. He cites the example of nonstrenuous jobs being reserved for workers with seniority and therefore unavailable to the disabled potential new employee. Another way in which labor union policies may restrict employment opportunities for disabled workers includes rigid standardization of jobs and job ladders (possibly not allowing flexibility to adjust jobs to the needs of disabled workers).

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[40] Miland E. Knapp, "Employment of the Handicapped," Postgraduate Medicine, July 1970.

It is important that this area be investigated for two reasons: (1) union policies may operate as barriers; (2) unions are in a powerful position to force employers to change the policies which tend to restrict job opportunities for the disabled. To elaborate on the second point, it may be that certain policies that affect the disabled worker adversely come primarily from the employer, or come from both the employer and the union. In either case, if the union can be convinced of the injustice or inutility of such policies, it may have a strong lever for changing them.

Work Environment, Equipment, and Job Structure

No study dealing with the extent to which work environment, equipment and job structures constitute barriers to employment of the disabled has been found. Yet various projects have demonstrated how modifications can make it possible for disabled people to perform jobs which are otherwise impossible or impractical for them or dangerous to their health.

Viscardi[41] describes a competitive workshop in which numerous inexpensive equipment modifications have been made to accommodate the needs of disabled workers. Nakamura[42] reports on the use of film and electronic equipment to detect the formation of pressure sores among workers in wheelchairs in a shop for disabled workers in Japan. He also describes equipment modifications, including on-off switches that can be controlled by blowing. Servicing the Disabled... Vauxhall describes environment and equipment modifications made to enable disabled workers to become fully productive in an automobile

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[41] Henry Viscardi, Jr., "The Adaptability of Disabled Workers," Rehabilitation Record, May-June 1961.

[42] Yutaka Nakamura, "Working Ability of Paraplegics," Paraplegia, August 1973.

manufacturing plant in England.[43] Schworles[44] describes in detail various modifications made in electronic data processing and microfilming equipment which were made specially for individual severely handicapped workers to allow them to become maximally productive. Competitive levels of production were reached by all or nearly all participants in this project, despite disabilities such as quadriplegia, multiple sclerosis, and cerebral palsy. Most of the equipment modifications described in the above articles and reports were relatively simple and inexpensive, and they clearly have applicability to other work situations where disabled people are--or could be--employed. There is a tremendous need to gather and organize what work has already been done in this area and to do further research. Moreover, means must be developed of communicating and applying the results, both in public and in private employment.

With regard to job structures as barriers, Viscardi[45] reports on some pioneering work. He reports that "requirements" for a particular job frequently are not actually necessary to its successful performance. He also reports that many jobs usually regarded as stand-up jobs can just as easily --or more easily--be performed sitting down. Greenleigh Associates[46] report that many State and local governments have job requirements that bear no relation to successful performance. For example, many require the taking of written civil service tests that mentally retarded people cannot pass for jobs that they are capable of performing. Rigid career ladders may also constitute

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[43] "Servicing the Disabled--How Vauxhall Motors Brought Their Disabled Employees Together Under One Roof with Optimum Environmental Conditions," Personnel Management (London), March 1974.

[44] Thomas R. Shworles and Irene G. Tamagna, Development of Modern Vocational Objectives for Severely Disabled Homebound Persons: Remote Computer Programming, Microfilm Equipment Operations, and Data Processing (Washington: George Washington University Rehabilitation Research Center, 1973).

[45] Viscardi, "The Adaptability of Disabled Workers."

[46] Greenleigh Associates, Inc., Model for Employment Services.

barriers for disabled workers who may, for example, be able to perform the requirements for higher level but not for entry level jobs, or for entry and higher-level jobs but not for intermediate jobs. There is also a great need for systematic research into the area of job structures in relation to the capabilities of disabled people.

Supply Barriers to Employment

The most severely handicapped are confronted with a number of factors which inhibit their participation in the competitive economy or in gainful work, such as low levels of education, lack of job experience, lack of job related skills, psychological barriers, the high costs of job searches, the unavailability and high cost of transportation, and the economic disincentives in the "welfare system."

Older workers under the age of 65 will tend to have some difficulty in becoming employed after becoming disabled than younger workers. Although there is little evidence that ability in occupational skills deteriorates much before age 60, older workers tend to be less able to adapt to change than younger workers. Older workers tend to be more concentrated in declining and static industeries. In addition, employers appear to discriminate against older workers because of their age.

The noninstitutionalized handicapped aged 18-65 show a considerably older age distribution than the nonhandicapped population, having a median age of 53 compared to a median of 40 for the rest of the population. They have a median of 9 years of school compared to 12 for the rest of the similarly aged population and are 20.5 percent black compared to the national per centage of 10.8 percent.

Since 43.5 percent of the severely handicapped have had disabilities for 10 years or more and 76.6 percent have been disabled for 3 years or more, it is highly probable that they have not developed the social skills needed to function in a competitive economic position.

Similarly, the level of experience gained on the job is low for such an old population. The median number of years of employment was six. The type of employment was much less skilled than for the rest of the population, with only 14.1 percent in professional or managerial positions.

Some studies of unemployment indicate that motivation appears extremely important in determining what a person is able to do economically. This observation is even more applicable to the severely handicapped who are confronted with severe psychological barriers to performance. However, although many of these individuals and their families probably have developed negative attitudes about the prospects of becoming employed and about their capabilities, it does not necessarily reflect a lack of interest in becoming employed.

Another aspect of this problem is that the disabled may have higher job search costs than the nondisabled because their employment opportunities are more limited, their networks of social contacts are less extensive, their mobility is restricted, and psychic barriers are harder to overcome.

The unavailability of transportation to likely places of employment or its excessively high price may deter many of the potentially productive severely handicapped persons from working. A survey by Abt Associates, Inc. of individuals limited in mobility found that of the entire handicapped population, 13 percent of the persons aged 17-64 indicated that they would be able to return to work if transportation were no longer a problem.[47] Since their survey sampled individuals with all kinds of disabilities some of whom were employed or partially

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[47] Abt Associates, Inc., *Travel Barriers, Transportation Needs of the Handicapped*, prepared for the U.S. Department of Transportation (DOT, 1969).

employed, the Abt Associates estimate may be conservative. In the chapter on transportation in this report, an estimate is derived using the Abt Associates' survey results that suggests approximately 200,000 persons would become employed if a national mobility program were instituted.

One of the most difficult barriers to evaluate is that of economic disincentives. Some severely handicapped persons are performing unpaid work, are underemployed, or are unemployed because they cannot afford to lose their disability benefits. The value of those benefits, such as Medicare or Medicaid and welfare-financed services such as attendant care, can amount to more than $7,000 per year.[48]

The disabled groups which have the most difficulty in finding employment are the mentally ill, the mentally restored, mentally retarded, the congenitally disabled, and older disabled workers. Table 13-8 portrays the relative magnitude of the different disorders on employment experience and suggests the employment potential by diagnostic category.

Although no figures are available from the 1966 Survey of Disabled Adults on the number of severely disabled who were congenitally disabled, it would appear that the congenitally disabled tend to be less well educated, less skilled than those disabled later in life and than the rest of the population. Simply because of their lack of human capital, the congenitally disabled would appear to have difficulty finding employment.

The mentally ill and retarded numbered approximately 506,000 in 1974.[49] Because the mentally ill who are not in institutions have difficulty in

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[48] Interview with Phil Draper, Center for Independent Living. This estimate is based on 7 severely disabled staff members. Twenty-three percent of the benefits were medical.

[49] Lawrence D. Haber, Epidemiological Factors in Disability: I. Major Disabling Conditions, Report No. 6, Social Security Survey of the Disabled: 1966 (DHEW, 1969), Table 7. Note: The number is updated by a factor of 1.164.

Table 13-8

Work History of Severely Disabled Adult Population in 1966: Percent of Persons in Each Diagnostic Category by Work History

Major Diagnostic Category	Severely Disabled		
Total Population	Never Employed	Employed in Past But Not in 1965	Currently Employed (1965)
Musculoskeletal disorders	6.0	55.1	38.8
Cardiovascular disorders	10.4	54.4	35.1
Respiratory and related disorders	8.8	58.6	32.0
Digestive disorders	9.7	48.6	41.7
Mental disorders	36.9	40.6	22.3
Nervous disorders	25.6	55.6	18.6
Neoplasms	9.9	42.2	47.9
Urogenital disorders	3.2	36.3	60.5
Diabetes	22.8	55.1	22.1
Visual impairment	23.6	49.4	26.9
Other and unspecified conditions	21.7	46.3	32.0

Source: Pearl S. German and Joseph W. Collins, "Disablility and Work Adjustment," The Social Security Survey of the Disabled, 1966, Report No. 24, July 1974, Table 7.

demonstrating the social skills needed for successful long-term employment, they have a hard time finding jobs. Most certainly, the mentally retarded face some employer discrimination.

Although the data do not reveal the IQ levels of those who are mentally retarded, it appears that 193,000 individuals between the ages of 18 and 65 in 1974 were severely disabled because of mental retardation.[50] In 1970, there were approximately 152,000 noninstitutionalized individuals aged 20 to 64 with IQs of less than 40. In the IQ range of 40 to 50, there were 96,000 individuals. Studies on employment of the mentally retarded suggest that those with IQs below 40 have very little prospect of becoming gainfully employed.[51] Approximately 40,000 of the mentally retarded in the severely handicapped population have IQs above 40 and a reasonable chance of becoming employed.

Work Values and Job Satisfaction of Disabled Workers

1. Work Values--Nagi[52] cites a study by Friedmann and Havinghurst showing that 72 percent of a sample of homebound, chronically ill people viewed work in terms of five functions identified by the authors as being functions of work for people in general: "economic support, regulation of life activities, identification association, and meaningful experience."[53] He cites another study indicating (for a limited group of cardiac patients) "that workers with impairments espouse much the same occupational goals as workers in general." These studies are clearly limited in their sample populations, and it is risky to generalize from them to the disabled population as a whole.

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[50] Ibid., Table 7. Note: The number is updated by a factor of 1.164.

[51] Ronald W. Conley, The Economics of Mental Retardation (Baltimore: Johns Hopkins University Press, 1973), pp. 202, 207.

[52] Nagi, "Work, Employment, and the Disabled."

[53] Friedman and Havinghurst, "Work and Retirement," in Man, Work, and Society (New York: Nosowand Farms, 1962).

The only in-depth study of disabled people's work values found is Kinnane.[54] This study is an investigation of the work values of four subsamples of disabled people: cerebral palsied, recent Vietnam War amputees recovering in a hospital, a group of patients from a mental hospital, and the deaf. A schedule of questions plus an empirically derived set of work value factors (such as altruism, independence, intellectual challenge, variety, and monetary rewards) was given to the four groups and to comparable nondisabled. The amputee group placed significantly higher values on altruism, prestige, and work conditions and associates than did the nondisabled. All of these factors relate to social values of work. The deaf sample placed significantly higher values on altruism, art, prestige, and work conditions and associates and somewhat lower values on intellectual challenge and leadership than did their control group. The male cerebral palsied placed significantly higher values on monetary rewards and work conditions and associates and somewhat higher values on prestige and variety than did their controls. This group seems to diverge from the pattern indicated in the other disability groups of valuing primarily the <u>social</u> values of work more than nondisabled do. The female cerebral palsied placed significantly higher value on leadership-prestige, and somewhat higher value on variety, scientific inquiry, and monetary rewards. The psychiatric patients placed significantly higher values than their controls did on art, scientific inquiry, prestige, and work conditions and associates, and significantly lower value on intellectual challenge. The authors conclude that in general, disabled people place a higher value on the social aspects of work than other groups. This conclusion seems somewhat questionable in light of the results for the cerebral palsied, the fact that only four groups of the disabled were examined, and the fact that the amputees, having

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[54] John F. Kinnane and Anlanas Swiziedelis, <u>Work Values of the Handicapped</u> (SRS, 1966).

recently returned from Vietnam with serious injuries, may have been a very special case, not representative even of amputees in general. Nevertheless, the results seem to indicate that the disabled are not a homogeneous group with respect to work values. The evidence suggsts that attitudes toward work do not represent any more of a supply barrier to work for the disabled than they do for the nondisabled.

Job Satisfaction--There is virtually no literature on the degree of satisfaction and fulfillment that disabled people experience on their jobs. Only two articles touched on this issue in an empirical way.[55]

Bauman's survey of 752 blind workers in clerical, service, and industrial positions indicates that these workers generally express satisfaction with their jobs, but that they express dissatisfaction with their lack of job mobility.[56] Typically they have little authority and little opportunity for advancement.

Boatner's survey of young adult deaf in New England[57] reaches a similar conclusion. While those who were employed indicated satisfaction with their present jobs, they had aspirations for jobs they would hold 10 years in the future which were very different from their present jobs in terms of wages, and responsibility; the jobs they were in were "dead-ended".

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[55] Bauman and Yoder, Placing the Blind and Visually Handicapped; and Edmund B. Boatner, "Occupational Status of the Young Adult Deaf of New England and Demand for a Regional Technical-Vocational Training Center," unpublished Final Report, American School for the Deaf, West Hartford, Connecticut.

[56] Bauman and Yoder, Placing the Blind.

[57] Boatner, "Occupational Status."

Attitudes of the Disabled Themselves and Family Members

Very little literature was found on this issue as a barrier to employment. Boatner found a marked incidence of very strong resistance among parents of deaf young people in rural areas to their leaving home to receive vocational training or placement.

Gellman[58] believes that disabled people internalize "discrimination-inducing behavior" and in this way act as a barrier to their own social functioning, including hiring for employment.

Scott[59] believes that many blind people are manipulated into dependent attitudes and behavior patterns by "blindness agencies" (including workshops) which keep them trapped, thus making it impossible for them to function in a normal commercial plant.

Bruckner[60] reports that in a study of severely head-injured people in England, he found that psychological symptoms are the greatest barrier to returning to work. Haber[61] cites a few studies (mostly English) indicating that attitudes toward self and work are more important determinants of return to work than are medical recovery or functional limitation.

There seems to be a need for further investigation of this area, particularly in the United States. It is possible that cultural differences would create significantly different findings in this country from those reported in the British studies.

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[58] William Gellman, "Roots of Prejudice Against the Handicapped," Journal of Rehabilitation, January-February 1959.

[59] Robert A. Scott, The Making of Blind Men (New York: Russell Sage Foundation, 1969).

[60] F. E. Bruckner and A. P. H. Randle, "Return to Work After Severe Head Injuries," Rheumatology and Physical Medicine, August 1972.

[61] Lawrence D. Haber, "Age and Capacity Limitation," Journal of Health and Social Behavior, September 1970.

POLICY OPTIONS FOR EMPLOYING THE SEVERELY HANDICAPPED

A wide range of approaches might be used to increase the employment of the severely handicapped. Those suggested in this section represent a few that seem possible. They are organized into two groups: one dealing with supply and the other with demand.

This analysis limits itself to policies that represent direct interventions in the labor market; it does not consider the other needs which are necessary for the severely handicapped in order to be able to work, such as medical, educational, rehabilitation and social services. Medical care is certainly a prerequisite for the severely handicapped to be able to carry out daily living functions. For children who are disabled, early educational and vocational counseling will improve the likelihood that they will be as productive as possible in later life.

A necessary ingredient in a policy mix aimed at improving the employment opportunities of the severely handicapped is a government commitment to maintain full employment. However, as most people know, full employment is not synonymous with zero unemployment. There are many people who would like to work but are unable to find work at full employment levels of economic activity because of labor market handicaps such as inadequate skills or undesirable characteristics and race, sex, or age discrimination. As we described above, the severely handicapped are likely to be disproportionately represented in the unemployed during full employment periods because the demand for their services appear to be smaller than the demand for the services of comparable nondisabled workers. Since we also expect the supply of severely handicapped workers to be smaller than the supply of comparable nondisabled workers, the demand differential does not necessarily imply a similar unemployment differential, although we suspect that a meaningful part of the supply differential may be attributed to the "discouraged worker" effect (i.e., workers dropping out of the labor force even though they would like to work because they do not think they can find work). Thus, in what follows, we discuss programs aimed at severely handicapped workers who have difficulties finding employment even when the economy is at full employment. The policies we describe, therefore, may be highly redistributive in nature, shifting employment opportunities away from other workers. While such redistributive measures may equalize the employment opportunities of severely handicapped workers, the costs of this equalization in terms of the employment opportunities lost by the nondisabled workers must be kept clearly in mind.

Demand: Public Sector Employment

It is highly unlikely even in times of prosperity and full employment that employers in the competitive labor market would absorb any but a fraction of the severely disabled people who could be brought to work capacity through vocational rehabilitation services. VR counselors and other rehabilitation specialists who responded to the Provider of Rehabilitative Services Questionnaire indicated that "lack of available jobs" and "resistance of the competitive labor market toward hiring the severely handicapped" were the most significant impediments to rehabilitating severely handicapped people. Also, experience over the years in the State-Federal VR program has shown that vocational placement of the severely handicapped takes place in increased numbers only through special training and placement programs designed especially for various disability groups (the mentally retarded, the blind, the deaf) and that activities have fallen far short of serving and placing all the severely disabled people in these disability categories who require and could benefit from their service. Moreover in many cases, when demonstration ends, job placements level off or decline.

Public Service Work Programs: The establishment ~~of~~ public service work programs for the disabled should be considered as a major means of providing meaningful paid employment to all severely disabled people who wish to work, who are now capable of working or can be made employable, and who will not find work in competitive employment. As envisioned, this program would operate in all the States through special grants to the State VR agencies. These agencies would be responsible for the administration of the program and would employ special staff for this purpose. The State VR agencies would establish public service work projects throughout the State with a variety of public service agencies--schools, health departments, recreation departments, transportation departments, public safety, hospitals--in fact, any agency with which a sound, meaningful work project could be developed. The project activity would be an essential activity, but one which the public service agency could not finance and conduct itself. The public service agency would provide the required facilities and the State VR agency the workers, to whom wages would be paid in relation to the services performed. Examples are school or recreational aide services; serving as attendants, readers, interpreters, tutors, etc., to people in their own homes or institutions who require such services; the microfilming of tax and other public records in a central location or in the homes of the disabled people if they are homebound; the repair and maintenance of books in public and school libraries; assisting public safety officers in the preparation and filing of reports; assisting courts in parole, probation, and paper work; serving as interviewers and enumerators (by phone if homebound), data processors and data analysts in educational, traffic, health, environmental and other studies and research; and as physical conditions permit, filling a variety of professional, artisan, clerical and manual jobs in constructing alteration and remodeling of public parks, buildings, and facilities. The State vocational rehabilitation agency and the local participating agencies should have great latitude in developing public service projects to encourage imaginative activities, particularly the kind that will lead to improvement in the quality of life and that will permit some of the project activities to be performed in the homes of those disabled people who are unable to leave their homes.

The Federal Government already has a number of programs for employing disabled people. Among them are the Randolph Sheppard Act program for blind vendors in Federal buildings[62] the Internal Revenue Service program to train and employ blind people as taxpayer service representatives[63] and the Postal Service program to employ deaf people as distribution clerks.[64] There is also the Federal policy of allowing vocational rehabilitation agencies (and the Veterans Administration) to certify men~~tal~~ly retarded and other handicapped persons for a variety of positions, obviating the need for them to take examinations.[65] A more thorough review ciency in solving the employment problems of the disabled. Judging from figures presented by Rose their overall impact is not great. A total of only 152 disabled people per year were placed in Federal jobs under the various programs

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[62] William W. Thompson, Adapting the Randolph-Sheppard Vending Stand Program to the Advances of Automation: Final Report, 1968.

[63] Elmo A. Knoch, "Training Blind Persons to Work as Taxpayer Service Representatives for IRS," NTIS Microfiche, May 1971.

[64] Edward R. Rose and Hedwig W. Oswald, "Decade of Change-Growth of the Federal Government's Program to Hire the Handicapped," Rehabilitation Record, September-October 1971.

[65] Greenleigh Associates, Employment Services; and Rose and Oswald, Decade of Change-Growth.

considered in that article. There is no evidence on what might happen if the existing programs are expanded.

Greenleigh[66] Associates report that the major barriers to public sector employment of disabled workers exist in State and local governments. While at least one state (Maryland) has progressive programs similar to those of the Federal Government, most State and local governments do not. Many have examination and physical requirements that are irrelevant to the adequate performance of the respective jobs. A thorough national investigation of such policies would be the first step toward removing this barrier.

Feldstein[67] discusses a large-scale public employment program as a policy alternative for substantially increasing the employment of disabled people. He opposes it, however, preferring employer and employee subsidy alternatives. His reasons are (1) that a public employment program would draw disabled workers away from private employment, and (2) it would be likely to protect or foster inefficiency. Argument 1 is not convincing since there is no intuitively obvious reason why disabled workers should be primarily in private as opposed to public employment. Argument 2 is stronger and suggests a real danger in large-scale public employment programs. Another danger would be isolating disabled workers from other workers. However, it should be possible to design a public service employment program that would encourage high productivity among disabled workers and provide integration in work situations.

Demand: Sheltered Work Positions

Many severely handicapped persons are currently employed part-time or unemployed could be employed in the competitive economy if sheltered work positions are developed. These positions provide jobs that are especially

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[66] Greenleigh Associates, Employment Services.

[67] Martin Feldstein, "The Economics of the New Unemployment," The Public Interest, 1973.

tailored to the capacities of the handicapped worker in a competitive work environment. The few demonstrations that have been developed suggest that assisting an employer in designing the appropriate work environment is potentially very effective in creating employment for the severely handicapped.[68]

Many severely handicapped people need the protective environment and services of a sheltered workshop in order to work. Some have been idle so long that they have completely lost their work skills; others are incapable of working an 8-hour day on a sustained basis. The nature and pressures of the competitive labor market will not permit the hiring of workers who in any way fall short of meeting normal job standards. We discuss workshops in the Chapter on Rehabilitation Facilities.

Demand: Wage Subsidies

Another way of stimulating demand is to make the severely handicapped less costly to employers by subsidizing some of their wages. Under such a program the Federal Government would pay the employer the difference between the value of the worker's product and the minimum wage rate or pay a fixed percentage for certain kinds of employed handicapped. These subsidies could go to both competitive and sheltered enterprises. Although the cost of this program is not calculated here, it would be possible to arrive at a guesstimate by using the wage rate of those in sheltered workshops as a proxy for the value of labor and by calculating the difference with the minimum wage.

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68. Nagi, "Work, Employment, and the Disabled," p. 31; D. Clarke and A. Biscardi, "Industrial Therapy in a Large Psychiatric Hospital," Psychiatric Quarterly, October 1963, pp. 648-651; Abilities Incorporated of Florida, "Employment of the Physically Disabled in a Competitive Industrial Environment," Pamphlet, 1966; Viscardi, "The Adaptability of Disabled Workers,"; Shworles and Tamagna, Development of Modern Vocational Objectives. For a discussion of the experience with job creation in Western Europe see: Beatrice Reubens, The Hard-to-Employ: European Programs (New York: Columbia University Press, 1970).

The WIN Tax Credit of the Revenue Act of 1971 is one public program that has implemented this approach, although it is more complicated than the one proposed here. Under this Federal program, deductions are allowed for training costs and supplementary benefits.

The effect of the subsidy in stimulating demand for labor is a subject of study and debate. The European experience with wage subsidies suggests that they have not been very effective in generating employment and must be set a high levels in order to affect the demand for disabled labor.[69] An Urban Institute study of the WIN Tax Credit indicated a slight increase in employment of welfare recipients.[70]

Several studies of wage rate changes have arrived at different conclusions as to the impact of the program on employing low-skilled labor. Some suggest small effects while others suggest potentially strong employment effect.[71]

One supplementary means of increasing employment opportunities for the disabled with private as well as public employers is to provide subsidies or direct grants for making appropriate work environment and equipment modifications. Provisions for such modifications are included in the 1973 Rehabilitation Act, but data are not available to assess utilization.

A number of writers have urged the use of publicly financed employer subsidies.[72] Sometimes this recommendation is predicated on the belief that

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[69] Reubens, The Hard-to-Employ, pp. 162-173, 396.

[70] R. Crandall, C. D. MacRae, and L. Y. Yap, "Employment and Wage Effects of the WIN Tax Credit," Working Paper 3603-2, The Urban Institute, Washington, 1973.

[71] Alan Fechter, "Full Employment and Income Security: The Role of Wage Subsidy Programs as Policy Weapons," Working Paper 963-29, The Urban Institute, Washington, 1973.

[72] E.g., Paul M. Ellwood, Jr., "The Rehabilitation-Industrial Complex: Toward a New Rehabilitation Market," Journal of Rehabilitation, March-April 1969; and Wolkowitz, "Demand for Disabled Workers."

disabled workers are less productive than other workers. Although many disabled workers are (or would be) less productive than other workers on some jobs and some disabled workers would be less productive than others on most jobs, evidence on productivity indicates that if job and worker are matched, disabled workers are generally at least as productive as others.[73] This still leaves unanswered the question of whether or not the main reason why more disabled workers are not hired is that most unemployed disabled workers are relatively unproductive for jobs in which people are being hired. If this is the case, employer subsidies to make up for the relative inefficiency of these disabled workers (as a stimulus for hiring them) would make sense. However, if the problem lies primarily in employer prejudice, irrelevant or overly strict job requirements, overcaution on the parts of company physicians, and/or restrictive union policies, then employer subsidies may have to be extremely high to offset this barrier.

Feldstein[74] assumes that disabled workers are less productive than others and proposes that either an employer subsidy system or an employee subsidy system (allowing employers to pay less than minimum wage) be used to make up for low productivity. The employer subsidy system that he outlines tries to avoid the problem of compensating employers for hiring the disabled workers whom they would have hired anyway. It would pay only the difference between what the employer is willing to pay the worker and the minimum wage, and a disabled worker would be able to go to any employer with his subsidy. Apparently, only employers of those disabled workers who are judged to have low productivity would be eligible, although the author does not discuss this point.

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[73] The Performance of Physically Impaired Workers.

[74] Feldstein, "The Economics of the New Unemployment."

Demand: Employment Quotas

Several European countries, notably Great Britain and West Germany, have required firms above a certain size to hire handicapped workers as a given percentage of their employees. In Great Britain, individuals are registered whenever they have a disability which will last longer than a year. The quota rate is set at 3 percent for all eligible firms. Firms not meeting this quota cannot hire a unregistered person without a special permit. All disabled laborers must be paid the same wages as their coworkers except for those activities exempted by the law. Despite some difficulties in getting potential handicapped registered and the uneven geographic distribution of jobs, the British system appears to have significantly reduced the employment problem for the handicapped. Although more restrictive in terms of eligibility, the West German quota system appears to have been equally effective.[75]

One of the costs of such systems is that abled-bodied laborers may be displaced and the production of goods and services may be more costly. In periods of high unemployment, under the quota system the handicapped would not be fired as quickly as they would without public intervention. Since all firms would be under the same constraints, it would not create inequities in the short run, although in the long run some firms might relocate in areas with few unemployed handicapped people.

Demand: Projects with Industry

The Project with Industry program was authorized in 1968, but did not become operative in a substantial way until 1971. This program authorizes cooperative arrangements and funding with employers and organizations for special projects that will prepare handicapped people, particularly those who are severely

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[75] Reubens, The Hard-to-Employ, pp. 110-152.

disabled, for paid employment in the competitive labor market through training and employment in realistic work settings. There are 11 such projects involving about 500 private industries representing almost all facets of the American business community. The extent of their involvement varies considerably, but in most cases it includes training and employment components. Industries in some cases provide direct cash payment or, as is the usual practice, staff and equipment support.

About 5,000 disabled people have entered this program since its inception and about 70 percent have been placed in paid employment following their training in the industrial setting. They are working as cable splicers, optics grinders, short order cooks, furniture repairmen, information specialists, garment makers, bank and insurance company employees, waiters, waitresses, fork lift operators, hotel maids, stock clerks, computer programmers, and audit clerks.

There may be advantages in this program to the handicapped people who enrolled and to the industries involved. The handicapped people are provided expanded job placement opportunities, opportunities for entry into employment with major corporations, and opportunities to benefit from advanced training in industrial techniques with career advancement possibilities. Industry obtains a prescreened and trained employee, saving these costs in exchange for offering the position.

Preliminary reports show that the cost of training and placing disabled people through the Project with Industry program may be less than the traditional training and placement methods in VR. The Projects with Industry program should b examined to see if these cost factors and the apparent benefits warrant program expansion.

Supply: Extended Counseling and Evaluation

An essential component of any public program for improving the employability and the productivity of the severely handicapped is an active outreach program coupled with a system of providing competent counseling well coordinated with medical rehabilitation and opportunities for extended evaluations. Of the severely handicapped identified in the Social Security Administration Survey only 2 percent had received guidance or counseling. One study of paraplegics and quadriplegics found that much of the high unemployment of this severe disability group was attributable to inadequate medical followup and poor counseling.

One function of an extended counseling and evaluation program would be to provide a realistic outlook on how the disabled person can be maximally productive. Counselors should be able to provide extended evaluation to determine the capacity of the handicapped to perform or learn certain types of jobs. The extended evaluation period could also include counseling and training for the disabled person and family members in preparing the individual for self-care and independent living, as prerequisites for moving into employment. In cases where the client has little competitive or sheltered employment potential or little interest in employment, the counselor can encourage the client to engage in unpaid work such as reading to others or working for charitable and nonprofit organizations. A potentially effective adjunct or alternative to traditional counseling might be provided by consumer groups. A program such as the one sketched here would probably require counselor time and would continue over a longer period of time than current counseling in VR programs.

Chapter 14

SOCIAL INTERACTION

A person's career and life style are frequently the basis for judging his success or failure. An individual's development of a sense of competency is reinforced and strengthened by achievements in work, in quality of life, and in the level and satisfaction of social interaction with others. This is no less true for the handicapped population, and the limitations imposed by a severe disability can significantly hinder the development of personality, self-concept, and competency.

Social Interaction and Self-Concept

Efforts on behalf of severely handicapped persons have been concentrated on restoration and rehabilitation to the highest level of independent functioning, especially toward the goal of self-support. For the severely handicapped, many of whom are not and may never be employable, this presents special difficulties. Self-concept and identity are established through major life roles and role relationships and the absence of work deprives one of a significant source of social validation. Without interaction in work, where most individuals achieve primary nonfamilial interaction, social isolation and a lessened self-concept can result. The following comments of persons in the survey of individuals rejected by VR reflect how disability and its resultant dependency can significantly damage a sense of self.

"I live in a dead world."

"I feel as if I am in the way. I am very bitter and grumpy, just want to die. I used to have a good disposition and helped others, now I am helpless. I am just hanging in the middle."

"I only have one friend, no family. I just stay in winter and summer. I just don't know -- I'm lucky to live."

"...as for the future, what future?"

"I am all alone waiting for the time to pass."

"Just sitting in a chair looking like a human being."

"Let's just say I'm like a person in quicksand."

"I think they think I can't do anything."

These remarks not only reflect a diminished self-concept but isolation ..."the absence of meaningful social roles or rolelessness."[1]

Isolation of the Handicapped in the VR Survey

The VR survey attempted to measure the social interaction of handicapped persons by asking a number of questions relating to family and social life. Although an individual may live with family members, often the dependency created by disability affects self-concept, his view of himself often being diminished by his handicap. The handicapping condition distorts the perception of the individual's role within the family. Survey results substantiate the fact that although many handicapped persons have opportunities for social contacts, they may still be in a state of social isolation.

Of the population sampled, 81 percent resided with family members and 65 percent of the sample had at least one relative living within 10 miles. Nonetheless, participation was quite limited. Respondents were asked about the kinds of social activities they had engaged in during the last month. The most frequently occurring activities were visiting with friends or family and shopping. Even with these activities, 33 percent had not gone outside their residence to visit family or friends, and 22 percent had not been visited in their homes by family or friends even once during the past month. Other

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[1] Ruth G. Bennett, "Distinguishing Characteristics of the Aging from a Sociological Viewpoint," Journal of the American Geriatrics Society, Vol. 16.

social activities occurred even less frequently. In one month, 66 percent had not gone out to a movie, restaurant, or any other form of public entertainment; 80 percent had not attended PTA, lodge meetings, or other social or political group meetings; 93 percent had not done volunteer work; and 94 percent had not attended school or vocational training classes.

Affiliation with other disabled people was infrequent. Only one out of ten of the individuals surveyed knew of any groups for the disabled, and only one out of ten respondents were members of such groups. Of these, only half ever attended meetings or attended no more than once or twice a year.

Due to the high percentage of persons living with or near family members, it is not surprising that when faced with a serious problem, 62 percent of the sample indicated that they could discuss it with a family member; 11 percent mentioned pastors, priests, physicians, or lawyers; and 2 percent indicated that they could talk to agency personnel. Only 11 percent responded that they did not know of anyone or were unsure that they could talk with anyone about a serious problem.

For the majority of the disabled persons surveyed, social contact is limited to the family members with whom they reside. Some indication of the extent of social isolation can be inferred from the fact that one person out of three does not leave his home to visit family or friends or to go shopping even once a month. Other forms of social contact were engaged in by less than half the people surveyed. While these statistics provide a measurement of the kinds of social interaction and activities available to the respondents, they do not give an index of the quality of these social contacts and relationships as a factor in the reduction of boredom, loneliness, isolation, and feelings of helplessness and dependency.

Moves Toward Integration of the Handicapped

In recent years the handicapped population, through consumer and advocacy groups, have become more vocal in demanding equality in education, employment, housing, and transportation. In a sense this population's right to participate fully in all aspects of life has been denied. In recognition, Federal legislators and agencies have moved to compensate for this inequality. The integration of the handicapped into the mainstream of life and fuller participation in all activities of living is more a reality today than it was 25 years ago. The problems of handicapped individuals are multiple and the needs extensive. In evaluating what has to be done, priorities for the provision of vital services such as medical, physical restoration, special education, and rehabilitation are quickly established. The special social needs of the handicapped can easily be viewed as secondary. However, in terms of addressing the comprehensive needs of this population, program components designed to improve the quality of life and social interaction of the handicapped can contribute significantly to physical, intellectual, social, and emotional growth as well as functional development. Modern social philosophy has adopted the principle that social and cultural participation is a fundamental human and civic right. "The denial of the right because of the conditions of one's life such as intellectual, environmental or physical handicap requires that society has a responsibility to render special compensatory services to make the opportunity for participation fully available."[2]

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[2] John A. Nesbitt, "The Status of Outdoor Recreation for Disabled and Disadvantaged: An Enormous Need, A Denial of Opportunity," presented at the Public Forum on Outdoor Recreation, U.S. Department of the Interior, June 1972.

With the development of special education programs for handicapped children and the growing emphasis on placing these children in regular school systems whenever possible, today's handicapped children are being given greater opportunities for developmental experiences. Many adult handicapped persons have been deprived of daily life experiences by physical limitations, inadequate schooling, institutionalization, parental overprotection, and limited social opportunities. "This deprivation can lead to an inadequate personality development, passivity, dependence out of proportion to the degree of disability, and isolation."[3] Social or recreational programs can alleviate some of these deficiencies to a degree and provide social interaction and development experiences which may have been totally or partially lacking in earlier years.

In considering the design and implementation of a program for independent living, the effects of social isolation created by limited social interaction with persons outside the family should be a program concern. "A lack of planned life experiences appropriate to an individual's age and developmental level inevitably results in a deficiency in personality development and the ability to relate to people."[4]

A social or recreational component to meet the life-enrichment needs of the handicapped should be considered in program design. Rehabilitation professionals have long held that social interaction through recreational activity can substantially contribute to rehabilitation.[5] The Rehabilitation Services Administration and the U. S. Bureau of Education of the Handicapped

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[3] Giovanna Negro, "Recreation and Adult Education," presented at the International Conference on Models of Service for the Multi-Handicapped Adult, October 1973.

[4] Edythe L. Heaton, Skills in Living... Toward a Richer Tomorrow (New York: United Cerebral Palsy Associations, Inc.).

[5] Papers on Program Development in Recreation and Physical Activities for the Handicapped (San Jose: The Institute for Interdisciplinary Studies, 1971).

have provided grant monies for research and training in the area of recreation for the handicapped, recognizing the therapeutic value of recreational activities and rehabilitation.

Because of the limited extent of social integration of the most severely handicapped in particular, they may require compensatory kinds of services. The ideal should be wholly integrated and accessible facilities for all. However, a need exists for programs and facilities to provide special opportunities to those handicapped persons who lack the skills necessary to be integrated into routine programming. Special activities could be planned and designed in much the same manner as community-based programs for the elderly: community centers, social clubs, activities, and transportation. Experiences would be provided to offer the disabled an opportunity to discover areas of competency and grow away from isolation and total dependency. The development of new skills and interests would provide transitional experiences and orientation, working toward social adjustment and inclusion in regular community programming.

The establishment of recreation programs as a related human service and its importance in relation to other supportive services has not been accepted by Federal agencies or by Vocational Rehabilitation itself. But the provision of recreational services to compensate for lack of personal and social adjustment has long been integral to the planning of voluntary social agencies. These groups have recognized the vital function recreation plays in the personal adjustment, recovery, and rehabilitation of disabled individuals.

Many adult handicapped persons have reached adulthood chronologically but the deprivations imposed by disability have resulted in inadequate schooling, overprotection, circumscribed social opportunities, expectation of failure, inadequate personality development, passivity, isolation, and dependence.[6] Recreational activities can be designed to compensate or alleviate many of these deficiencies and provide multiple opportunities for social interaction. It has been found that "when work does not permit self-actualization and self-expression, leisure activities tend to take on a compensatory meaning as a source of self-definition."[7]

Private Efforts at Integration

The Rehabilitation Institute of Chicago has initiated a program of horseback riding for paraplegics. Therapists at the institute consider this a therapeutic program since it increases independence and muscular coordination. Psychologically, the program provides for individual accomplishment and an improvement of self-image. Riding gives a sense of movement and command that is heightened and combined with a sense of achievement when the rider is a paraplegic.[8]

The results of a recent study on the physical and mental reactions of physically handicapped children to riding reveals that, in addition to the pleasure experienced, statistically significant results were measurable in increased mobility, motivation, and courage.[9]

Recreation can be a crucial element in helping a handicapped person gain self-confidence through new skills and interests. The 18th National Wheelchair Games held in 1974 demonstrate the wide range of competitive activities that can contribute to increased personal feelings of competency. Three

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[6] Negro, "Recreation and Adult Education."

[7] Elmer A. Spreitzer and Eldon E. Snyder, "Work Orientation, Meaning of Leisure and Mental Health," Journal of Leisure Research, Summer 1974.

[8] "Boots, Saddle, to Horse, and Away," Rehabilitation Record, July-August 1973.

[9] Sol Rosenthal, M.D., "Risk Exercise and the Physically Handicapped," Rehabilitation Literature, May 1975.

hundred disabled athletes competed in archery, shotput, discus, javelin, table tennis, weightlifting, distance races, and swimming events. Wheelchair basketball and wheelchair and blind bowling leagues are numerous and provide opportunities for social interaction and achievement.

Existing recreational programs and facilities in local communities hold the potential for reducing the social isolation of the handicapped. But it will be necessary to investigate funding sources and program design in an effort to implement all means of integrating the handicapped into community-supported programs.

Federal Approaches to Integration

At present, the Federal programs that address the social integration of the handicapped in activities concerned with social needs are primarily in the area of outdoor recreation. Passage in 1963 of P. L. 88-29, the Outdoor Recreation Program Act, set forth a policy that all Americans should be assured adequate outdoor recreation resources.

The Bureau of Outdoor Recreation of the Department of Interior has developed a Nationwide Outdoor Recreation Plan mandated by the Act to assess Congress, Federal, State, and local governments and the private sector on the formation and development of recreation programs. The plan calls for all levels of administration to focus on the needs of all people, including the handicapped in the planning and development of facilities, and states:

> The special recreation needs of the mentally and physically handicapped are often overlooked in the planning and provision of recreation opportunities. Physically handicapped people frequently are prevented from utilizing outdoor recreation opportunities by construction features of buildings and facilities.

The Architectural Barriers Act of 1968, noted earlier, complements this legislation by requiring that all buildings and facilities constructed in whole or part with Federal funds must be made accessible and usable by the physically handicapped. All applicants for funding from the Bureau of Outdoor Recreation must comply with the Architectural Barriers Act and follow the design criteria specified in the American National Standard Specifications for Making Buildings Accessible to and Usable by the Handicapped. The guidelines for development projects also state that "adaptations for use by the handicapped of facilities otherwise eligible for funding is strongly encouraged." Grant-in-aid funds are made available through the Land and Water Conservation Fund created in 1965 to help finance Federal land acquisition, State recreation planning, and State and local land acquisition and development.

The 1973 Vocational Rehabilitation Act states that "No otherwise handicapped individual in the United States...shall solely by reason of his handicap, be excluded from participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance."

The pieces of legislation cited have significant impact on the rights of handicapped persons to participate in recreation programs and facilities. While this legislation would appear fairly adequate to insure accessibility for the handicapped, one has only to visit a local facility to be convinced that existing requirements are not enforced. The establishment of a system of regional, State, and local monitoring would seem appropriate to insure that all Federal and State laws and regulations are being complied with. In addition, no provisions exist at this time for the modification of existing structures, a fact that contributes significantly to denying access to and participation of the handicapped.

In the absence of direct Federal appropriations for recreation of handicapped individuals, billions of tax dollars[10] are appropriated annually to various Federal, State, and municipal agencies with recreational interests. Investigation of how some of these tax dollars could be channeled across funding sources to support programs for the handicapped should be undertaken.

Progress has been made particularly in providing access to outdoor recreation facilities. The privately owned recreational enterprises (theaters, restaurants, clubs, etc.) to a large extent remain inaccessible to potential handicapped users. This may be largely attributed to lack of awareness on the part of the business sector. Public information programs designed to inform local communities and businessmen of the needs of the handicapped and to stress the community's responsibility to respond to these needs would seem an essential first step. Dissemination of information to local businessmen on facility modifications and design, techniques, and methods useful in accommodating the physically handicapped would increase awareness of the rights of the handicapped person to have access to places of recreation. Sensitizing communities through public information programs on the nature of disability and the needs and rights of the handicapped is essential to breaking down the attitudinal barriers that have set apart the handicapped in the general public's mind. The private business sector has made considerable investment in modifications to attract the able-bodied; modifications to accommodate the handicapped can be an equally good investment.

Overcoming Barriers to Social Activities for the Handicapped

The major barriers that prevent large numbers of handicapped persons from social activities are in attitudes, architecture, and transportation.

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[10] National Forum on Meeting the Recreation and Park Needs of Handicapped People, sponsored by the President's Committee on Employment of the Handicapped and the National Recreation and Park Association, August 1974.

"You have to operate on the basis that you can never move away from the reality of the situation which is that you are going to have those awful moments of not understanding and the total mental barriers between the handicapped and the normal population."

The disabled population can contribute significantly to the modification of indifference. Advocacy groups within the local community, provision of information on the needs of the handicapped citizen, lobbying for the rights of accessibility to local facilities, and increased visibility of the handicapped, all offer two-way educational experiences for both groups. Persistent pressure by handicapped individuals in an organized manner can create change. The general public will learn to accept the presence of the handicapped in places of employment, education, commerce, entertainment, and recreation.

Architectural barriers are the manmade features of buildings and facilities which prevent the handicapped from utilizing public and private social and recreational opportunities. These features of parks, theaters, restaurants, beaches, etc. exist because in the design and planning phases the needs of handicapped citizens are not considered. These barriers reflect the indifference and lack of awareness by architects, urban planners, builders, and local officials in the design and construction of facilities and effectively deny the handicapped the right to work, travel, and recreation. Incentives to create a barrier-free environment and to ameliorate the conditions which exist for the handicapped in using private facilities have yet to be addressed.

Involvement in social activities assumes a high degree of mobility. The lack of adequate and accessible transportation denies large numbers of handicapped persons the mobility necessary to become integrated into the social, cultural, and recreational activities available in their local communities.

Disability often means low income. If public administrators accept the responsibility of integrating the handicapped into community-supported activities of a social or recreational nature, they must acknowledge that programs do not provide funds for the special needs of the handicapped. In the planning sequence of programs, evaluation of the problems that in effect preclude accessibility for the handicapped even when programs exist must be considered.

The existence of attitudinal, architectural, and transportation barriers constitute the major deterrents that prevent the handicapped from receiving a fair share of community supported social and recreational services or reasonable alternatives. A major principle was enunciated by the President's Committee:

> All disabled citizens, each according to his/her individual ability, shall be guaranteed access to recreational programs, activities, and facilities which are considered public. (The term "public" to be considered both tax supported and publicly used but privately owned.)[12]

If this is to become a reality for the handicapped it must be translated into legislation, policy implementation, and attitudinal changes on the national, State, and local levels of government organizations and agencies.

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[12] The President's Committee on the Employment of the Handicapped, Committee on Recreation and Leisure, August 1974.

Chapter 15

COMMUNICATION BARRIERS

The inability to communicate effectively in itself constitutes a significant handicap to functional competency. Frequently communication problems are symptomatic of or linked with other primary disabilities such as cerebral palsy, post-stroke aphasia, or retardation. Since the establishment of an effective client-counselor relationship is central to the rehabilitation process, the inability to communicate may precipitate unsuccessful case closure, reducing the probability of rehabilitation for many.

A small number of persons having communication impairments as their primary disability were surveyed in the VR survey. Twenty persons with visual impairments (2.2 percent of the total survey population), 9 with hearing impairments (1 percent), and 5 with speech impairments (.6 percent) were surveyed. These low numbers are due to the fact that the proportions of such persons in the total population of persons rejected from VR is small, and oversampling of this group was not possible, since <u>all</u> consenting respondents within a reasonable distance from the interview sites had to be selected for interviewing to reach the desired number of interviews.

BARRIERS IDENTIFIED BY INTERVIEWS

There were a number of indications other than primary diagnosis of the presence of communication difficulties, including interviewer assessment of communication impairments, communication services received and needed, and communication equipment used and needed.

Interviewers simply noted at the end of the interview whether communication problems of various sorts were evident during the interview. Table 15-1 summarizes these results. With the exception of impairments in reading and writing, interviewers were able to make this assessment more than 98 percent

Table 15-1

Communication Problems at Time of Interview

Impairment	VR		CMRC	
	N	%	N	%
Listening (understanding) impaired	91	10.2	30	9.8
Speaking (content) impaired	89	10.0	64	20.8
Speech (intelligibility) impaired	88	9.9	79	25.[illegible]
Cultural barriers to communication--slang, heavy accent	33	3.7	18	5.9
Hearing impaired	75	8.4	24	7.8
Vision impaired	147	16.5	130	47.3

of the time. Hearing impairments were noted for 8 percent of both the CMRC and VR populations. The CMRC patients, probably because of the large number over 65 years of age, had more than twice the number of visual impairments compared to the VR population (47 percent compared to 16 percent). Speech impairments of either content or intelligibility were present in about one out of every four CMRC patients surveyed, which was more than twice as often as in the VR population. This is probably accounted for by the large number of persons surveyed in the CMRC population who had suffered strokes (43 percent had this as their major handicapping condition, compared with only 4 percent of the VR population). Impairments in understanding, however, were cited for only one out of ten in both populations.

These interviewer measures suggest a much higher level of communication impairment than might be suggested by diagnosis alone. However, these are gross measures which tell nothing about the level of impairment, whether these impairments are serious enough to require special services or devices, whether they are correctable, or whether the same individuals are suffering multiple communication handicaps. It does lead to some speculation that the reason these persons may have been closed from VR may have been partially due to difficulty in communication.

A global measure of the level of impairment in "communication and vision" was obtained by trained nurses in the CMRC survey, using the PULSES Profile[1] (see Table 15-2). At the time of interview, 38 percent had no communication problems. Another 45 percent were completely independent in communication and vision, but had a mild to moderate level of impairment (such as needing glasses or other devices). The only persons who would qualify as having severe communications problems were those who were dependent upon assistance from an interpreter or supervisor in communication (13 percent), and those who were totally dependent with respect to communication, such as individuals who could not speak at all or who

As Table 15-2 indicates, there was considerable change from admission to discharge from the CMRC in communications skills. Almost all (97 percent) were communication-dependent upon admission, compared to only 12 percent on discharge. Most of this gain was retained over the time interval from discharge to interview (roughly 1 1/2 years).

Analysis of the individual communications items (listening, speaking, cultural barriers, hearing, and vision) checked by the interviewers over this time period reveals considerably less change. All of the percentages in Table 15-3 are based on the total number for which the item could be determined. Discharge percentages for all but hearing and vision were based on a

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[1] The PULSES Profile measures the need for professional and nonprofessional assistance in six broad areas of activity. See Chapter 8, Analysis of Individuals Who Received Services at Comprehensive Medical Rehabilitation Centers.

Table 15-2

CMRC Survey--Communication Ability as Measured by PULSES Over Time

Status of Communication and Vision	On Admission N	On Admission %	On Discharge N	On Discharge %	On Interview[1] N	On Interview[1] %
Independent with no impairment	-	-	152	49.5	117	38.1
Independent with mild impairment	10	3.3	107	34.9	137	44.6
Dependent upon assistance, interpreter or supervision	186	60.6	36	11.7	39	12.7
Dependent totally	111	36.2	1	.3	12	3.9

1. Interviews occurred about 1 1/2 years after discharge.

Table 15-3

CMRC Survey--Changes in Communication from Admission to Discharge to Interview[1]

Communication Impairment	On Admission N	On Admission %	On Discharge N	On Discharge %	On Interview N	On Interview %
Listening	51	17.3	32	12.2	30	9.8
Speaking (content)	79	26.8	56	23.3	64	21.0
Speaking (intelligibility)	93	31.3	80	37.4	79	26.1
Cultural Barriers	21	7.2	20	6.8	18	5.9
Hearing	34	11.6	31	10.4	24	7.9
Vision	102	35.3	100	33.6	130	42.6

1. Percentages based on number of respondents for which this was determined.

partial sample, from 14 to 30 percent being undetermined for other items. Hence the discharge figures should be viewed with caution.

From admission to the time of discharge, gains in communication were made in the ability to understand that which was spoken, speech content, speech intelligibility, and hearing. Vision became more impaired. However, most of these gains were not particularly dramatic. A comparison of Tables 15-2 and 15-3 suggests that interviewers tended to rate persons as impaired when the level of impairment was insufficient to produce actual dependence on interpreters or others, and that the measure employed in Table 15-3 is not suitable for indicating severity of communication impairment.

Other indicators of communications impairments are provided by looking at the service needs of these persons (see Table 15-4). Speech and/or hearing therapy was received by a very small proportion of the VR sample, and by roughly one quarter of the CMRC sample; the percentages still needing speech or hearing therapy were 5.3 and 7.5 respectively.

Specific services received for the deaf and blind were asked only of VR respondents; those were received rarely, and current needs for these are also minimal. (Table 15-5) This is fairly consistent with the proportions of persons whose primary disability was a visual or hearing impairment.

A slightly higher proportion had equipment needs, however, relating to communication impairments. Equipment needs were higher for the VR than the CMRC population.

POPULATION AT RISK

Because the incidence of communication disorders affecting speech, hearing, and use of language is so closely related to the effects of other disabling conditions, there is great variation in the definitions used, criteria for severity are not uniform, and the data are incomplete. The National

Table 15-4

Communication Services Received and Needed, VR and CMRC Samples

Services	Received from VR		Received from Other Sources		Still Need		Received from VR		Received from CMRC		Still Need	
DEAF: Interpreter or other communication services	2	.2	0	0	6	.7	0	0				
BLIND: Reader services, braille instructions, management services	7	.8	5	.6	9	1.0	0	0				
BLIND: Orientation and mobility training/self-management services	2	.2	0	0	7	.8	0	0				
SPEECH/HEARING THERAPY	8	.9	11	1.2	47	5.3	4	4.1	73	23.8	23	7.5

Table 15-5

Equipment Aiding Communication, VR and CMRC Samples

Aids	VR Survey						CMRC Survey					
	Have		Use		Still Need		Have		Use		Still Need	
	N	%	N	%	N	%	N	%	N	%	N	%
Aid for Vision[1]	69	7.8	62	7.0	37	4.2	5	1.6	3	1.0	8	2.6
Seeing eye dog	-	-	-	-	2	.2	-	-	-	-	-	-
Hearing Aids	18	2.0	13	1.5		2.4	8	2.6	7	2.3	3	1.0
Speech Aids	4	.4	3	.3	1	.1	-	-	1	.3	1	.3

1. May include glasses on the VR survey.

Institute of Neurological Disease and Stroke estimates 8.5 million persons have hearing impairments in one or both ears of handicapping magnitude, 10 million have some sort of speech disorder, and 2.1 million have disorders as a result of impairments of the central nervous system.

The study has already described the blind and deaf in some detail. Other persons with speech impairments include those whose larynx or voice box has been removed. Many of these people are taught to speak with either a device or with special breathing techniques with permit vocalization. Stuttering was not counted among our most severely handicapping conditions and so was not explored. Other aspects of the approach to the communication-disabled ran into voluminous though fragmented literature, which primarily consisted of reports on techniques for dealing with individual problems in communication. The other dimension of this literature was its emphasis on technological solutions to communication problems. Much of it dealt with devices such as reading machines for the blind, special typewriters for those with cerebral palsy, video-magnification machines for those with residual sight. Much of the material was described in the chapter on technology; some of it is significant enough to warrant mention here.

TECHNOLOGY FOR REHABILITATION

One report[2] describes a device by which an electric typewriter can be operated by a person with very limited motor coordination. A number of efforts have been directed along similar lines, but this one is most noteworthy because of the degree to which it achieves three often conflicting objectives: ease of operation; adaptability to suit a wide variety of

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[2] Douglas A. Ramsay, Arthur G. Snapper and Pieter Kop, "A Foot-Operated Typewriter," Archives of Physical Medicine and Rehabilitation, April 1972.

individual circumstances; and the relatively high typing speed which even a quite severely disabled person could potentially attain.

A device called MAID (Multi Access Interface for the Disabled)[3] allows a person who is totally paralyzed to exercise a considerable degree of control over his or her environment by activating a single microswitch. By using the microswitch to drive a light along the rows and columns of a 9 x 10 matrix until it reaches the proper square, the disabled person can operate an electric typewriter, turn several other appliances on and off, and alert an attendant in another room with one of a number of preselected messages.

Communications services in the VR program have tended to be concentrated on the deaf and blind. Comprehensive programs for the mentally retarded routinely include this specialty, as do programs for the deaf-blind, autistic and mentally ill, and stroke patients in Comprehensive Medical Rehabilitation Centers. Such services in an independent living rehabilitation program would probably be expanded as part of an overall effort. Finally, there are other suggestions for enhancing communications in various chapters of this report.

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[3] J. Agzarian and J. H. Read, "A Multi-Access Interface for the Disabled (MAID)," Medical Journal of Australia, February 1973.

Chapter 16

THE MENTALLY ILL

If one looks at the possibility of an independent living rehabilitation program, or a rehabilitation agency-based program for the mentally ill, two immediate areas of concern arise. The first is the problem of definition: Who is disabled? Who is severely disabled? The second area is the interface between rehabilitation and the sets of public and private resources serving this group. From the perspective of what needs to be done to promote self-care, there is a question as to the boundaries between rehabilitation and community health centers, outpatient care, and mental hospital care.

Most of the rules, concepts and regulations one might develop for the physically or even the developmentally disabled simply do not apply in the case of the mentally ill. With the latter the diagnostic technology is underdeveloped and less precise. As treatment technologies have become highly dependent on psychotherapeutic drugs, many individuals whose symptoms are suppressed have been discharged from hospitals and do not require institutional care. But they are unable to participate in the labor market or fully adjust to unsupervised community living.

The requirements of supporting this deinstitutionalization to "independent living" include developing and managing group homes, teaching self-care skills and similar activities. There are few Federal State, or local agencies responsible for case management and coordination. Given the traditional responsibilities of State mental hospitals and other State-local programs, the question arises of how rehabilitation might differentiate itself from these service delivery programs. It is clear that some improved mechanism for serving the severely mentally ill is needed, but whether rehabilitation is the program to deliver these services is subject to debate.

There is probably little conceptual problem in identifying a group of chronically mentally ill persons who have long histories of illness often associat with more than one period of hospitalization. However, others are more difficult to identify. A person in an acute episode is too disturbed for rehabilitation, but many who go into remission are hardly impaired at all and may show no particular disabling condition at intake.

Some individuals who have had acute psychiatric episodes may have no relapses in their lives, or may have only rare episodes. Still others such as manic depressives have cyclical difficulties, but in remission, they exhibit few self-care problems.

In large measure this degree of ambiguity is reflected in the way VR treats the mentally disabled. From an analysis of VR program data we find that the menta ill are among the groups which have the highest probability of being accepted to VR if they get to applicant status. It is also one of the groups which, on acceptance, has a high probability of ending up not successfully rehabilitated. Our analysis also shows the mentally ill likely have the characteristics most associated with severe work disability, that is, with characteristics like those in the 1966 Social Security Survey of Disabled Adults who reported inability to work and had not worked for a long period. There would seem some degree of confusion in a program which accepts at intake a group which must be presenting itself as feasible of rehabilitation but, finally, holding constant age, sex, race, unemployment, agency budget, and the like, shows a relatively high degree of unsuccessful closures. If there is slippage in VR, the problem in independent living rehabilitation is likely to be more significant.

Of course, these data are for the national program. Individual States, as we point out later in this section, have developed very good programs for working with the mentally ill.

One way to deal with the problem is to adopt a "once ill, always ill" rule. Thus, if one has been severely enough impaired, say, to have been hospitalized for psychiatric services for some period and is medically considered to have continuing care needs, one could be considered in the target group for rehabilitation. Severity, however, is another matter.

While the problem of defining who is or is not most severely handicapped by mental illness has many dimensions as yet unresolved, for many of those at the extreme where some consensus exists, service needs are parallel to those of the physically disabled. The chronic schizophrenic released after 20 years in an institution needs help in finding suitable housing, learning transportation systems, developing ability to purchase goods and prepare meals, and, in effect, learning all the skills of self-care of which the impairment and institutional have deprived him. Many will be so impaired as to require attendant care, like many of the physically disabled. Also, there is of course an ongoing requirement for medical and psychiatric care.

One of the things one suspects about deinstitutionalization-- though there have been no definitive studies--is that there has been no ongoing case management responsibility. As a consequence, a number of severely impaired mentally ill, have been left worse off after released from institutions. They have either fallen through the cracks and received no service or have been connected to another system, such as Supplemental Security Income, that provides no service. Finally, these individuals are left to hit-and-miss connections with service providers in other programs.

The Community Mental Health Centers Act of 1963, administered by the National Institute of Mental Health, has helped to make available community-based inpatient and outpatient psychiatric services. However, rehabilitation is considered one of the optional services of a community health program, rather than an essential service required for funding eligibility.

Despite authorization to serve the mentally ill, which was given in 1943, the ability of State Vocational Rehabilitation agencies to serve this group really began with the 1954 Amendments to the Vocational Rehabilitation Act, which increased funding and broadened authority. These Amendments added separate Federal authority for training grants and research. Short-term training grants in psychiatric rehabilitation were instituted; long-term training grants to colleges and universities included components in the fields of psychiatry and psychology; grants for inservice training of State personnel included programs for the rehabilitation of the mentally ill.

Regulations for the 1968 Amendments to the VR Act broadened eligibility requirements for VR services to include among the mental illness category persons with "behavior disorders." A large number of public offenders were found eligibl on this basis, and the national total of rehabilitations under this category grew from 12,202 in 1968 to 37,956 in 1972.

The regulations for the Rehabilitation Act of 1973 do not permit eligibility for VR services on the basis of a behavior disorder alone. Public offenders or other clients who have previously been served on this basis may, however, still be found eligible on the basis of other diagnostic factors recognized by the psychiatric and psychological professions.

While rehabilitations of many mentally ill people with psychotic disorders have increased in absolute numbers, as a proportion of rehabilitated clients such rehabilitations have declined from 6.6 percent in 1969 to 6.0 percent in 1970 and 5.5 percent in 1972.

DEFINITION OF SEVERE MENTAL ILLNESS

One of the first steps on this front in this study was to turn to the various public and private agencies with primary concern for the mentally ill. Their responses follow.

<u>The National Association for Mental Health</u>: How many people are we talking about? We don't know. The services are disconnected, and control dispersed; there is no uniform reporting system. Furthermore, their impact on society is far in excess of their numbers. Witness the recent state-wide scandals in New York and California. Many receive attention only from the police, courts, and correctional systems.

The 1957 Commission on Chronic Illness reported 109 in every 1,000 people have a mental disorder and 49 percent of the people entering State mental hospitals have been there at least once before. The more often patients have been admitted to a mental hospital, the more likely they are to return in the future.

The National Center for Health Statistics reports that 10 percent of the people with chronic conditions are unable to carry out major activities due to mental problems. The National Institute of Mental Health Biometry Branch is currently conducting a study on chronically mentally ill people.

<u>International Committee Against Mental Illness</u>: There is no really hard data as to the number of persons--in terms of either incidence or prevalence--encompassed within the major categories of mental disorders. Such data as exists are usually extrapolations of limited and usually unrepresentative epidemiological studies in specific communities, for example, the Midtown Manhattan Study, or are based on standard institutional reports from a number of Federal and State agencies giving statistics on admissions, readmissions, discharges, etc. from such facilities as Veterans Administration hospitals, state and county mental hospitals, private psychiatric facilities, community mental health centers, psychiatric departments of general hospitals, outpatient clinics, and similar service units.

The difficulty in assessing the chronicity or degree of severity of many psychiatric syndromes is due in part to the dynamic fluidity of the psychophysiological processes involved. Judgments as to service needs and anticipated functional capacity of the physically disabled--the blind, deaf, paraplegics, etc.--although taking into account the derivative psychological concommitants of such disabilities--are generally less complex than parallel judgments required to be made for the psychiatrically disabled.

POPULATION AT RISK

There is no national system for the collection of prevalence and incidence data on mental disorders. There is, however, a statistical system which provides systematic data on the number, distribution, and characteristics of psychiatric facilities and of patients utilizing them. For example, Table 16-1 gives the number of patient care episodes in psychiatric services in 1971, by type of facility, and the percent in each type.

Table 16-1

Patient Care Episodes in Psychiatric Services, 1971

Type of Facility	Number	Percent
All Facilities, All Episodes	4,190,913	100.0
Inpatient Episodes	1,755,816	41.9
State and County Mental Hospitals	745,259	17.9
Private Mental Hospitals	97,963	2.3
Veterans' Administration Hospitals	176,800	4.2
General Hospital Psychiatric Services	542,642	12.9
Residential Treatment Center for Emotionally Disturbed Children	28,637	0.7
Community Mental Health Centers	130,088	3.1
Other Multiservice Facilities	34,427	0.8
Outpatient Episodes	2,316,754	55.3
Community Mental Health Centers	622,906	14.9
Other Outpatient Services	1,693,848	40.4
Day Care Episodes	118,343	2.8
Community Mental Health Centers	43,653	1.0
Other Day Care Services	74,690	1.8

Source: Statistical Note 92, Department of Health, Education, and Welfare, National Institute of Mental Health, Office of Program Planning and Evaluation, Biometry Branch, Survey and Reports Section.

There is no way to provide a definitive answer to the question of how well presently available mental health services are meeting the country's need. However, by hypothesizing varying levels of need, as suggested by various community surveys of the prevalence of mental disorders, by utilizing the data on the use of facilities, and by assuming that all persons counted needed the service provided, some rough estimates can be made as to the extent to which these facilitie are meeting various levels of need.[1]

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[1] Morton Kramer, "The Role of a National Statistics Programmer in the Planning of Community Psychiatric Services in the United States," in J. K. Wing and H. Hafner, eds., Roots of Evaluation (London: Oxford University Press, Ely House, 1973).

Such estimates were developed in an unpublished paper on "Issues in the Development of Statistical and Epidemiological Data for Mental Health Services Research."[2] This report estimated a low range of 4.3 million persons needing care in 1975 and an upper limit of 43 million persons.

The number and percent of episodes of inpatient and outpatient services by diagnosis is shown on Table 16-2. The high proportions of schizophrenia should be noted. This disorder accounted for over 22 percent of all patient care episodes--almost 32 percent of inpatient episodes and 16 percent of outpatient episodes.

Chronic schizophrenia must be considered one of the more severely handicapping mental conditions. The shortened hospitalization time, the impossibility of a permanent medical cure known to medicine, the lack of community resources to maintain extrainstitutional adjustment, the slight probability of employment for the vast majority of schizophrenics, and a readmission rate of 50-60 percent within 2 years are all part of the dilemma in schizophrenia.

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[2] *Ibid.*

Table 16-2

Number and Percent Distribution of Patient Care Episodes by Diagnosis for Inpatient and Outpatient Services, 1971

Diagnosis	Numbers		
	Total	Inpatient	Outpatient
Total	4,009,506	1,692,752	2,316,754
Mental Retardation	122,609	46,766	75,843
Organic Brain Syndromes	216,153	157,691	58,462
Schizophrenia	901,119	537,174	363,945
Depressive Disorders	615,261	321,708	293,553
Other Psychoses	61,851	27,810	34,041
Alcohol Disorders	353,020	227,626	125,394
Drug Disorders	117,069	68,162	48,907
All Other Disorders	1,300,728	263,403	1,037,325
Undiagnosed	321,696	42,412	279,284

Note: This table omits outpatient psychiatric services of Veterans Administration hospitals, partial care services (e.g., nightcare, halfway houses), and psychiatric services in hospitals or outpatient clinics of Federal agencies other than the Veterans Administration.

Source: Statistical Note 92, Department of Health, Education, and Welfare, National Institute of Mental Health, Office of Program Planning and Evaluation, Biometry Branch, Survey and Reports Section

The identification of the severely disabled among the mentally ill is a difficult task, even more complicated than the identification of the severely disabled among the physically handicapped. For example, social and environmental factors are even more crucial in the treatment, remission, or cure of mental illness than is the case with many physical disabilities.

The Rehabilitation Services Administration lists the following criteria for States to use in reporting the severely disabled mental ill.

Psychotic disorders:

> If now requiring institutional care in a mental hospital or psychiatric ward of a general hospital; or has history of being institutionalized for treatment for 3 months or more, or on multiple occasions; or meets the description for moderate or severe below.

Moderate:

> Definite disturbances of thinking, with definite but mild disturbances in behavior. Includes hospital discharges who require daily medication to avoid rehospitalization. With provision of rehabilitation services, capable of maintaining themselves in the community and of engaging in low-stress competitive employment, but at least initially requiring continuing supervision, guidance, motivation, and support. Misunderstanding of instructions, activity, self-isolation, or overraction in gesture, speech or emotion may be displayed during the Vocational Rehabilitation process, and may cause concern to people in the work milieu.

Severe:

> (a) Severe disturbances of thinking and behavior that entail potential harm to self or others; (b) or in the extreme, severe disturbances of all components of daily living, requiring constant supervision and care. Persons in (a), with the provision of rehabilitation services, may be capable of maintaining themselves in the community and engaging in limited or sporadic productive activity, but only under continuing supervision in sheltered or protective environment, including halfway houses.

Unable to communicate readily; have difficulty differentiating between their fantasies and reality; behavior is disruptive and often menacing to others; shouting, vulgarity, carelessness of dress and excretory functions; or possible suicidal attempts necessitate continuing observation, professional intervention and medication, especially during early stages of the rehabilitation process.

Psychoneurotic disorders:

If now requiring institutional care in a mental hospital or psychiatric ward of a general hospital; or has a history of being institutionalized for treatment for 3 months or more, or on multiple occasions; or meets the description for moderate or severe below.

Moderate:

stress reactions which modify patterns of daily living. Can maintain themselves in the community and perform adequately in low-stress competitive employment with the provision of rehabilitation services. May require medication and continuing supervision, motivation, and support at least during early postplacement. Their fears, indecision, loss of interest, or occasional odd behavior will be evident during the rehabilitation process, and may moderately interfere with job performance and other workers' activities in employment when stressful situations arise.

Severe:

Stress reactions to daily living that result in continuing regression and tissue-organ pathology. Capable of productive work but only under sheltered, noncompetitive conditions in a highly structured or protective environment, at least initially. May require continuing medication. Bizarre and disruptive behavior, loss of interest in activities of daily living, problems with memory and concentration will be evident in the counseling process and, with their interference with other workers, necessitate continuing supervision, guidance, motivation, and support by professional staff in the work situation. Conversion reactions, poor eating, and cleanliness habits may create considerable health problems.[3]

What do these people need? The National Assocation for Mental Health reported the following at a special conference of voluntary agencies.

> The chronically mentally ill need assistance in the basic skills of community living, such as finding housing, using public transportation, managing money, shopping for food, finding companionship, having activities to occupy their days, and protection from those who would hurt them. The ex-patient needs a supporting, accepting reference group which views him as a valuable, functioning group member. He must have economic and social stability. If these things cannot be found alone, assistance must be given. It is important to remember that their

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[3] Rehabilitation Services Manual, (RSA, SRS, DHEW). Section 3005.03(60).

inability to cope with the daily stress of living in our complex society is a significant characteristic of the illness, and treatment involves consideration of this limitation.

Finding housing is difficult for many people on low incomes and almost impossible for those who don't have the stamina to struggle for survival. Frequently the communities where these people can afford housing are not the ones which provide protection. Some people are not able to live alone and need help finding halfway houses, homes, foster homes, board and care homes. Many housing facilities for former patients are licensed and defined by state or local governments or, if there are no licensing procedures, the conditions will depend on the operator.

Many people who are chronically mentally ill are not able to prepare food for themselves. Even if they have the skill there may be emotional obstacles to obtaining and preparing food - immobilized by fears, apathy and withdrawal. Group living situations or a "Meals on Wheels" program may be an answer to provide food. Adequate programs must be developed and made available to the mentally ill.

Assistance in learning about and applying for financial aid often is needed. Agencies do not purposely make it difficult to obtain assistance, but bureaucratic procedures, inadequate staffing, complicated regulations, can put unbearable pressure on a mentally ill person. An advocate is needed to lead the way, open the right doors, help fill out forms.

The chronically ill are those who are unable to work in regular work settings. Therefore they need some meaningful activity to keep them as alert and involved in life as possible. Without activities, the disabling conditions will worsen instead of improving, and daily living could become as disabling and immobilizing as life in an institution. Those who are not able to participate actively in vocational training are especially vulnerable to the forces of deterioration.

The lack of motivation is one of the major disabling factors for the chronically mentally ill. Many have had years of dependence on other people in hospitals or their homes - making the decision about what and when to eat, when to sleep, when to go out - every moment scheduled and controlled. They are immobilized. The person who suddenly finds himself alone out in the world needs both mental health and social services to supply the drive and direction needed to achieve independence. Difficulties in personal relations and unacceptable social behavior may exaggerate all the aforementioned needs. The mentally ill are also met with fear, stigma, and discrimination in the community, further complicating their lives and destroying their own limited self-confidence.

REHABILITATION PROGRAMS FOR THE MENTALLY ILL

The National Association reported further:

Programs to resocialize former patients must enhance personal interaction, restore responsiblity and encourage independence. They involve primarily behavior change, not psychiatric therapy. There are several examples of programs that have worked to move the chronically mentally ill from the hospital to independent living status in the community. Some people have progressed far enough to hold jobs, even though that was not the intent of the program.

Frequently as people move through the rehabilitation process they must progress step by step - from hospital, to halfway house or day or night hospitalization or to an intensive outpatient service or foster care. The distance between a totally dependent environment and the community is awfully great for most people - it keeps many of the mentally ill in the hospital. In halfway houses several mentally ill people live together in a homelike atmosphere. Patients learn how to get along in the community, how to do household and daily living tasks. A supervisor may or may not live in the house. A mental health professional may visi to help work out problems and give support to the people in the house. There are usually 10 to 20 people living in the house. The facilities may be transitional for the patient, as the name would indicate, halfway between hospital and patient. Many halfway houses are either privately funded or self-supporting; that is, the residents are employed and able to cover living costs. Since halfway house residents in many instances must be employed, this avenue of rehabilitation is closed to most of the chronically mentally ill.

Partial hospitalization allows people the protection of the hospital during the day or the night while easing back into the community occupie the rest of the day. People may come to the hospital during the day to participate in rehabilitation programs while staying in the community at night. Or someone may need to return to the hospital at night after being in the community all day. Partial hospitalization is a required service of all community mental health centers.

Most important, any rehabilitation program must offer a non-threatening environment. In ex-patient groups the common denominator of prior psychiatric hospitalization can produce a high degree of solidarity. Expectations are not as high, and tolerance of deviant behavior is high.

NAMH cited a few examples.

The Fairweather Program in Minnesota enables a small group of mentally ill people to live and work together in relative stability. The cooperative provides members with a "family" and identification as a citizen, not a patient. The "family" does its own shopping, menu planning, deals with the telephone company, utility companies, banks. Life is less stres ful and lonely than independent living and more normal than life in a hospital or boarding home.

Two in-hospital groups feed into the community group by organizing the group, having regularly scheduled meetings, planning for discharge and making recommendations for their own rehabilitation. The program is fund by the state mental health authority, the county mental health mental retardation board, the state Department of Vocational Rehabilitation, earnings of the group and $25.00 monthly for people on Social Security or SSI. People chosen for the program have little or no work experience, have been hospitalized for a long period of time or have been in and out of the hospital over a long period of time, have no family able or willing to take them back into the home.

The OUR (Organized Unit Responsibility) Homes in Nebraska do not operate in such close contact with the hospitals. Their slogan is 'Greater Independence Through Cooperative Living.' People usually find their way to one of the 14 homes through community agencies who are responsible for them after they leave the hospital. In a OUR home the chronic patients find support from each other and from a staff coordinator. Former patients may be hired to cook, or do laundry, or clean house for the rest of the residents, while others may find jobs in sheltered workshops. Some may not be able to work. The staff helps residents adjust to the community and use the services available to them. The residents have helped the community adjust to them. Residents may move out to apartments, but if they find the going too stressful they may move back, or retain the support system by frequent visits.

The Mental Health Association in Nashville, Tennessee, has set up as a demonstration project a House of Friendship which takes referrals from the local community mental health center, which has the major responsibility for people as they return from the state hospital. Returning patients are offered some meaningful activity as well as help in readjusting to community life in programs similar to those described above.

Studies of Post-Hospital Adjustment of Former Mental Patients[4]

NAMH recounted several examples of post-hospital adjustment of former mental patients.

An early VR-sponsored project in Massachusetts conducted a three to seven year follow-up of 160 patients released from three State mental hospitals between 1951 and 1954. The investigators, Grob and Olshansky, estimated that about 25 percent of released mental patients with 90 or more days of hospitalization would be potential members of the labor force. Of this group, over half would be able to locate and sustain their own employment with little or no assistance. Some would be unable to obtain employment even with help. The remainder, about 40 percent, would be of marginal employability and would need, for months or even years, some combination of community services.[5]

The study in Vermont of mental patients served between 1955 and 1960 noted a tendency for many patients to gravitate to association with some type of institution, or to seek supportive contacts from staff members who treated them. The report states that almost 70 percent of chronic

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[4] Drawn primarily from the RSA Fisal Year 1975 R & D Plan.

[5] Samuel Grob and Simon Olshansky, Survey of Employment Experience of Patients Discharged From Three State Mental Hospitals During Period 1951-1953 (Boston: Massachusetts Association for Mental Health, 1959).

psychiatric patients can be placed in the community if adequate transitional and vocational rehabilitation services are provided.[6]

Some follow-up studies of mental patients have attempted to show the relationship between readmission rates and certain demographic variables. These efforts have met with moderate success. Linn found that the highe the number of hospitalizations, the greater the chances of being readmitted in less than a year.[7] Freeman and Simmons on the other hand found that the key variable in predicting length of time in the communit is length of hospitalization.[8] The shorter the hospitalization, the greater the success in remaining in the community. Lorei,[9] Pishkin and Bradshaw,[10] and Robins[11] found both length and frequency of hospitalization are related to outcome..

The detrimental effects of long-term institutionalization of the mentall ill have been well documented and are now widely recognized. Wing's study of schizophrenic patients in London pointed out that from the rehabilitation standpoint, a long-stay schizophrenic patient has two sorts of handicaps: the chronic symptoms which identify him as a schizophreni and which limit his capacity for work and independent living, and the secondary handicaps acquired during his hospital stay. He concluded tha "Chronicity may in fact be more a function of a custodial inert atmosphe than of the disease..."[12]

A number of studies of post-hospital adjustment have shown that return to a conjugal setting generally leads to higher social performance and prevents rehospitalization, whereas return to parental settings often leads to regression.[13] A strong relationship has also been shown betweer employment and ability to remain in the community,[14] with readmission rates for the unemployed being higher than for the employed.[15]

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[6] George Brooks and William Deane, *Five Year Follow-Up of Chronic Hospitalized Patients* (Burlington, Vermont: 1967).

[7] M. Linn, "Rehospitalization: Time in the Community as an Expression of Adjustment, *Diseases of the Nervous System*, 1964.

[8] H. Freeman and O. Simmons, *The Mental Patient Comes Home* (New York: John Wiley and Sons, Inc., 1963)..

[9] R. Lorei, "Prediction of Length of Stay Out of Hospital for Released Psychiatric Patients,"*Journal of Counseling Psychology*, 28(4), 1964, pp. 358-63.

[10] V. Pishkin and F. Bradshaw, "Prediction of Response to Trial Visit in a Neuropsychiatric Population," *Journal of Clinical Psychology*, 1960, pp. 85-88..

[11] A. J. Robins, "Prediction of Outcome of Convalescent Leave of Patients from a Public Psychiatric Hospital,"*Psychiatric Quarterly Supplement*, Part 2, 1955, pp. 1-27.

[12] J. K. Wing and G. W. Brown, "Social Treatment of Chronic Schizophrenia: A Comparative Survey of Three Mental Hospitals," *Journal of Mental Science*, 1961.

[13] Freeman and Simmons, *The Mental Patient Comes Home*; and S. Dinitz, M. Lefton, S. Angrest, and B. Pasamanick, "Psychiatric and Social Attributes as Predictors of Case Outcome in Mental Hospitals," *Social Problems*, 1961, 8, pp. 322-28

[14] Linn, "Rehospitalization," Lorei, "Prediction of Length of Stay," and T. Vitale and M. Steinbach, "The Prevention of Relapse of Chronic Mental Patients, *The International Journal of Social Psychiatry*, 10(2), 1965, pp. 85-96.

[15] Y. Dudgeon, "The Social Needs of the Discharge Mental Patient," *International Journal of Social Psychiatry*, 10(1), 1964, pp. 45-55.

Social adjustment of former mental patients has also been extensively studied, and loneliness and social isolation have been seen as major reasons for high readmission rates.[16] Chronic patients who are constantly released and readmitted seem to be characterized by marginal community ties, severe interpersonal difficulties, and lack of material and emotional support in the community. This has a direct bearing on ability to remain employed.

Approaches to Maintaining Community Adjustment

The growing recognition of the importance of community services for former mental patients has led to development of a wide variety of programs involving one or several community agencies. Precise information on the effectiveness of specific types or combinations of services for specific types of clients is surprisingly lacking. Many of the available reports are limited by an inadequate number of subjects, lack of comparison or control groups, lack of follow-up or too limited duration of follow-up.[17]

In view of the considerable evidence of social isolation as a major factor contributing to recurring hospitalization of former mental patients, many have advocated the ex-patient club as a way of maintaining adjustment. A nationwide network of social clubs is Recovery, Inc., which in 1970 listed 784 groups in 43 states and four Canadian provinces with 7,100 paid members. Outside the Recovery network, it has been estimated that in 1970 there were in the United States more than 150 ex-patient clubs, started under various auspices. The Association of Therapeutic Self Help Clubs is a loose national organization of local groups of former mental patients.

Interest in self-help organizations has been rather conspicuously lacking in the literature, and only a handful of studies have analyzed self-help groups in any depth. Katz in a review of self-help in rehabilitation pointed up a number of advantages of such groups for populations of deviant, deprived, handicapped, or disadvantaged people. Such groups can assist in overcoming isolation, providing a possibility for participation with others in constructive activity, facilitating open communication, securing personal and group satisfaction through engaging in mutually beneficial activities, and developing grass-roots approaches to problem solving.[18] Hurvitz points out that there is considerable evidence that peer self-help approaches are in fact substantially more effective than professionally organized and administered services for certain types of people.[19]

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[16] M. Raskin and W. Dyson, "Treatment Problems Leading to Readmission of Schizophrenic Patients," Archives of General Psychiatry, 19, 1968, pp. 356-60; and D. Miller and M. Schwartz, "Chronic Leave Patients: Passengers on the Hospital-Community Shuttlebus," Mental Hygiene, 49, 1965, pp. 385-90.

[17] Raymond Glasscote et al., Rehabilitating the Mentally Ill in the Community: A Study of Psychosocial Rehabilitation Centers (Washington: Joint Information Service, American Psychiatric Association, 1971).

[18] Alfred H. Katz, "Self-Help in Rehabilitation: Some Theoretical Aspects," Rehabilitation Literature, 28(1), 1967.

[19] Joseph Weinberg, A Study of the Contribution of Workshop Experiences to the Vocational Rehabilitation of Post Hospitalized Schizophrenic Patients (Newark, N.J.: Jewish Vocational Service, 1963).

Psychiatric Rehabilitation Facilities

A survey of rehabilitation facilities operated by State VR agencies was made by the Interagency Project of the National Rehabilitation Association in 1968. At that time the general VR agencies in 26 States and in the District of Columbia, Guam, and the Virgin Islands (29 agencies in all) reported that they were operating 212 rehabilitation facilities. Agencies in 19 States reported that they operated 52 rehabilitation facilities either exclusively or predominantly for the mentally ill.

Data on caseload, staffing and costs were provided for 48 of the 52 facilities for the mentally ill. Those 48 facilities served 17,814 residents and 9,661 nonresidents in fiscal 1968. They were staffed by 1,232 man years and the cost of their operation was over $11,000,000. The following tabulation summarizes the vocational rehabilitation services provided in the 52 facilities:

Table 16-3

VR Services at Psychiatric Facilities

Services	Number of Facilities
Evaluation	50
Adjustment[1]	50
Physical Restoration[2]	42
Training[3]	42
Maintenance[4]	44
Counseling	52
Social	46
Extended Employment	12
Other (Placement)	9

1. Includes work adjustment training, personal adjustment training, and other forms of adjustment services.
2. Includes a wide variety of medical or psychiatric treatment such as physician services, the various therapies, and nursing care.
3. Includes prevocational training, remedial education, skill, vocational and all other kinds of training except adjustment training.
4. Includes "bed and board" and similar expenses.

Of the 52 facilities, seven (three of which were halfway houses) were reported to be operated unilaterally by the State vocational rehabilitation agency. The other 45 were reported by the State vocational rehabilitation agency to be operated in cooperation with another public agency such as a State hospital or community mental health center.[20]

The programs at these rehabilitation facility units for the mentally ill vary as do the organizational, administrative, and financial arrangements. It is safe to say that the vast majority of their clientele would be considered severely disabled.

Cooperative programs for the rehabilitation of the mentally ill have also been undertaken to a limited extent by State VR agencies and local public schools. In at least one State, county welfare departments and the State VR agency are working together in processing clients to and from the State mental hospitals and utilizing community resources such as local sheltered workshops as a part of the common effort.

Many other examples of cooperative program[21] efforts in the vocational rehabilitation of the mentally ill could be cited. It is not known how many of the clientele in these programs would be classified as severely disabled. The programs are noted, however, since many models could be adapted to serve the mentally ill who are severely disabled.

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[20] In addition, 22 of the 52 facilities have cooperative arrangements with agencies or groups other than the host agency or its parent department.

[21] Cooperative relations between discrete agencies include many different forms of relationships. They may be simply referral arrangements whereby people seeking or needing help are referred to a more suitable agency for some or all of the services needed. They may involve arrangements for the purchase of the services of one agency by another.

Cooperative programs of services between discrete agencies involve more complicated relationships since they are characterized by joint agency responsibility in the staffing of the program or in the provision of services to clients. Changes in organizational and administrative structures and delegation of authority are often involved. Arrangements vary from out-stationing of agency personnel and services from one agency on the premises of another to an actual pooling of staffing, services or funding.

The rehabilitation research program has done much to encourage use of workshops in psychiatric rehabilitation. More than a dozen major projects were supported, several by Jewish Vocation Service (JVS) or Goodwill Industries in various cities. The initial series of projects led to a series of 13 selected demonstrations on work adjustment centers for disabled people with emotional problems.

Most of these projects had no control or comparison groups. Two of the projects with experimental and control groups succeeded in demonstrating the advantages of a work adjustment training program over counseling alone or over more limited posthospital services. JVS in New Jersey was able to employ 60 percent of a workshop group and 50 percent of a group which received vocational counseling only, but only 9 percent of a group with no special services.[22] Similarly, a study at the Institute for the Crippled and Disabled in New York succeeded in placing 75 percent of an experimental group which received comprehensive vocational services, but only 50 percent of a control group which received only services from the VR agency.[23]

Only about 17 percent of the groups were able to maintain employment during the followup period, and there was no differential influence on rehospitalization rates for either the experimental or control groups. The projects, even those working exclusively with chronic patients, succeeded in placing 50 percent or more of those trained, and some placed substantially larger percentages.

The Berman School project for severely disturbed adolescents succeeded in helping 75 percent of clients, and 50 percent were successful in maintaining jobs 6 months or longer.[24] JVS in Cincinnati placed 83 percent of those trained, but at a 1-year followup only about half of those placed were still working.[25]

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[22] Weinberg, A Study of the Contribution of Workshop Experiences.

[23] Dudgeon, "The Social Needs of the Discharged Mental Patient."

[24] G. K. Berman and J. E. Slutzsky, A Structured Therapeutic Work-Study Program for Emotionally Disturbed Adolescents (Freeport, N.Y.: 1963).

[25] L. Oseas, A Workshop Rehabilitation Program for Persons with Emotional and Mental Disabilities (Cincinnati, Ohio: Jewish Vocation Service, 1963).

Goodwill Industries in Fort Worth, working with chronic patients, placed 70 percent of the women and 63 percent of the men. However, at a 4-year followup, 20 percent of the women and 36 percent of the men had returned to the hospital.[26]

Through these projects a number of excellent models of vocational adjustment programs for chronic mental patients have been developed. Available followup data, however, seem to indicate that for some patients, time-limited vocational services alone are not enough to enable them to maintain an adequate vocational and community adjustment. Many need continuing or periodic assistance to overcome problems with living arrangements or family and social relationships. Some may need long-term sheltered or semisheltered employment and/or living arrangements. The VR program should continue to explore more effective ways to serve these severely handicapped individuals.

Community-Based Residential Services

A recent study of community services for the mentally ill estimated that there are approximately 200 halfway houses serving the mentally ill in the United States. An optimistic projection of the total number being served would be only about 3,000 people at any one time, as contrasted with between 500,000 and 600,000 residents in various psychiatric inpatient facilities. The author of the study estimates that there would be as many as 100,000 such persons who might well be able to live in the community, provided there were openings for them in halfway houses. This would indicate the need for several thousand halfway houses, rather than the present 200.[27]

The VR program has supported more than 20 research and/or demonstration projects on various types of transitional residential facilities, most of them

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[26] Asher Soloff, A Work Therapy Research Center (Chicago: Jewish Vocational Service, 1967).

[27] Raymond Glasscoe, et al., Halfway Houses for the Mentally Ill: A Study of Programs and Problems (Washington, D.C.: Joint Information Service, American Psychiatric Association, 1971).

halfway houses. Models have been developed and successfully implemented for operation of halfway houses and other residential facilities by State VR and/or other State agencies, or in some cases as an interagency effort. This has been done in Vermont, Kentucky, New Jersey, and Georgia, where a statewide halfway house program exists. Successful programs have also been developed in affiliation with Community Mental Health Centers or hospitals.

Available reports provide information on the process of establishing a residential facility, methods for securing community participation, types of services which may be provided, methods for selecting clients most likely to benefit, and the rehabilitative processes which operate in such facilities. Some of the projects also provide outcome data on the rehabilitation success of clients served. The reports are almost unanimous in concluding that the halfway house services met important needs of the clients served.

Unfortunately, documentation of effectiveness from a research point of view is limited by the fact that most of the projects did not have control groups. Glasscote's review of the literature on halfway houses states that the lowest reported rehospitalization rate was 9 percent and the highest 45 percent. It is difficult to make comparisons, because the houses were working with clients with varying degrees of disability and the basis for computation of rehospitalization statistics was not uniform.

Comprehensive Psychiatric Rehabilitation Programs

There are, at present, only about a dozen comprehensive psychiatric rehabilitation programs in the entire country, if "comprehensive" is defined as including a combination of residential, social, and vocational services. Six such programs are described in detail in a recent report of the Joint Information Service of the American Psychiatric Association. They are Fountain House in New York; Council House in Pittsburgh; Horizon House in Philadelphia; Thresholds in Chicago; Portals House in Los Angeles; and Hill House in Cleveland. These programs provide excellent models of comprehensive services for severely handicapped former mental patients.[28]

The VR program has supported rather extensive research on the effectiveness of services at Fountain House, Thresholds, and Horizon House, with rather promising results. A Horizon House project, working with mostly chronic patients, conducted a major evaluative study of the effects of combining personal counseling, resocialization, recreation, vocational training and placement, and halfway house and psychiatric consultation services.

At an 18 month followup, 76 percent of clients were living in the community and 34 percent were employed or in job training. However, 31 percent of clients had been rehospitalized for varying periods. No differences between control and project samples were noted with regard to rehospitalization rates. Investigators conclude that, although a complete "cure" may not be realistic for some of the types of clients served, an ongoing comprehensive rehabilitation program may minimize and reduce the interruptions of chronic and acute psychiatric conditions.[29]

Two major research projects at Fountain House, New York, have accumulated evidence that the program there is effective when well-attended, especially when begun in the early part of the posthospital adjustment period. Vocational services include an innovative transitional employment program, through which a large number of jobs are made available to the agency by local employers. Fountain House assures employers that jobs will be covered if clients are unable to work, and staff fill in for clients, if necessary.

Clients are assigned to jobs on a rotating basis for part-time work of about 3 months' duration. This gives them a variety of work experiences and a

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[28] Glasscote, Rehabilitating the Mentally Ill in the Community.

[29] M. A. Roecker and P. W. Dillon, Foster Family Homes for Adults (Olympia, Washington: 1971).

chance to gain confidence before finding a permanent job. The residential program of apartments in various parts of New York which are rented to two or more clients for varying periods of time. The agency also offers extensive social and other prevocational activities to members.

A followup of experimental and control patients at 24 months showed a significant difference between the two groups in rehospitalization rates. The research also showed that "reaching out" efforts succeeded in increasing attendan at Fountain House and reducing the number of rehospitalizations.[30]

Little systematic evidence is available indicating the effectiveness of any combination of rehabilitation services in reducing rehospitalization rates of very chronic patients. The finding that halfway houses or social clubs are useful suggests that those, along with more comprehensive vocationally-oriented services such as transitional employment should be part of a comprehensive program. The need for "reaching out" to insure that clients most in need of help utilize available services also merits the attention of State agencies.

Another comprehensive approach to rehabilitating the chronic patient is the Lodge system, developed by Fairweather and others at the Palo Alto VA Hospital in California. Patients in the hospital were organized into small cohesive groups, trained in decisionmaking and mutual support roles, and transferred to a former motel in the community. There they established, owned, and operated a janitorial, maintenance, and gardening services business. No live-in staff were provided, and professionals served only as technical consultants. Over a 3-year period, the 75 men originally participating earned some $52,000 through their work.

The Lodge succeeded in becoming self-sufficient and still exists, with some of its members having been on their own for more than 5 years. The success of

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30. James Schmidt, An Evaluation of Rehabilitation Services and the Role of Industry in the Community Adjustment of Psychiatric Patients Following Hospitalization (New York: Fountain House, 1969).

this program has spawned a number of replications elsewhere in the country, with about 24 such programs extant as of mid-1974.

While research in the rehabilitation of the mentally ill has covered a wide range of topics, from modalities of treatment to the use of halfway houses and workshop programs, it does not cover evaluation of the diverse programs for rehabilitation of the mentally ill conducted by State VR agencies.[31] Consequently the literature does not reflect the bulk of program activities on the mentally ill, nor the variety and complexity of the organization and delivery of service.

THE CHANGING FIELD OF MENTAL HEALTH

The introduction of drug therapy in the treatment of the mentally ill took place in the mid-1950's.[32] It was accompanied by a growing realization that treatment of the mentally ill was both possible and desirable. The need for resources in the community began to be recognized.

A significant event was the passage in 1963 of Federal legislation authorizing construction grants for community mental health centers (CMHCs).[33] The objective of the legislation was to create a community-based alternative to county and State mental hospitals for the treatment of mental illness. Congress stated its belief "that the development of new methods of treatment, the impressive evidence of the possibilities for rehabilitating the mentally ill, and a lessening of our disposition to reject and isolate sufferers, all argue strongly for the treatment of mental illness in the community."[34]

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[31] Except for isolated projects involving particular State agency efforts or certain aspects of them.

[32] Tranquilizers were first used extensively in State and county mental hospitals between 1955 and 1956.

[33] Title II of P.L. 88-164, the Mental Retardation Facilities and Community Health Centers Construction Act of 1963.

[34] Senate Report 93-1137 accompanying S. 3280, Health Services Act of 1974.

Since this period, there has been a major shift in formal care from mental hospitals to outpatient clinics. The following table shows the proportion of the total episodes each type of facility cared for in 1955, compared with the proportion in 1971.

Table 16-4

Episodes by Type of Facility

	Percent 1955	Percent 1971
All Facilities	100.0	100.0
Mental Hospitals	61.5	25.0
Psychiatric Services of General Hospitals	15.9	13.3
Outpatient Psychiatric Clinics	22.6	41.5
Residential Treatment Centers for Emotionally Disturbed Children	(1)	0.7
Community Mental Health Centers	(2)	19.5

(1) Data not reported in 1955. Percentage probably less than 1 percent.
(2) Community Mental Health Centers were not in existence in 1955.

Source: "Issues in the Development of Statistical and Epidemiological Data for Mental Health Services Research."

The emerging delivery system places responsibility on community mental healt centers to provide mental health services to all mentally ill people, including chronic cases within a geographically defined catchment area. Further, making the community mental center system the focal point for all services and accountab for their delivery calls for a working relationship with the rehabilitation services. In State hospitals VR agency staff have for many years been an integral part of the patient care team. Their role in determining if a patient is suitable for vocational rehabilitation has long been recognized. There seems to be a basis for the same kind of relationship between the VR agency and the community mental health center.

The VR agency now provides support and services for a patient while the evaluation to determine suitability for vocational rehabilitation is taking place.

The evaluation may require several weeks or may last up to 18 months under an "extended evaluation." The VR agency and the community mental health center can work together to determine the patient's psychological and social needs, often making referrals to other agencies which can provide necessary social services.

Since patients frequently need services from several different social agencies, a focal point or coordinator is needed in order to help find the needed services with the minimum amount of patient stress. The community mental health center has the obligation to provide such services.

The new Community Mental Health Center Act would require centers to provide aftercare services. This new service will provide more opportunities for VR agencies and CMHCs to work together to provide adequate services to the chronically ill.

Rehabilitation should be a part of the aftercare services delivered through the community mental health system, rather than a separate system. As the focal point of the system, the community mental health center should also be the planning agent for the chronically mentally ill patient, as well as the conduit for aftercare and rehabilitation funds for the necessary services.

Although rehabilitation or vocational rehabilitation services are not required in CMHCs under either existing or proposed legislation, such services are not precluded and, in fact, exist in many centers. A study was published in 1974 by the Mental Health Administrator, Department of Health, Education, and Welfare, of 400 centers, in which 242 responded. These centers were queried about their activities and relationships with local Vocational Rehabilitation and Veterans Administration facilities. None of the categories in the national summary differentiate between Veterans Administration and Vocational Rehabilitation, but regional summaries show that almost all centers had some sort of contact and relationships with Vocational Rehabilitation. The major trends in the relationships are quoted below.

> Most of the replies to the original letter of inquiry came from the Eastern half of the United States. The replies show that there is no single pattern of relationship between centers and vocational rehabilitation activites and services, although they do tend to fall into a trend. The major trends are as follows:
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> 1. No formal relationship exists between the center and the Vocational Rehabilitation agency although they refer to each other on an informal basis. The center supplies evaluative and psychological services to the Vocational Rehabilitation agency and the Vocational Rehabilitation agency accepts clients from the center.
> 2. Formal and often signed agreements exist between the two agencies which provide for the services to be rendered to each. These fall into varying patterns as enumerated below.
> 3. Each agency designates a liaison person or committee so there is fixed responsibility for channels of referral.
> 4. A representative from the local Vocational Rehabilitation agency visits the centers on a regularly scheduled basis to see clients.
> 5. A representative of the Vocational Rehabilitation agency attends staff meetings regularly and instant referrals can be made.
> 6. The State Vocational Rehabilitation agency places vocational counselors, secretaries, and other staff at the mental health centers. The mental health center in these cases provides space. At one center in Kentucky, the center is paying for the telephone of Vocational Rehabilitation staff. Vocational Rehabilitation staff in centers appears to be Statewide in Kentucky and this has been worked out through a central office agreement between the two agencies. Florida and Puerto Rico also seem to follow this pattern.
> 7. A small group of centers have sheltered workshop on their grounds, often including mentally retarded clients. These are found at Rockland in New York State, Rutgers in New Jersey, and San Fernando in California.
> 8. The mental health center has an affiliation with a sheltered workshop such as Fountain House in New York, Horizon House in Philadelph and Friendship House, which is affiliated with the Dumont and Hackensack (New Jersey) Mental Health Centers.
> 9. Some Vocational Rehabilitation programs have special emphasis or are especially directed to alcohol or drug involved clients.

10. In a few cases a Vocational Rehabilitation agency is represented on the Board of the Center or has an input into the policy-making structure of the center.

Several VR State agencies presently have very good working agreements with State mental hospitals and community mental health centers. Resolution of the division of labor has been difficult at times; but because the vocational focus has been evolved, the procedures are being worked out.

CHAPTER 17

THE MENTALLY RETARDED

The class of disability called mental retardation causes fewer definitional problems than is the case with the mentally ill. Where the intellectual function is very low and the behaviors quite maladaptive, there is good consensus that these persons are among the most severely handicapped. For the Comprehensive Needs Study, our concern is the relationship of Vocational Rehabilitation and a proposed Independent Living Rehabilitation (I.L.R.) program to the existing service delivery patterns and system for this group. At the level of the most profoundly retarded multiply handicapped, there seems to be relatively little of a vocational objective into which to invest funds. Voluntary agencies and State programs in the past few years have received infusions of Federal funds through Medicaid and Social Services. The Developmental Disabilities Act serves as a coordinative mechanism. All of this suggests that independent living may be left to the experts in the field of services to the mentally retarded.

VOCATIONAL POTENTIAL OF THE RETARDED

There are, however, some suggestions that the retarded as a group are more vocationally capable than is reflected in current VR programs, where almost one-eighth of the rehabilitations have a retardation diagnosis. Approximately 400,000 retarded citizens, it is estimated, could be in some productive activity if the jobs or workshops were available. There is even some suggestion that the VR program, if it were to abandon a concern for benefit/cost ratios, could go a longer way in helping severely handicapped retarded than some of the more traditional retardation experts. In a program of the Texas Blind Rehabilitation Agency, a number of young, blind, profoundly retarded individuals are enrolled in a long-term project on the grounds of a State institution for the retarded. These young people are provided services directed toward their adaption to self-care within the institution, with the eventual objective of discharge to the community and ultimately to employment. After 2 years a few have actually been put into the regular VR program and actually placed. For the remainder, it is a long process of finding the means to channel behaviors in the desirable directions. While progress is slow, it is there. While the costs are high, the costs of doing little but retaining the individual in an institution are even higher.

In an analysis of the potential costs of shifting from a custodial to a developmental strategy for serving the inmates of institutions for the retarded in Florida, it appears that the resource investment costs are approximately equal, while the potential results are individuals out of institutions and into the community.

It was not until the late 1950's that the disability of retardation received any significant attention by State agencies administering VR. From 1956 to the present, rehabilitations of the retarded grew to be a significant part of total rehabilitations claimed. From 1 in 100, the number has climbed to where "retardation" is the primary disability in almost 1 in 8 of all rehabilitations. However, the severely handicapped retarded (SHR) are still a small minority of the retarded treated.[1]

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[1] See discussion in Section II.

Use of IQ for Eligibility

Semantics is perhaps one of the great hurdles that various groups interested in the revised VR program must overcome if real problems are to be addressed. To begin with, there is no clear definition among program people of who the severely handicapped retarded (SHR) are. To some it means a specific IQ group, i.e., the severely retarded;[2] to others the severely handicapped retarded is a group defined by its ability to function with little reference to IQ.

Retardation, in its popular conception, refers to an individual with low intellectual ability manifested by short attention span, by difficulty in learning tasks, and often by emotional problems. Operationally, this popular conception of retardation has been mulled over, with changes in technically accepted definitions occurring about once every 10 years.

One of the desires among advocates for those who have low intellectual functioning is to avoid labeling. In classifying retardation, therefore, the American Association on Mental Deficiencies (AAMD) insists, in its series of definitions, that low intellectual function be accompanied by problems in adaptive behavior in order for an individual to be labeled retarded.[3]

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[2] In its presentation to Congress discussing H.R. 8395, DHEW listed only the number of severely retarded rehabilitated among its estimate of the severely disabled in its caseload for VR. In conversations with RSA personnel, this view that the SHR and the SR were synonymous was continually reinforced. As discussed later, this error is on the low side. The VR program actually does a much better job working with SHRs than it claims. But as will also be shown, there is much more that could be done.

[3] R. F. Heber, "A Manual on Terminology and Classification in Mental Retardation," American Journal of Mental Deficiencies, Monograph Supplement, September, 1959, p. 3; H. F. Grossman, Manual on Terminology and Classification in Mental Retardation (Washington, D.C.: AAMD, Special Publication Series No. 12, 1973).

Many persons with IQs below 70, who would be labeled retarded, function very respectably, even to the extent that their friends and colleagues might not realize they are "retarded." Adaptive behavior may not surface as a problem in a counseling situation until several sessions have passed or until material is gathered and analyzed. For eligibility evaluation, it is safer to assume that a person with a score below 70 on the Wechsler Adult Intelligence Scale (WAIS) and having employment problems also has adaptive behavior problems than to assume the converse. Heber estimates that over half of the individuals with IQ between 60 and 70 have such problems. The proportion jumps to 95 percent at IQ 55.[4] For planning purposes, a designation of retardation as IQ below 70 on the Wechsler Scale provides an operational definition for measuring the extent of the target population

Retardation affects nearly 3 percent of the U.S. population. Of the nearly 6 million so impaired, 400,000 are over 65 years of age and 2.6 million are under 20.[5] In the prime working age (20-64), 1.5 million (half of the remainder) are working. An additional 650,000 are gainfully occupied, primarily in keeping house. On the other hand, over 500,000 retarded adults in the community are not gainfully occupied either at work, keeping house, or as students, who, by their aggregate statistics, could be so occupied. In addition, approximately 240,000 SHRs are institutionalized in 24-hour care settings. It is estimated that well over half of these placements are inappropriate but occur because of lack of alternatives.

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[4] R. F. Heber, Special Problems: The Vocational Rehabilitation of the Mentally Retarded (DHW, 1965).

[5] Jerry Turem and Ronald Conley, Roles of the Retarded, Report to the Joseph P. Kennedy, Jr., Foundation, September 1972, p. 29.

Judging from the above facts, retardation by itself has not precluded a majority of this severely disabled group from gainful occupation. However, many factors in addition to retardation seem to compound problems for a large segment of this group.

If estimates are correct, at least 400,000 retarded persons living in the community have the potential to work. Most of the remaining 750,000 nonemployed adult retarded have some potential for additional development of activities of daily living (ADL) which will reduce their dependence on others.

Separating those who have ADL potential but not vocationsl potential from those with virtually no potential, on an aggregate basis, is impossible. Too many factors make for the success or failure of individual cases. Thus, it is most logical to look at the entire target group as a continuum of potentials.

However, some guidance can be gained from prior reports and studies related to the SHR group. These studies have shown that:

1. While IQ is indicative of the potential kind of work an individual will be able to do, it cannot be used as a screen to filter those who have work potential from those who do not.

2. Age appears to retard the training process. Older retarded adults (in their 40's and 50's) tend to be less flexible and amenable to change.[6]

3. "More retarded workers fail on the job because of problems of living than because of problems of working."[7]

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[6] E. Katz, Work Training Center, Final Report (San Francisco: National Association for Retarded Children, Inc., 1961).

[7] President's Committee on Mental Retardation, These, Too, Must Be Equal: America's Needs in Habilitation and Employment of the Mentally Retarded (Washington: The Committee, 1969), p. 14.

4. The physically handicapped retarded appear to have the most difficult time obtaining services and then being considered for jobs. Retarded citizens have higher rates of unemployment and non-employment and lower rates of pay than their average for the U.S. population.

According to Conley, there are over a million mostly older, untrained, and generally unprepared mentally retarded in the community unoccupied with work or keeping house. Because of the years of neglect, many of these individuals would need sheltered positions in workshops or in jobs specifically engineered for them in the market sector if they were to be gainfully occupied.

This group is basically over 30 years of age, untrained, semiliterate, and not used to working; their retardation is often compounded by behavioral (40 percent based on overall averages) and/or at least one physical problem (30 percent). They need training, understanding, and much preparation for work.

The public cost of retardation includes earnings loss from enforced non-employment, impaired work, and unused homemaking services of the retarded, with a deficit of $4.1 billion for 1974. Accepting Conley's calculation for excess public program costs, the cost to the economy rises to $6.65 billion.

These are not all of the costs. Productive potential of employed retardates is not always fully developed. Not rising to the highest level of employment possibly does not reduce national product; others just advance more quickly and the retarded are left behind. The retarded individual bears the burden of less than full potential earnings.

Families of the retarded and the retarded themselves bear most of the rest of the burden which might be termed the "disutilities of retardation." No direct dollar figure can measure the discomfort caused by these disutilities; some families are barely bothered, while others will go to any expense to ameliorate the situation.

With a large and fairly well defined population which has consistently demonstrated rates of success equivalent to the rest of the VR population, the natural question to ask is, Why are there not more retarded accepted into the VR program? For one thing, the VR program appears to be the last step in a fairly intricate, but new, chain of services. Because it is relatively new, it has missed most of those who would have embarked on the series earlier.

Rusalem, Baxt, and Miller amplify the issue with their report on a demonstration involving the adult retarded. While we have tended to label the group with a single name, their problems are very diverse, ranging from attitude of parents and employers to the readiness for work and the availability of such work.[8] As individuals there is a need for differential programming. "Unfortunately, not only is differential programming unavailable in most communities, but even the most general of vocational rehabilitation services may not exist in the areas in which they live."[9]

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[8] Herbert Rusalem, Roland Baxt, and Alfred Miller, Vocational Rehabilitation of the Mentally Retarded Adult, RD 2346, SRS-RSA (Springfield, Va.: The National Technical Information Service, PB 214 491, microfiche filmed 3/12/73), p. 5.

[9] Ibid., p.4.

According to the researchers, differential programming means more than just individualized programming, but programming built on assumptions which differ from those upon which the current VR-MR program is built.[10]

The State in which a person lives, and whether the residence is urban or rural, has a significant effect upon the extent of VR services and the very ability of VR to serve the SHR. States with poorly developed programs of special education or special counseling for the retarded lack an important link in the vocational development of the severely handicapped, but not totally disabled, retarded.

This statement is borne out by the vast variation in State VR agency rates of acceptances of the retarded, and their consequent closure rates. These rates varied almost sixfold among the States, from a low of 3.6 percent to West Virginia to a high of 20.7 percent in Missouri in FY 1972.

Even more striking is the variation among States in the treatment of the severely handicapped. Taken here as comprised of the moderately and severely retarded as reported by the States, the percentage of the total completed caseload varied from a low of 0.5 percent in Kentucky to a high of 5.8 percent in neighboring Indiana.

Why Are Some SHR Underserved?

It might be argued that a tremendous amount of screening of the retarded takes place before they reach the VR counselor, with only the most likely successes recommended. Special education counselors in several States have working agreements with State VR agencies for prescreening. The VR counselor serves mainly as an employment conduit with little counseling provided.[11] The 1969 profile further reinforces

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[10] Ibid., p. 5.

[11] Armstrong determined that a man-year spent wholly on counselin retarded produces 42 rehabilitants whereas it produces less than three

this surmise. Almost 55 percent of the VR-MR caseload was referred by educational institutions, compared with 10 percent for the rest of the VR caseload.

There is evidence to suggest that the VR counselor is not equipped to improve the status of the severely handicapped retarded person. The training of VR counselors in verbally oriented (as opposed to behaviorally oriented) therapy techniques may also reduce their potential effectiveness with the retarded.[12] Since a high degree of association has been made of low intellectual functioning and social maladaptation, even to the extent that the American Association on Mental Deficiencies has included it in its definition of mental retardation,[13] the inability of counselors to work with behavioral problems of retardates indicates this concomitant disability may be significant in rejecting a person for services.

Improving Present VR Program

Among the problems sometimes encountered by the job seeking retarded are: (1) lack of training; (2) discrimination on the part of employers and potential colleagues; (3) difficulty in locating jobs suitable to their abilities; and (4) inability to complete job application forms. While availability of work fluctuates, many retardates are idle in good times, even though they would be hired if somehow they and the potential employer could be brought together. The National

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(cont'd) with mentally ill clients and slightly over three with orthopedic/amputees. Philip Armstrong, "An Analysis of the Allocation of Counseling Resources in Vocational Rehabilitation Agencies," Working Paper 163-13, The Urban Institute, Washington, March 1973.

[12] William I. Gardner and John M. Stamm, "Counseling the Mentally Retarded: A Behavioral Approach," Rehabilitation Counseling Bulletin, September 1971, pp. 46-47.

[13] R. F. Heber, "A Manual on Terminology," p. 3.

Association of Retarded Citizens contracted with the Bureau of Apprenticeship and Training of the U. S. Department of Labor to find job openings for the retarded. Of the 1,500 openings found, they could fill only one-third over a 2 year period. The retention rate was 80 percent.[14]

With several hundred thousand potential workers among the one million idle retarded, opportunities such as these should not be missed.

A vast amount has been written on various aspects of the habilitation and rehabilitation of the mentally retarded. Almost 200 research demonstrations specifically targeted at mental retardation have been supported by the Social and Rehabilitation Service Administration of the Department of Health, Education and Welfare since 1955. Several others of a more general nature also treat this subject. Yet, in reviewing those reports which were obtainable little of a generalizable nature could be gleaned.

Moreover, a review of literature using Mental Retardation Abstracts as the principal source yielded no neat answers as to approach, although all agreed that deinstitutionalization was directly dependent on the amount of services. Cobb states, from his review of research through 1968:

> ...if there is one clear conclusion to be drawn from this array of studies, it is that no simple formula for prediction is possible, that the relationship between predictors and criteria are enormously complex...[15]

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[14] Final Report of the MDTA-OJT Project to Promote Job Opportunities for the Mentally Retarded (Washington: Bureau of Apprenticeship and Training, U.S. Department of Labor, 1967).

[15] H. V. Cobb, The Predictive Assessment of the Adult Retarded for Social and Vocational Adjustment: Part II, Analysis of the Literature, Report on SRS-RSA RD Project 1624, (Springfield, Va.: The National Technical Information Service, PB 205 669, filmed 2/28/72).

Butler and Browning cite "the diversity of findings and the lack of consensus among investigators concerning dimensions of and underlying reasons for the rehabilitation success of the retarded."[16] One of the main reasons for the diversity, they suggest, may be the diversity of populations used in the sample, as well as type of job placement considered.[17] Ayer and Butler found that counselor empathy, respect, genuineness, and concreteness varied widely and could be at the base of the difference between success and failure.

Model Transitional Programs in Institutions

One of the most effective transitional programs described in the literature was a project conducted at the Elwyn Institute in Pennsylvania, through which 65 clients were successfully placed in the community. These clients had IQs between 50 and 80, and had spent from 2 to 49 years in the institution. Through the project a traditionally custodial institution was transformed into a rehabilitation facility. Comprehensive services included formalized personal adjustment training, as well as a Community Work Program which allowed early detection of adjustment problems before clients were discharged.

By the end of the 4 year project, none of the clients discharged had required reinstitutionalization. Subjects were reported to be doing well in unskilled and semiskilled occupations. They had avoided serious legal difficulties and were coping adequately with daily living. The report notes, however, that levels of income remain marginal, and that clients show a need for continued advice, support, and assistance in order to maintain community adjustment.

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[16] Philip L. Browning and Alfred J. Butler, "Predictive Studies on Rehabilitation Outcome with the Retarded: A Methodological Critique," in P. L. Browning, ed., Mental Retardation (Rehabilitation and Counseling) (Springfield, Ill.: C. C. Thomas, 1974), p. 199.

[17] Ibid., p. 204.

Another transitional project, conducted by the Arkansas Rehabilitation Service, worked with 276 mentally retarded clients who had been in a custodial unit of the State mental hospital. Clients selected without regard for potential employability were offered a comprehensive rehabilitation program designed to prepare them to live and work outside the institution. The rehabilitation counselor was stationed at the institution itself and provided a powerful source of linkage between the institutional program and community resources. At the end of the project, 50 clients were closed as rehabilitated, 58 were closed as not rehabilitated, and 168 were receiving services. Unfortunately, follow-up on post-institutional adjustment was not reported.

These and other projects have demonstrated how effective vocational rehabilitation services can enable many retarded individuals to leave institutions and become employed in sheltered or competitive employment in the community.

Demonstration projects working with SHRs such as reported by Rusalem and Katz have indicated the value of developmental services for VR rejects and sustaining services for VR failures. Studies such as these as well as others have demonstrated the arbitrariness of eligibility based solely upon judgments of vocational potential.

~~Other~~ research has shown that vocational potential may be just as much related to the adequacy of services as the adequacy of the individual being served.[18] Thus the fact of failure under one set of service circumstances does not preclude the possibility of success under another set.

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[18] D. Brolin, "Value of Rehabilitation Services and Correlates of Vocational Success with the Mentally Retarded," American Journal of Mental Deficiencies, September, 1971, pp. 644-651. A board of 3 raters judged whether services provided were adequate or inadequate. Client success was correlated with these judgments. These receiving "inadequate" services did significantly worse than was predicted on a pre-service assessment.

With ADL considered as part of a continuum, the problem of eligibility determination will be eliminated. But the need for planning -- that is, predicting the aggregate need for and usefulness of services -- becomes even more crucial. In order to obtain this greater degree of accuracy it is necessary to develop a schedule which reflects, on aggregate, the potential beneficial effects of VR and ADL services. The list developed here is based on fairly scattered evidence on vocational and independent living potential discussed in the following report. It should not be used as a guide on individual cases but may be useful for planning.

The priorities suggested are almost a mirror image of the current VR-MR caseload in most States. Table 17-1 reflects the almost unanimous findings of several reports that vocational potential is not related to IQ. However, when other mental and physical disabilities are added, the person with higher IQ maintains some potential, while the person with a very low IQ has questionable potential, at best. The ordering is based on the premise that if a potential exists, the most severely disabled should receive the highest priority. While this assumption may not maximize returns based on benefit-cost calculations, it minimizes leakages of services to those with marginal needs.

Thus, in planning the development of services for the SHR, Table 17-1 should be converted into a probabilistic table reflecting the percentage of individuals in each subgroup who would be helped by (a) ADL services and (b) VR services. Such an undertaking would need data from past experience related to what proportion of each subgroup experienced net benefits from specific services at what cost.

Table 17-1

Priority Scale for VR Services to Severely Handicapped Retarded

Level of Retardation	Level of Physical Disabilities	Social Maladaptation			
		None	Mild	Moderate	Severe
Mild MR	None	L	L	M	H
	Mild	L	M	M	H
	Moderate	M	M	H	H*
	Severe	H	H	H	?
Moderate MR	None	L	L	M	H
	Mild	M	M	M	H*
	Moderate	H	H	H	?
	Severe	H	H*	H	?
Severe MR	None	M	M	H	H*
	Mild	M	H	H*	?
	Moderate	H	H*	?	?
	Severe	H*	?	?	?
Profound MR	None	H	H*	?	?
	Mild	H*	?	?	?
	Moderate	?	?	?	?
	Severe	?	?	?	?

Priority

L = Low
M = Moderate
H = High
? = Questionable as to vocational and ADL potential
* = ADL only

A beginning of these estimations can be developed from a project now in progress at California State Hospital at Pomona. Researchers under the direction of Dr. Richard Eyman have been collecting longitudinal information on retarded clients in various programs in eight States. While no VR program is now included, the services provided are similar to those that will provide SHRs in a revised VR program for ADL.

The Pomona study uses service categories established in the Developmental Disabilities Act to cluster the variety of individual services provided to retarded clients. The researchers are also measuring change in 10 demains of adaptive behavior and associating these changes with the presence or absence of a service or service category in a client's service record.

Some very preliminary figures were supplied to the Comprehensive Needs Study by the Pomona researchers. These figures suggest that services in the category of sheltered employment can be associated with improvements in client functions in the fields of independence, physical development, economic activity, developing a number/time concept, ability to do domestic work (but not general work), and socialization.

Table 17-2 provides a summary of those services associated with some positive change in adaptive behavior domains in these very early figures from the Pomona study. The importance of sheltered employment, recreation, and domicilary care services in improving adaptive behavior is an interesting one, requiring a great deal of followup study and analysis before a general conclusion should be reached.

Table 17-2

Service Areas Related to Improvement in Adaptive Behavior[1]

Adaptive Behavior Domain	Service of "significant help"[2]
Independence	Treatment, sheltered employment, recreation.
Physical development	Sheltered employment.
Economic activity	Education, sheltered employment, domicilary care.
Language development	Education, recreation, domicilary care.
Number/time concept	Evaluation, day care, sheltered employment, personal care, domicilary care, counseling, referral follow-along.
Domestic work	Training, sheltered employment, domicilary care.
General work	Counseling.
Self direction	Domicilary care.
Responsibility	Education, personal care, domicilary care.
Socialization	Day care, sheltered employment, recreation, personal care, counseling, referral, follow-along, transportation.

Note: These associations are based on very early reports and quite subject to change as more information is gathered.

[1] Based on case reports on 207 moderately and severely retarded clients developed by the California State Hospital, Pomona.

[2] Based on a change of one standard deviation in adaptive behavior score over one year.

In an accompanying letter, Dr. Eyman, principal investigator on the study, indicates that "change has much to do with initial level of functioning and age." It will indeed be interesting to see what services aid groups of different ages and levels of functioning.

Activities of Daily Living

Improving the ability of the retarded to cope with the Activities of Daily Living (ADL) has been an integral part of the VR program.

Unfortunately, VR has not taken due credit for its partial successes in reducing client dependency. When the client is closed not rehabilitated, the work going into such a client is viewed almost as wasted. Even worse is the calculation that must be made very early in a case as to the vocational potential of the client, rather than the ability of the program to help him, stepwise, to his highest potential, whether it is vocational or not.

Extended evaluation was supposed to improve this progression, but has provided less of a contribution than would have been expected. Of 71,240 VR applicants in 1973 who could be classified as mentally retarded, 19,061 (26.8 percent) were closed at applicant status. Of the 52,179 who continued, only 1,920 (3.6 percent) were closed during extended evaluation. It could be claimed that the latter percentage is indicative of the successfulness of extended evaluation in getting individuals into the VR program. However, it is even more indicative of the lack of risk taking in the extended evaluation portion of the program.

Many more SHR individuals could be admitted to extended evaluation than now occurs. If independent living were seen as a separate goal of the VR program, part of a continuum which leads to the maximum development of client potential, many individuals now considered too risky with respect to vocational potential would eventually be accepted for VR services.

In accepting these additional individuals and providing services to them, some will not progress, and some will progress only to a plateau of independent living. These two subgroups are now virtually excluded from VR. In this eligibility process, many persons with vocational potential were also probably excluded. If ADL is made an acceptable goal, not only will additional SHRs be placed in jobs, but many others will gain invaluable self-esteem while permitting excess social costs to be reduced.

Community Adjustment of Retarded Persons

The report of the Elwyn Institute project on deinstitutionalization previously described also reviews 11 followup studies of deinstitutionalized retarded persons. One which was supported by the VR program was a followup study of retarded people who had left a State institution 10 years earlier. Without detailing these studies, which varied as to the nature of population, type of community placement, length of time in the community, and other factors, it can be stated that all of them show chances of "successful adjustment" as about 60 to 80 percent. In view of this, Goldstein has concluded that "...the majority of higher grade mentally retarded inmates of public institutions will make a relatively successful adjustment in the communities when training, selection, placement, and supervision are all at an optimum." This conclusion seems to represent a consensus of attitudes of researchers in this area.

One followup study of mentally retarded supported by the VR program was carried out in Connecticut by the Connecticut Association for Retarded Children. About 215 subjects who had been identified as having IQs between 50 and 75 were studied to determine factors on successful community adjustment. The investigators conclude that the characteristics associated with success are in areas open to manipulation. Such factors include efficient use of intelligence, social competence, parental support, and presence of an emotional support figure. The report also indicates that those retarded persons with the greatest adjustment problems appear to have unutilized potential.

CURRENT RESOURCES TO MEET SERVICE NEEDS

Cooperative programs between State VR agencies and programs of special education have been mentioned as one important linkage in the vocational development of the severely handicapped retarded. The development of these programs has greatly enhanced the vocational and living potential of the retarded, particularly those with no other problems than low intellectual functioning. In FY 1974, the Office of Education allocated about $100 million for services and training for the mentally retarded.

Community mental health centers, mental retardation centers, Medicaid (Title 19), and social services under Titles 4A and 6 of the Social Security Act as amended (1973) provide the bulk of the remaining service funding (Table 17-3). These services were mentioned earlier as especially useful in reducing social, emotional, psychological, and medical dependence. The Developmental Disabilities program provides coordinative function over these and State programs. All of these programs experience tremendous variations from State to State and even within States.

TABLE 17-3

Expenditures for the Mentally Retarded,
by Source of Outlay
(in millions of dollars)

	FY 73	FY 74 (est.)	FY 75 (est.)
Medicaid[1]	226.0	280.0	350.0
Developmental Disabilities	28.4	28.4	28.4
VR	93.6	98.0	105.0
Titles 4A, 6[2]	126.4	200.0	260.0
Title 5 (Maternal Child Health)	21.5	22.0	23.0
Community Mental Health and Other Public Health Funds	15.0	17.0	19.0

1/ Medicaid increases attributed to increases in the Intermediate Care Facility program, which is primarily for long-term care, not developmental services.

2/ Much of the increase in 4A and 6 funds is for deinstitutionalization, establishment of community services, and services directed primarily at the child population. About 15 percent is available for services to the SHR adult.

Aid to States under Title VI of the Elementary and Secondary Education Act of 1965 will probably have the most far-reaching impact for the retarded. Through the development of teaching techniques and experimentation, the extent to which the retarded can actually be trained is finally being understood. The self-perpetuating relationship between mental deficiency and inability to learn is being tested. Because of these "demonstrations," court tests of equal educational opportunity have been brought in several States with the verdict almost always requiring the State to extend resource availability to this special group.

The 1962 Report to the President of the President's Panel on Mental Retardation spoke to the issue of the primary importance of VR-education links:

> ...it is clear that the first line of attack is through the educational system,.... What is needed for vocational preparation is a program starting during the teens which coordinates special education, evaluation, and guidance with prevocational training and vocational training.[19]

During the 6 years following the report, 43 VR-Research-Demonstration projects were funded to explore the potential of this relationship through work-study, These projects apparently gave sufficient impetus to work-study as to promote over 1,000 cooperative agreements between State VR agencies and school systems. In 1969, close to 100,000 students were served by these agreements, with many more being served by informal arrangements.

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[19] The President's Panel (now Committee) on Mental Retardation, A Proposed Program for National Action to Combat Mental Retardation (1962).

Models of Program Planning, Coordination, and Service Integration

The growing trend to transfer responsibility for care and rehabilitation of the retarded from the institution to the community highlights an old and familiar problem -- the difficulty in achieving coordination and integration of services to meet the multiple needs of this group. Recognition of this problem led the President's Panel in 1962 to stress the need for a continuum of care for the retarded, which was defined as: "...the selection, blending, and use, in proper sequence and relationship, of the medical, educational, and social services required by a retarded person to minimize his disability at every point in his life-span." The panel also recommended that there should be available in every community a fixed point of referral and information which provides consultation service for the retarded.

Five projects that attempted to bring about coordinated services for the mentally retarded were supported by the VR program in the late 1960s, and a comparison of the differences, strengths, and weaknesses of each of the five models was completed by the University of Wisconsin. The five projects were under the auspices of the different coordinating agencies: a voluntary association of professionals in San Francisco; a parents' group in Bridgeport; the private service delivery agency in Milwaukee; a traditional welfare federation in Cleveland; and a specially created coordinating structure that emerged from a joint powers agreement between city, county, and State governments in Los Angeles.

The report concludes that although none of the projects was fully effective in establishing a continuum of care, some of the barriers to complete success had to do with structural and political constraints in the community and the larger political system and were therefore outside the control of project staff. Recommendations and conclusions from this report, quoted below, appear to have applicability not only to coordinating services for the retarded, but also to work with other groups, including the mentally ill.

1. Funding intended to create permanent coordination or integration of services in local communities should be channeled through agencies of the state and county government, not through private, local agencies.

2. Demonstrations should always have built into their design, as a condition for getting such funds, provisions either for continuing funding from alternative sources, or for assuring dispersion of the lessons and the resources of the project to related agencies.

3. The sponsoring organization for such an activity should be as neutral as possible with respect to the interests of the units being coordinated, and should have a high degree of legitimacy in the community.

4. Mechanisms should be established so that parents, community groups, and other interested citizens can participate in goal setting and policy development for integrated service delivery systems.

5. The professional leadership of service integration and delivery structures should, however, be insulated from immediate control by advocacy groups.

6. A planning unit should be an integral part of any integrated delivery system.

7. Categorical aid programs...should be consolidated under a single, central funding facility.

8. Coalitions of agencies should be utilized as one way of establishing service integration systems.

9. Limitations on the amount of financial resources made available to a service delivery and/or coordinating organization in an integrated service delivery system in order to restrict the rate of growth to no more than twenty-five percent in a given one-year period of time.

The Developmental Disabilities legislation is designed to lead to implementation in each State of coordinated services for the retarded. Findings of available research on alternative approaches to service integration should be taken into account by the DD and VR program in planning for implementation of the current legislation.

IMPLICATIONS FOR VR

The Rusalem project provides some generalizations which, while needing further substantiation, provide a starting point for working with the older retardate. To begin with, an abundance of social services should be available: specially trained counselors, supportive services such as mobility and self care training, family counseling, long-term followup and follow through.

Sheltered employment both in special workshops and in competitive areas needs to be developed even more for this group, with longer evaluation and training periods, job site development (with much more individualized attention than is now given) even down to planning automation which will assist the client to obtain and maintain a job.

Overcoming social dependency can be a long process. The older a client, the longer the process usually takes. Counselor discouragement with client progress toward ADL during extended evaluation is one of the major reasons why a client is not accepted for full-scale rehabilitation work. The Rusalem study urges that, "The usual time boundaries set by state vocational rehabilitation agencies for free services should be waived..."[20] Having certain deadlines of time rather than seeing client progress, no matter how slow, discriminates against the SHR who is particularly socially dependent.

Part of the problem may be that the funding of extended evaluation and service purchases through Section 2 of the Vocational Rehabilitation Act funds puts such work in competition with other areas which a counselor might have decided was more important. Greater emphasis should be placed on extended evaluation through separate funding and greater flexibility in time.

The connection between State agencies offering family and community services and VR is often competitive and very tenuous. Some agency relationships work to the disadvantage of the SHR. An integral part of almost all recommended programs is family counseling and community acceptance. Often the social service agency has resources which can be drawn upon by the VR counselor who chooses not to use them, or worse, is ignorant of them. Counteracting social dependency is one of the major objectives of these social services which are authorized under various titles of the Social Security Act. There is need to bring the agencies conducting these programs together, cooperatively, and this move may

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[20] *Ibid.*, p. 20.

require a mandate in both Acts. Housing both in an umbrella agency, however, is apparently not a sufficient condition to bring the services together at the client level.

While the treatment modalities for psychological and emotional dependency are different from that for social dependency, the policy implications are almost identical. Greater and more flexible use of extended evaluation as well as other federally funded (and other) social service programs. Community mental health centers funded under various titles of the Public Health Service Act should assist in overcoming the problems associated with emotional dependency -- perhaps to the extent that the client's VR status be held open until a recommendation to close or continue to full rehabilitation is provided by the other service agency.

Services for the psychologically dependent (psychotic) mentally retarded are extremely difficult to find. Apparently the technique that has had the most success, behavior modification, is difficult to administer and often appears inhumane. Counselors usually have little background in this area, and there are few community resources to draw upon for assistance to the adult psychotic retarded. Since most of the retarded who manifest psychological dependence function at the higher levels (mild and borderline), the potential for vocational rehabilitation into fairly productive areas is high, once the dependence is removed. However, outside of a very few prisons, and other institutions work in this area remains primitive or nonexistent.

Too often the generalist-counselor is attempting to solve problems of dependency for which others may be more extensively trained and better able to handle. Just as he defers to the medical practitioner for alleviation of medical problems, so he might serve as the coordinator of services to alleviate social , emotional and psychological dependency. Serious efforts to better relate rehabilitation and developmental disabilities with respect to the severely handicapped retarded is essential with or without an independent living program.

Chapter 18

THE BLIND AND THE VISUALLY IMPAIRED

The total absence or loss of vision or a severe restriction in usable vision causes many problems for the individual. For the person who is blind from birth or very early childhood, these problems necessitate adjustments in preschool training, in vocational and academic education, and in preparation for adult life. The person who becomes blind as an adult must accomplish many adjustments, modifications, and substitutions from the sighted way of life in order to function effectively as a blind individual. In most instances the person who becomes blind as an adult will need considerable assistance from trained professionals in order to make successful adjustments in attitude, in daily living activities, and in vocational activities to permit a full and meaningful life.[1]

Blindness happens not only to an individual, but to a family, a community, a school, an employer, and in fact, to a whole culture. While this is also true of other disabilities or handicaps, there is a good bit of evidence that throughout history blindness has been regarded as a different thing. The blind person was rejected more in some cultures and protected more in others.[2]

The greatest need of the blind person is for understanding and acceptance of the disability by family and by the community. The ramifications of blindness are severe and varied and should never be underestimated. For some individuals,

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[1] Roy J. Ward, "Rehabilitation Teaching," in Richard E. Hardy and John G. Cull, eds., Social and Rehabilitation Services for the Blind (Springfield Ill.: Charles C. Thomas, 1972), pp. 350-59.

[2] Mary K. Bauman, "Research on Psychological Factors Associated with Blindness," in Hardy and Cull, <u>Social and Rehabilitation Services</u>, pp. 153-73.

the period of psychological trauma and subsequent adjustment is long; for others, relatively short. Whatever the duration, it is a period of significant stress. Thomas J. Carroll termed it "the period of mourning."

Unless the family accepts and assists the blind person in achieving the goals of employment or independence in travel and other activities of daily living, rehabilitation efforts are likely to fail. Countless case histories reveal that a great deal of time, effort, and money can be spent in helping a person overcome visual disability and achieve independence in travel and in other activities of daily living, only to find upon return home that the family was not prepared for the independence displayed and systematically went about destroying it.

Community acceptance of blindness as a disability has been slow. Investigations indicate that blindness engenders a universal and profound feeling of fear on the part of most people. In one study it was found that blindness is exceeded only by cancer as the disabling condition most feared by the public. The need for community acceptance is, however, essential to rehabilitation, and much work has gone into creating public understanding and acceptance. Better programs of public education are being carried out, the number of volunteers working in behalf of the blind exceeds by far the number working with other disability groups, and the number of blind and visually impaired persons who are successfully returned to the community is steadily increasing. Fears are gradually being overcome. However, the battle is not yet won and much more remains to be done.[3]

POPULATION AT RISK

Definitions - Blindness and Severe Visual Limitations

As defined in the Social Security Act amendments of 1967,

> An individual shall be considered to be blind if he has central visual acuity of 20/200 or less in the better eye with the use

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[3] Douglas C. MacFarland, "Social Services and Blindness," in Hardy and Cull, Social and Rehabilitation Services, pp. 366-78.

> of a correcting lens. An eye which accompanied by a limitation in the fields of vision such that the widest diameter of the visual field subtends an angle no greater than 20 degrees shall be considered for purposes of the first sentence of this subsection as having a central visual acuity of 20/200 or less.

Persons with "severe visual limitations" are broadly defined by the National Center for Health Statistics as those with both eyes involved who cannot read newsprint, even with best correction.

Prevalence, Incidence, Principal Groups, Causes

Based on the above definitions, the National Society for the Prevention of Blindness (NSPB) estimates that there are approximately 475,200 blind persons in the United States today and that 35,000 persons lose their sight each year. The National Center for Health Statistics (NCHS) estimates the number of persons with severe visual limitations at about 1,000,000 throughout the country. It is also estimated that nearly half the U.S. population suffers from a visual disability that requires corrective lenses.

It is generally agreed that in the "blind" and "severe visual limitations" groups, more than 50 percent and perhaps in excess of 60 percent are 60 years of age and older. A review of the chronological tabulations published by the NSPB in 1966 and 1969 indicates a significant increase of blindness with advancing age. Despite the fact that the elderly constitute the greatest number of the blind and those with severe visual limitation, only a modicum of rehabilitation, restorative, and social services is available to them. Robert Scott, in The Making of Blind Men, says that two-thirds of the organizations and programs for the blind cater exclusively to either children or nonaged adults and that at least 60 percent of all economic resources available to the blind are earmarked for these two groups.

At the other end of the age range are the school-age and preschool groups of blind and severely visually impaired individuals. According to the statistics cataracts, glaucoma, diabetes, and degenerative conditions.

REHABILITATION OF THE BLIND AND THE VISUALLY IMPAIRED

Services to the blind began in the United States with the establishment of the Perkins School for the Blind in 1832 by Samuel Gridley Howe. Perkins was organized as a private school with the primary purpose of providing educational services to blind elementary and secondary school children. Subsequently, State after State established residential school facilities for blind children. Those States which do not have residential schools purchase educational services from neighboring public and private residential schools or have established special education programs in the regular public school systems. There are only a few schools operated today under private auspices, and they are largely funded through public monies.[5]

For the adult blind, services were also initiated by private and voluntary agencies. Charitable organizations, workshops, Lighthouses for the Blind, and similar private agencies were organized in the metropolitan centers throughout the Nation. In fact, the adult blind could secure services only from private agencies until 1893, when the Connecticut legislature created the Connecticut Agency for the Blind to provide teaching services to the adult blind.[6] The American Foundation for the Blind lists approximately 800 separate private voluntary agencies now offering multiple services for the blind. More than 400 of these agencies provide direct services to blind persons through the use of professionally trained and qualified mobility instructors, braille and typing teachers, home economists, occupational therapists, psychologists, social workers, counselors, and work evaluators. In addition, many agencies utilize volunteers for reading, friendly visiting, shopping trips, and social, cultural, and reactional activities on behalf of the blind.

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[5] George A. Magers, "Occupational Information and Career Planning for Blind Persons," in Hardy and Cull, Social and Rehabilitation Services, pp. 275-88.

[6] Robert L. Pogorelc, "Developing Social Programs for Subprofessionals and Volunteers," in Hardy and Cull, Social and Rehabilitation Services, pp. 108-14.

These voluntary agencies are an invaluable resource to the public agency in each State that is responsible for administering the vocational rehabilitation program for the blind. From these private agencies many State VR agencies purchase services for their clientele. Most of the voluntary agencies are dependent for the survival and solvency upon the continued capacity of the State agencies to purchase such services. There is necessity for a continued-close cooperative effort between the public and private agencies, as no single program can deliver all the vital services required by the blind and the visually impaired for their rehaviiitation. At present extensive vocational rehabilitaiton services are available to a blind or a severely visually impaired person in every State.[7] While the States vary in the organizational structure and setting of the agency responsible for administering the rehabilitation and restorative services delineated in the Rehabilitation Act of 1973 and the implementing regulations.[8] Some agencies, particularly in those States where a separate agency has been established specifically for the blind, will, in addition, function as the licensing agency for the Randolph-Sheppard Vending

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7. See George A. Magers. "States Agencies Serving the Blind and Visually Handicapped," <u>AAWB Annual</u>, 1969.

8. These services for the blind and the severely visually handicapped include: diagnostic and rehabilitation evaluation services; counseling; physical and mental restoration, including surgery to restore or improve vision; vocational and other training and books, tools, etc. related to such training; maintenance; transportation; services to family members when such services and orientation and mobility services; telecommunications, sensory, and other technological aids and aid devices; recruitment and training to provide new employment opportunities in rehabilitation, health, welfare, public safety, law enforcement, and other public service fields; placement in suitable employment; post-employment services; occupational licenses, tools, equipment and initial stocks and supplies; and such other goods and services which can reasonably be expected to enhance employability. Federal Register, December 5, 1974.

Stand Program within the States. The agency will offer home teacher services for the elderly or other homebound cases; some sort of prevention of blindness program, usually directed toward children; and access to the talking book program of the Library of Congress. A number of State agencies for the blind have responsibility in the administration of the public assistance program for the blind. In some States, the agency is responsible for the operation of sheltered workshops, and increasing numbers of State agencies are establishing and operating comprehensive rehabilitation centers. A few agencies are involved in special education, usually through the operation of the State's residential school for the blind.

In 1965, 37 States vested administrative responsibility for the rehabilitation program for the blind in a State agency or organization other than the general rehabilitation agency. Today only 23 such State agencies exist. This trend to place the program for the blind in the State agency serving other handicapped people has given rise to a great division of opinion as to whether the blind will benefit or receive poorer services. A conference on future planning for the blind held in St. Louis in 1973 took the following position:

> Many State programs have lost their identity and are now a part of a multiservice bureau that serves both blind clients and those with other disabilities. One frequent result of such mergers is that blind clients no longer receive the close attention they have enjoyed in the past, and often the public worker is not professionally qualified to assist the blind client specifically during his rehabilitation period. Thus, if better services for blind and visually impaired persons are to be delivered in the decade of the '70's efforts must be directed toward preserving and strengthening State agencies for the blind, and recognizing them as specialized agencies....[9]

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[9] George Mallinson and Donald Blasch, eds., Planning Services for the Blind for the Decade of the 70's (St. Louis: 1973).

Training, Job Opportunities, and Employment

When the Smith-Fess Act was approved in 1920, blindness was generally regarded as a totally disabling condition. Idleness was accepted as a necessary consequence of visual loss. If a blind person were particularly gifted and ambitious, it was hoped that he might perhaps be put to useful employment performing some tedious, repetitive function at a sheltered workshop. Vocational objectives aimed toward a higher level of productive activity were dismissed as idealistic and unrealistic.[10] Blind men and women are today employed in jobs under practically every category in the Dictionary of Occupational Titles. Placement in highly skilled jobs calling for considerable technical expertise or in the professions is common. Certain occupational titles -- vending stand operators, dictaphone typists, switchboard operators, darkroom technicians, masseurs, broom makers, and mopwinders -- continue to represent "traditional" outlets for blind labor. The list of " "blind trades," however, is constantly being expanded. The list now includes occupations such as computer programmers and service representatives for public agencies.[11]

Increased resources have made it possible for workers for the blind to be increasingly imaginative and more sophisticated in helping their clients to establish vocational objectives. The improvement of diagnostic services and the development of more refined evaluative techniques have resulted in less frequent resort to occupational titles traditionally regarded as appropriate only for the blind. Clients who have successfully been rehabilitated by agencies for the blind are today lecturing in various college classrooms. Former clients argue cases in open court and, in some places, sit on benches to decide cases. They hold elective offices and serve on the staffs of governmental agencies

The Rehabilitation Services Administration reports that in FY 1974

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10. *Ibid.*
11. *Ibid.*

compiled by the American Printing House for the Blind, in 1970 there were 12,812 blind children attending the public schools and 7,951 children enrolled in residential schools for the blind. As to the severely visually disabled children, two estimating ratios are generally accepted in establishing incidence. One is that 1 out of every 500 school children in the United States has a visual impairment severe enough to warrant special consideration. The other estimate is, that there are approximately one and one-half times as many severely visually impaired persons as those falling within the definition of blindness.

Of great concern is still another group of blind and severely visually impaired individuals, those with multiple handicaps. Suffering from severely disabling conditions in addition to blindness, this group is posing new problems for the educator and rehabilitation worker. As a result of the rubella (german measles) epidemics of 1963 and 1965, approximately 30,000 babies were seriously affected by this seemingly mild disease. If a woman has rubella in the first trimester of pregnancy, her baby may be born deaf, blind, deaf-blind, mentally retarded, or with other severely limiting conditions. It is anticipated that thousands of blind and deaf-blind children will be applying for educational services as a result of the 1963 and 1965 rubella epidemics. A comprehensive study of multiply handicapped blind youngsters, covering all blind children in California, found that more than 50 percent of the 1,900 blind children in the survey were multiply handicapped. If these data are applied on a percentage basis across the Nation, it soon becomes evident that what was thought to be a sound educational program for blind children in the past will be inadequate for those enrolling for educational services in the next several decades.[4]

The most common traces of blindness in infants and children are congenital defects and injuries, respectively. In adults, the most common causes are

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[4] Ibid.

29,000 blind and visually handicapped individuals were rehabilitated at an estimated cost of $51,122,000. About 8,900 of these individuals are blind. Of these 8,900, over 1,000 found jobs in a wide range of professions--teaching psychology, law, social work, chemistry, physics, and in managerial pursuits. Two thousand or more are in manufacturing operations and over 2,000 in service, sales, stenographic, and clerical occupations. The balance are in workshops, agriculture, and homemaking.

By way of contrast and indicative of the year-by-year progress, Magers reports that prior to 1943 fewer than 1,000 blind people in the United States moved into the competitive labor market each year through the State-Federal vocational rehabilitation program.

The increase in the numbers of blind persons in schools of higher education is also indicative of the expansion of work opportunities for the blind. In 1970 about 2,500 blind persons were enrolled in over 450 colleges and universities throughout the country, majoring in almost every subject area offered.[12] Today almost twice that number are enrolled.

Notwithstanding the vastly expanded employment opportunities for the blind, agencies serving them must constantly devote a major portion of their efforts to job placement. Negative attitudes and prejudices toward the employment of the blind persist. Changing these attitudes requires highly trained personnel and personal contact and educational programs through all available media. With more sophisticated technology in jobs, it is becoming increasingly more important for the rehabilitation agencies to give their counselors specialized training in placement and the technological assistance of industrial engineers, electrical engineers, and other professionals.

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[12] See Magers, "Occupational Information."

Of the approximately 35,000 persons estimated by the National Society for the Prevention of Blindness who lose their sight each year, it is estimated that 25 percent have excellent potential for competitive employment..

In order for the State agencies to provide vocational rehabilitation services to the 9,000 persons who are newly blinded each year and at the same time make reasonable inroads into the backlog of the blind and the severely impaired in vision who also need rehabilitation services, increases in State and Federal appropriations to these agencies are required.

The Randolph-Sheppard Program

The Randolph-Sheppard program offers one of the major opportunities for managerial positions for the blind. More than 500 blind people enter this program each year, and their average annual earnings are constantly rising.

From 1936, when the Randolph-Sheppard Act became law, to 1954, when the Act was first amended, the number of vending stands increased from fewer than 100 to 1,599. The 1954 amendments, among other things, changed the term "Federal buildings" to "Federal properties," thereby expanding vending stand opportunities, and permitted the setting aside of funds from the operation of stands for the purchase, maintenance, and replacement of equipment, management services, and a fair minimum return to operators.

Since 1954 the vending stand program has continued to grow at a steady pace on both Federal and non-Federal property. Major emphasis has been placed by the States on the establishment of better-equipped and more attractive stands and on improvement of operating techniques which would result in higher earnings for blind operators. Table 18-1 reflects program growth in terms of total number of vending stands, operators, average net earnings, and gross sales.

While initially the Randolph-Sheppard Act was enacted for the purpose of providing employment opportunities for the blind in Federal buildings, its real

Table 18-1

Growth of the Randolph-Sheppard Vending Stand Program

Years	Total Number of Vending Stands	Total Number Operators	Annual Average Net Earnings of Operators	Gross Sales
1954	1,599	1,659	$2,193	$21,972,549
1955	1,664	1,721	2,345	23,538,907
1956	1,727	1,804	2,532	25,849,730
1961	2,174	2,332	3,900	42,057,385
1962	2,257	2,425	4,140	45,737,979
1963	2,365	2,542	4,392	49,512,287
1964	2,442	2,641	4,452	53,916,331
1971	3,142	3,452	6,516	101,304,773
1972	3,229	3,583	6,996	109,847,028
1973	3,306	3,636	7,428	119,350,995
1974	3,377	3,698	8,076	133,721,276

Source: For data to 1964, Jennings Randolph, "The Story of the Randolph-Sheppard Act," in AAWB Annual, 1965; later years from Rehabilitation Services Administration.

expansion has resulted from establishments on State and private property. FY 1974 data reveal that while 891 (23 percent) of the total number of vending stands are located on Federal property, the remaining 2,486 locations are on State, city and private property.

In 1974 the Randolph-Sheppard Act was again amended, with the Congressional declaration of purpose that "The potential exists for doubling the number of blind operators on Federal and other property under the Randolph-Sheppard program within the next five years...." The amendments give priority (rather than preference) to blind vendors on Federal property; require that after January 1, 1975 all buildings, owned, leased, occupied, or renovated include satisfactory sites for a blind vending facility; require the assignment to the stand operator of 100 percent of vending machine income from machines in direct competition to the operator. They also provide for uniform and effective training to blind individuals and upward mobility training and follow-along services to trainees;

direct studies pertaining to set-aside funds, retirement, and health insurance for blind licensees, and methods of assigning vending machine income; promulgation of uniform regulations by the Rehabilitation Services Administration for State licensing agencies on such matters as accounting procedures, set-aside fund control and the establishment of new vending facilities; and authorization for aggrieved blind licensees of the right to full evidentiary hearings and prescribing procedures relative thereto.

Workshop Employment

Sheltered workshops for the blind were the spearhead for employment opportunities for blind persons in the United States. The first such workshop was established in 1840 in Massachusetts to provide employment to graduates of the Perkins School for the Blind, on whose grounds the workshop was established. Later the workshop was separated from the school. For years sheltered workshops were the main avenues of employment for the blind and in some communities the sole opportunity for employment. While today employment opportunities for the blind are open in almost every field of work, there is still need for the sheltered workshop, both in the rehabilitation process and as a source of remunerative employment for many blind people who otherwise will remain unemployed.

There are 30,000 to 40,000 blind persons in the United States who could benefit from workshop services.[13] Many of these people in addition to being blind have been further disabled by cerebrovascular and cardiovascular accidents, cerebral palsy, mental retardation, mental or emotional illness, deafness or

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[13] Harold Richterman, Services to the Blind: A Community Concern, Eleventh Institute on Rehabilitation Services (DHEW).

severe hearing loss, diabetes, orthopedic disorders including amputations, tuberculosis, alcoholism, drug addiction, and other disorders. Only about 5,000 such blind individuals are currently receiving the rehabilitation and employment services which the sheltered workshops have to offer, and these blind people are principally in the 87 workshops (in 36 States) affiliated with the National Industries for the Blind. Workshops for the blind, like those for other disabled people, have been supported over the years through voluntary contributions and philanthropic bequests. They have been strained to their financial limits and cannot, without direct public support, meet current needs. Further discussion of workshops is contained in our chapter on Rehabilitation Facilities.

THE AGING BLIND AND THEIR NEED FOR SERVICES

As noted earlier, persons 55 years of age and over who are blind or who have severe visual limitations constitute at least 60 percent of the approximately 1,500,000 Americans without sight or with vision loss that functionally approaches the legal definition of blindness. Little seems to be done to help this group of people reach a status of self-care. To attain this status they need a variety of rehabilitation services, preferably as sight is failing and not when total loss occurs, among which are the following:

1. Rehabilitation Teaching or "Home Teaching" Service - the teaching of the basic fundamentals of managing common skills of daily living without eyesight or with impaired eyesight. It encompasses specific and identifiable teaching techniques and skills to assist the blind and visually handicapped individual in developing personal independence, manual dexterity, skills in communication including teaching braille to those who are ready for it, home orientation, home management, general self-management, and when possible the working out of unique and original methods of performing without sight (or with limited sight) activities necessary to the particular individual's well-being which are special and peculiar to his case.

2. Orientation and mobility services - the teaching of methods of independent travel on foot without sight or with impaired sight. Mobility in this context is the act of moving, and orientation is awareness of pertinent factors in the environment which enable the person with partial or total impairment of sight to react, move, and travel in a safe, appropriate, and purposeful manner. Teaching of these skills encompasses both the immediate and personal surroundings of the blind individual and ranges out as far as his activities and interests may be expected to require him to go. It separates this particular area of self-management without sight from rehabilitation teaching services, except for

limited home orientation, which is sometimes given by the rehabilitation services teacher. Accepted orientation and mobility services may be based on use of dog guides or on the special technique based on manipulation of the cane, known by various names, sometimes the Hoover or Hines method, and sometimes termed peripatology. Certain electronic devices for detecting obstacles have come into existence recently and are presently under development; these require a third method of use and instruction if they are preferred.

The greatest loss a blind person experiences is mobility; freedom of movement from place to place, the ability to go from here to there unhampered by not seeing. The Rehabilitation Services Administration estimates that there are "probably 100,000 blind persons in this country today who could profit from a modicum of travel instruction plus some training in activities of daily living. These services alone could mean the difference between continuance in the family constellation and custodial care."

3. Supportive services such as: housekeeper and homemaker services; social adjustment services--the identification and utilization of educational, recreational, and other resources leading to community participation and the breaking out from a life of loneliness and isolation; housing services; individual and family counseling; domiciliary care; protective services; and guide and reader services.

The above services would not only make it possible for those older persons who are blind or who have impaired vision to live productive and more satisfying lives, but additionally would in many cases eliminate or reduce institutional costs. In most nursing home facilities, care for blind patients is considerably more expensive than services rendered to sighted patients in the same facility. The increased cost is based upon the assumption that all blind patients need to be led around, to be given intense assistance in coping with routine activities, and, in the majority of cases, to be fed by attendants. Recently this assumption has been brought into question by a project conducted by the Minneapolis Society for the Blind which had as its objective the closing of a segregated home for the blind and training the residents to get along in nonsegregated environments. The project appears to have been successful in realizing its objective, and is enhancing the positive attitude of blind residents, who now seem much happier in their new environments and new found independence.[14]

In regard to blind persons in institutions, many of whom are elderly, MacFarland states:

> There are literally thousands of blind persons who are now being held in mental institutions and in facilities for the mentally retarded. With the provision of good diagnostic evaluation, plus a modicum of self-help and self-care training, most of these persons could return to living arrangements with their families and in certain instances might even be trainable for self-support in a workshop or other employment situation. The techniques for dealing with this pitiful dilemma are well established. In facilities for the custodial care of the mentally retarded as well as in hospitals for the chronically disabled, only a few efforts have been made to identify blind persons who may be under custodial care without any reasonable basis other than that the person is blind, has been committed, and there is no one willing to take the responsibility for his release. Preliminary information brought to the attention of the Rehabilitation Services Administration is sufficient to indicate that there are eight to ten thousand persons now so incarcerated. These persons need all services to prepare for self-help and self-care, recreational services, and other services. There is a great need for the establishment of teams to visit institutions in question, identify blind persons now being retained by these institutions, assess their mental and physical capacities, and recommend an action program which can be put into effect.

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[14] MacFarland, "Social Services and Blindness."

Foremost among the multiply handicapped who require extra and special services for their education and rehabilitation are those persons who are both deaf and blind. The National Center for Deaf-Blind Youths and Adults, originally authorized by the 1967 amendments to the Vocational Rehabilitation Act and now operating under authorization of the Rehabilitation Act of 1973, is organizing and conducting a program to provide essential rehabilitation services to deaf-blind youth and adults throughout the country. A separate program, administered by the Bureau of Education for the Handicapped, U.S. Office of Education, serves deaf-blind children throughout the nation.

Development of Services for the Deaf-Blind

The education of deaf-blind children is generally considered the beginning point of organized services for the deaf-blind. In 1837 Laura Bridgman, a seven-year-old deaf-blind child, was admitted to the Perkins School for the Blind, then known as the Perkins Institution for the Blind, in Watertown, Mass. The fact that this child, who was totally deaf and practically blind since shortly after the age of 2 years, was able to learn to read, to communicate--though she never acquired the ability to speak--and to develop intellectually created a great deal of interest among educators and writers.[15]

About half a century later, Helen Keller was admitted to Perkins at the age of eight, after her mother had read about the work with Laura Bridgman in Dickens' American Notes. Helen, who had become totally deaf and blind as a result of an illness contracted at 18 months, had been trained and tutored for some years prior to her admission to Perkings by Anne Sullivan, a former student

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[15] Unless otherwise indicated, data in this section are from Harry J. Spar, "The Deaf-Blind," in James F. Garrett and Edna S. Levine, eds., Rehabilitation Practices with the Physically Disabled (New York: Columbia University Press, 1973), pp. 497-524.

at Perkins who had a major visual handicap all her life. The lectures and writings of Helen Keller brought her to the attention of persons of influence throughout the world. Other deaf-blind persons, not as well known as Laura Bridgman and Helen Keller, were also demonstrating that deafness and blindness need not constitute a barrier to useful and productive living.

Several schools for the blind in the United States opened special departments for deaf-blind children. But until recent years, the education of deaf-blind children in these institutions tended to be reserved for the most promising and to focus on the development of scholastic attainments rather than on the practical skills of self-care, social intercourse, and vocational preparation.

However, with the development of rehabilitation services for deaf-blind persons, educators came to recognize that successful living as a deaf-blind person does not necessarily correlate with academic achievement and need not be limited to the intellectually gifted. Even if a deaf-blind person is not able to read, to write, to compute, or to perform any academic activity above a very basic level, he can still be a helping member of his family, engage in remunerative employment, and accomplish many of the objectives of his non-handicapped peers if he is able to care for himself, relate to others, perform manual work tasks, and maintain acceptable work discipline. With this realization came the recognition that many more deaf-blind children than had been supposed could benefit from properly designed and properly administered educational programs. Recognition of this fact was strengthened by the increase in the number of multihandicapped deaf-blind children that resulted primarily from the 1963-65 rubella epidemic. Responding to the need for expanded educational services for such children, Title VI of the Elementary and Secondary Education Act was amended in 1968 to establish model centers for deaf-blind children.

In regard to deaf-blind adults, over the years there have been a few small islands of services for such persons throughout the United States. Usually, the services weremotivated and sustained by a desire to serve a few deaf-blind individuals in the sheltered workshops of particular agencies for the blind. When the deaf-blind clients would retire or for some other reason withdraw from the labor market, the services that had been built around them were generally discontinued.

An outstanding exception is the Industrial Home for the Blind in New York, which has provided specialized continuous services for deaf-blind adults for over 50 years. In 1945 these services were organized into a formal rehabilitation program for the deaf-blind, and in 1962, as a result of regional research and demonstration projects, they were greatly intensified and expanded to reach deaf-blind persons, mainly within the 15 northeastern and central eastern States. Prior to 1962, the specialized services for deaf-blind adults offered at the Industrial Home for the Blind were designed to enable the deaf-blind clients of the State rehabilitation agency to make maximum use of the services that the agency provided for its hearing-blind clientele.

With few exceptions, it was found to be impracticable to serve deaf-blind children or deaf-blind adults through services for the deaf. Understandably, workers with the deaf center their educational, rehabilitation, and employment efforts on the sense of sight. This being the case, a person who is blind as well as deaf can seldom be satisfactorily served in settings designed for deaf persons who can see.

The experience of the Industrial Home for the Blind has demonstrated that certain deaf-blind persons can make good use of many of the services designed for hearing-blind persons. Examples are training in suitable methods of communication and special instruction in physical orientation and independent mobility. However, integration of the deaf-blind with the hearing-blind could not be easily accomplished and often was, in fact, virtually impossible to achieve. With reluctance, it was concluded that separate residential accommodations, separate recreational programs, and a number of separate rehabilitation evaluation and training services were required to achieve maximum rehabilitation for most deaf-blind persons. For the few who were free from any major handicap other than deafness and blindness and possessed good mental capacity and high motivation, integration with their hearing-blind peers was possible, and in some case integration with their nonhandicapped peers as well.

As indicated earlier, the 1967 amendments to the Vocational Rehabilitation Act authorized the establishment of the National Center for Deaf-Blind Youths and Adults. Based on proposals submitted by organizations interested in operating the Center, the Industrial Home for the Blind was selected to operate the National Center under an agreement with the Department of Health, Education, and Welfare.

The National Center for Deaf-Blind Youths and Adults was created to:

1. Demonstrate methods of: providing the specialized intensive services and other services needed to rehabilitate handicapped individuals who are deaf and blind; and training the professional and allied personnel needed to staff facilities specifically designed to provide such services.

2. Conduct research in the problems of rehabilitating deaf-blind individuals and ways of solving these problems; and/or to improve the services for or help improve public understanding of the problems of deaf-blind individuals.[16]

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[16] Rehabilitation Act of 1973, Public Law, 93-112.

Definition and Enumeration of the Deaf-Blind

A major problem in the effort to identify the deaf-blind population lies in the fact that there is not as yet any common accord as to what constitutes deaf-blindness. In an agreement between the Department of Health, Education, and Welfare and the Industrial Home for the Blind in connection with the operation of the National Center for Deaf-Blind Youths and Adults, "Deaf-Blind" and "Deaf and Blind" persons are designated as those "who have substantial visual and hearing losses such that the combination of the two causes extreme difficulty in learning." This designation encompasses a fairly broad group of visually and auditorily impaired individuals. The size of the group can be significantly affected by subjective interpretation of "extreme difficulty in learning" as well as by the influence of mental ability, motivation, and other factors which are extraneous to the degree of visual and auditory losses involved. However, the designation provides practical parameters in which to develop a simple, objective, and restrictive definition of deaf-blind, with room for exceptions to the restrictions where clearly warranted in individual cases, and with a basis for giving priority attention to those most severely handicapped by visual and auditory losses who are least likely to receive any services from local resources.

The National Center currently employs a restrictive definition of "deaf-blindness."

> Blindness is defined as central visual acuity of 20/200 or less in the better eye with correcting glasses, or central visual acuity of more than 20/200 if there is a field defect such that the peripheral field has been contracted to an extent that the widest diameter of visual field subtends an angular distance no greater than 20 degrees, and deafness is defined as a chronic impairment of hearing so severe that most speech cannot be understood, even with optimum amplification.

In recent years, the increased incidence of brain damage accompanying deaf-blindness has pointed up the need for adding a specified decibel loss within the speech range to the definition of deafness to help assure that the inability to understand most speech results primarily from a major hearing loss rather than from mental deficiency. Particular care must be taken to avoid dissipating resources being developed for the rehabilitation of deaf-blind persons through misapplication to persons with communicatio difficulties who are not deaf and who might be more effectively served in programs specifically designed to meet the problems related to their particular handicaps.

Problems of definition inevitably create problems of enumeration. Testifying before a select Committee of the House of Representatives on July 18, 1967, Peter J. Salmon, administrative vice president of the Industrial Home for the Blind and director of the National Center for Deaf-Blind Youths and Adults, summed up the situation as follows:

> We do not know how many deaf-blind people there are in the United States, and we never will know until service is available to them. Estimates of the numbers seem to center around 4,000 or 5,000; but we dare say that there may be twice as many as this .
>
> One of the problems of recent origin which will have market effect on the deaf-blind population in the immediate future is the impact of the epidemic of German measles of 1964 and 1965. This brings a factor into the picture which is completely new, and one which has given great concern to those interested in the education of deaf-blind children. Those of us who are primarily concerned with rehabilitation aspects will need to plan for the rehabilitation of these children in the immediate years ahead.

Program Progress

The National Center for Deaf-Blind Youths and Adults has made considerable progress since the initiation of its operations on June 24, 1969. It is now housed in a former warehouse in New Hyde Park, N.Y. about 25 miles from mid-Manhattan and will remain in this temporary facility until completion of construction of its permanent quarters, anticipated to be ready for occupancy about October 1, 1975. The Congress appropriated $7,500,000 for construction and equipping of the permanent facility.

The temporary facility of the National Center cannot accommodate enough of the equipment required for the medical, indistrial arts, homemaking, and certain other services involved in rehabilitation, evaluation, and training. Therefore, some of these services are provided at the Industrial Home for the Blind (IHB) Rehabilitation Center, less than a mile from the National Center. These services are purchased at below cost for the clients of the National Center by their sponsoring agencies. No charge is presently made for any service provided directly by the National Center.[17]

Comprehensive rehabilitation evaluation and training services can be provided at the temporary facility of the National Center, supplemented by the Industrial Home's Rehabilitation Center, for approximately 18 clients at any one time. The exact number of clients that can be served varies somewhat according to the composition of the client group, since more capable clients are able to make greater use of IHB facilities than those who require protracted use of less complex activities of the type that can be provided at the National Center facility.

Since March 1970, the National Center has opened five regional offices in Glendale, Calif., Atlanta, Chicago, Philadelphia, and Dallas. Since its inception on June 24, 1969, the total number of clients served by the National Center is 732. During the 1974 calendar year, 496 clients received services, 129 were served by headquarters personnel and 432 were served by four regional representatives, including 65 who were served by both headquarters personnel and regional representatives.

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[17] National Center for Deaf-Blind Youths and Adults, Reports of Progress January 1, - December 31, 1974 (RSA, DHEW).

Of 36 persons in the Center in 1974, 19 completed their training; 4 were placed in competitive employment; 3 were placed in sheltered workshops; 2 returned to college; 1 started college; 1 was placed in on-the-job training in a paraprofessional position; 1 reassumed responsibilities as a homemaker; 1 is working in a family business; 1 returned to a professional position; 2 are awaiting placement in sheltered workshops; 2 are awaiting placement in competitive employment; and 1 withdrew. Twenty-one applicants were being processed at the end of the 1974 year for possible enrollment at the National Center, and 17 of the 1974 enrollees were carried over into 1975.[18]

In addition to the direct services provided to clients, the Center conducted an extensive community education program; provided consultation to a variety of local, State, regional, and national agencies concerned with the deaf-blind; conducted research independently and in cooperation with the National Aeronautics and Space Administration and International Business Machines on new equipment and new methods to advance and facilitate rehabilitation of the deaf-blind; and conducted training programs for workers in agencies for the blind and agencies for the deaf to develop greater skill in working with their deaf-blind clients. Over 100 staff members of these agencies from 36 States, the District of Columbia, and the Virgin Islands have attended these one-week training courses. Trainees have come from many fields--counseling, education, social work, psychology, nursing, rehabilitation, adult education, and the teaching of braille and language arts.[19]

There is a close working relationship between the center and the education program for the children who are deaf-blind to provide among other things, for

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[18] *Ibid.*

[19] *Ibid.*

ready transition into the Center's (program of those children who, upon completion of their educational programs, will require the Center's services.

We cite that at some length to make several key points. There is probably little debate that the deaf-blind are among the most severely handicapped. Yet, in this program and in some of the State Blind Agency programs such as New Jersey's, persons are being brought up to their potential by rehabilitation. The professionals rush for breakthroughs in technology to make the job easier, and with ingenuity they are developing means to get services across. But such services are expensive. And that too is an important point we make over and over. It is not limits in the people, it is not even limits in knowledge; it is the limitation of resources which creates the unmet needs.

Chapter 19

REHABILITATION OF THE DEAF

As noted earlier, there is not much reliable information on a national scale on our disabled population and even less on particular disabilities and the characteristics of people with a given disability. This is not true of the deaf.

A census of the deaf (National Census of the Deaf Population) was undertaken in 1970 to determine the size, distribution, and principal demographic, educational, and vocational characteristics of the deaf population. It was financed in large part by a grant awarded in 1969 to the National Association of the Deaf by the Social and Rehabilitation Service of the Department of Health, Education, and Welfare. The Deafness Research and Training Center at New York University was responsible for the technical aspects of the study. A number of professional, religious, and social organizations concerned with the deaf formally sponsored the census and the National Center for Health Statistics and the Annual Survey of Hearing Impaired Children and Youth provided valuable assistance. The resulting report, "The Deaf Population of the United States," was published in 1974. The section below on salient characteristics of the deaf relies primarily on the data and findings in that report.[1]

SALIENT CHARACTERISTICS

There is no legal definition of deafness and there are many ways to define it. Each of the many different definitions reflects in large part the particular interests of the professional discipline using it. For example, precise

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[1] Jerome D. Schein and Marcus T. Delk, Jr., The Deaf Population of the United States (New York: Deafness Research and Training Center, 1974). The full report should be examined for further details on characteristics of the deaf population, e.g., variations by sex and race, marital status, housing, etc.

measurements are needed in the field of audiology. The definition selected by the National Census of the Deaf Population (NCDP) is a broad specification, significant and meaningful in education, rehabilitation, sociology, and psychology. This paper, therefore, adopts that definition: "Deafness is the inability to hear and understand speech."

"Unlike definitions of blindness, definitions of deafness have tended to take the age at which the loss occurred into account. The reason probably involves the fact that the earlier hearing is lost the more severe are the consequences to speech and language development. Persons who become deaf after developing speech usually retain it, while prelingually deaf children have great difficulty acquiring speech. Language development also is more seriously disrupted by early childhood deafness than by deafness occurring in teenage."

The NCDP focused on the extreme end of the hearing impairment continuum--a group it labeled prevocationally deaf. This group consists of persons "Who could not hear and understand speech and who had lost (or never had) that ability prior to 19 years of age."

The prevocationally deaf number over 400,000. These are the most seriously handicapped among the 1.8 million deaf population, but the deaf as such, regardless of age at onset, are the most seriously handicapped among the 13,400,000 people who have impaired hearing.[2]

Tables 19-1 and 19-2 show the size of the problem of hearing impairment among the regions of the country and the age distribution of the prevocationally deaf.

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[2] The National Census of the Deaf Population (NCDP), did not include data on the institutionalized population.

Table 19-1

Distribution of Hearing-Impaired Population By Regions: United States, 1971

Number in Population	Hearing Impaired	Deaf	Prevocationally Deaf
United States	13,362,842	1,767,046	410,522
Northeast	2,891,380	337,022	83,909
North Central	3,683,226	541,465	135,653
South	4,280,177	562,756	123,260
West	2,508,059	325,803	67,700
Rate per 100,000 Population			
United States	6,603	873	203
Northeast	5,977	697	173
North Central	6,563	965	242
South	6,807	895	196
West	7,170	931	194

Note: The number by state for the deaf ranged in 1971 from 2,664 (of whom 553 were prevocationally deaf) in Alaska to 185,708 (with 38,595 prevocationally deaf) in California.

Source: National Census of the Deaf Population

Table 19-2

Prevalence and Prevalence Rates for Prevocational Deafness in the Civilian Noninstitutionalized Population, by Age: United States, 1971

Age	Number	Rate per 100,000 Population
All ages	410,522	203
Under 6	8,071	38
6 to 16	86,278	191
17 to 24	46,154	169
25 to 44	56,865	119
45 to 64	93,839	225
65 and over	119,315	617

Source: See Table 19-1.

It should be noted that prevalence rates were higher in the 6-to-16 and 17-to-24 age groups than they were in the 25-to-44 age group. This will mean an upsurge in demand on both secondary and post-secondary educational programs and on vocational rehabilitation agencies in the next few years.

One out of every three deaf people has a disability in addition to deafness. The effects of the second disability, which may in itself be mild, are often compounded because of the problem of communication. For example, most professionals, including medical professionals, are not trained in communication with the deaf. Table 19-3 depicts the distribution of health conditions, other than deafness, reported by respondents 1 to 64 years of age in 1972.

Table 19-3

Percent Distribution of Health Conditions, Other than Deafness, Reported by Deaf Respondents: United States, 1972

Health Conditions	Percent
All conditions	100.0
No other condition	66.6
Asthma	8.3
Vision	3.1
Neuropsychiatric condition	2.8
Arthritis	2.0
Heart trouble	2.0
Mental retardation	1.6
Cerebral palsy	.9
Cleft palate	.4
Other	15.1

Source: See Table 19-1

The educational achievement of deaf adults (measured in terms of the highest grade completed) is below that for the general population. The median is 11.1 for the deaf as compared to 12.1 for the general population. Over 28 percent of the deaf have completed 8 years of school or less; over half have not completed 12 years. On the other hand over one-third have completed high school and some (2.7 percent) have completed college.[3]

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[3] The ratio of the number of deaf persons in college to the number of deaf students in schools at the turn of the century was approximately the same as a like ratio for the general population. The ratio for the deaf remained fairly constant until 1960 although general population rates increased dramatically. The proportion of deaf students attending institutions of higher learning has since grown appreciably since 1960 but still remains comparatively low.

The equivalence of grade completed as a measure of academic achievement in comparing deaf students with nondeaf students is highly questionable. Recent studies have shown that the average deaf student lags several years behind his normal-hearing peers. Although some deaf students score better than a hearing student, the fact remains that the average do not and thus the 1-year difference in the median of the highest grade completed is magnified to ~~an~~ even greater educational deficiency. This has serious implications for the adequacy of the education provided the deaf individual, the career opportunities open to him, and the quality of his life.

Communication, basic to education of the deaf and nondeaf child alike, is a very real problem for those children whose loss of hearing occurs at any age prior to the end of schooling. The unique educational needs of deaf children require special education programs. These are available in four types of settings: residential schools; day schools (special schools with no living quarters for students); day classes (classes for deaf students within a regular school); and regular schools (with the occasional assistance of an itinerant speech therapist or of a resource teacher).

Most public education for deaf children is provided by residential schools, day schools, and day classes. The majority of prevocationally deaf students spend at least part of their educational years in residential schools.

The type of school attended may reflect not only age at onset of deafness but also the availability of educational facilities in various States and the educational emphases at particular times and places such as the current educational emphasis on "mainstreaming," or placement of handicapped children into regular classes. It is, however, unlikely that any one type of schooling will be best for all students. It should also be noted that special programs for children with hearing problems accommodate less than half of them. Just as crucial is the quality of the education provided to deaf students.

The data in the NCDP on occupations of the deaf were compiled before the sharp rises in unemployment among the general population in 1974. Consequently the effect of current economic conditions on the employment of the deaf is unknown, and the data and trends apparent in the early 1970's must be considered with that caveat in mind.

In 1972, the unemployment rate of deaf males (less than 3 percent) compared favorably to the unemployment rate for all males (4.9 percent). Deaf females, however, were more frequently unemployed than females in general. The rates for nonwhite deaf were much worse. Nonwhite deaf males had an unemployment rate five times that of white deaf males. Nonwhite deaf females had nearly double the unemployment of white deaf females.

Most prevocationally deaf people were employed, and most of those employed worked for private concerns.[4] They had positions in all industries, but the heaviest concentration was in the manufacture of nondurable goods. Concentrations in services were low.

Deaf persons were employed in all principal occupations, from professional to domestic. The largest proportion (31.1 percent) were "nontransit" or machine operators. Craftsmen constituted another large group (29 percent). Together they equalled over 60 percent of the occupational classifications of the employed deaf. The bulk of the remainder were in professional and technical occupations (9.2 percent), clerical (8.1 percent), nonfarm laborers (8.2 percent), and service workers (8 percent).

Employed deaf people are often seriously underemployed; that is, employed in positions incompatible with the workers' intelligence, skills, and education.

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[4] The small proportion of deaf persons in government service arises from the few white males employed by Federal, State, or local government. Female and nonwhite deaf persons worked for the government at a higher rate than for the general population.

"The deaf college graduate linotype operator or pressman is quite common, for example. Everywhere we find deaf men and women of normal or above abilities operating automatic machines, performing simple assembly line operations, or otherwise occupied in unchallenging routines..."[5]

The average income - family or personal - of the employed deaf tends to be below the average for the general population. It is lower for women than for men and lower for nonwhite deaf persons than for white. This is best illustrated by the following Tables 19-4 and 19-5 on family and personal income in 1971.

Table 19-4

Median Family Income for Deaf Heads of Households Compared to General Population Households: United States, 1971

Respondents' Sex & Race	Deaf	General[a]
All groups	$8,662	$10,285
Male	9,263	10,930
White	9,450	11,143
Nonwhite	6,000	8,067
Female	4,146	5,114
White	4,347	5,842
Nonwhite	2,662	3,645

Source: U. S. Bureau of the Census, unpublished data.

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[5] B. R. Williams and A. E. Sussman, "Social and Psychological Problems of Deaf People," in A. E. Sussman and L. G. Stewart, eds., Counseling with Deaf People (New York: Deafness Research and Training Center, New York University, 1971).

Table 19-5

Median Personal Income from Wages and Salary of Respondents 16 to 64 Years of Age: United States, 1971

Respondents' Sex & Race	Deaf	General[1]
All groups	$5,915	$8,188
Males	7,084	9,631
White	7,338	9,902
Nonwhite	4,166	6,771
Females	4,306	5,701
White	4,405	5,767
Nonwhite	3,166	5,092

Source: U. S. Bureau of the Census, unpublished data, 1973.

[1] Includes persons 14 and 15 years old and 65 and older.

Mental Health and Mental Illness among the Deaf

Emotional instability, social immaturity, and behavior problems are not, of course, endemic to the deaf. When they occur among the deaf, however, they pose special problems because of the difficulties inherent in deafness itself. For example, the lack of communication may lead to misunderstanding and misinterpretation and in turn to inability to cooperate with others, frustration, or some kind of unacceptable behavior. At the same time, communication is essential if the behavior is to be corrected or modified.

A study of multiply handicapped deaf adults at ~~the~~ Hot Springs Rehabilitation Center in Arkansas revealed that communication inadequacies and behavioral problems were central obstacles to rehabilitation. The implications of the study for educational programs for the deaf were even more important since language development and communication skills are basic to an adequate education in childhood and adolescence. They are just as basic to good mental health.

Some deaf people are mentally ill as well as deaf. The prevalence of mental illness among the deaf in the United States is unknown but is believed to be at least of, if not more than, the same order of magnitude as among the hearing, which is 1 in 10. The number of deaf in mental hospitals is also unknown and even the number in such hospitals misdiagnosed because of deafness. The misdiagnosis of the deaf as mentally ill or as mentally retarded is all too frequent due primarily to the confusion resulting when the professional and the "subject" cannot communicate with each other and aberrant behavior is thus misunderstood.

What is known from the few attempts to gather data on mental illness among the deaf and to treat such illness illustrates the importance of considering this aspect in planning and executing special programs for the deaf as well as mental health and rehabilitation programs as such.

The NCDP indicates that 2.8 percent of deaf respondents 1-64 years of age, reported a neuropsychiatric condition in addition to deafness. (As noted above, the NCDP included only the noninstitutionalized population).

A series of investigations begun in New York State in 1955 gives a general idea of the size of the problem in the mental hospitals of that State. It was found that deaf patients in the State hospital system numbered some 250 at a given time. This number was only a small fraction of the State hospital population of the period. It represents, however, a group found "to be isolated, wearing inaccurate diagnostic tags, poorly evaluated, and virtually untreated."[6]

Only a handful of mental health programs in the country are dealing with the mental health problems of the deaf. The New York program was the first of these. It opened the country's first psychiatric outpatient clinic for the deaf and in 1963 initiated a program of comprehensive mental health services for the deaf.

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[6] John D. Rainer, M.D. and Kenneth Z. Altshuler, M.D., Expanded Mental Health Care for the Deaf: Rehabilitation and Prevention (New York: Research Foundation for Mental Hygiene, Inc., 1970).

During this period the outpatient clinic was expanded. In addition a special inpatient unit for the deaf was set up at Rockland State Hospital. The unit housed 30 inpatients. Fifty patients were treated during its first 3 years. The first patients were transferred from other State hospitals, but subsequently acute cases from the community were accepted. Still lately, chronic cases were rotated from other State hospitals for trial treatment when space was available and returned when they had received maximum benefit or were no longer improving.

A significant portion of the clinic patients were deaf adolescents -- "students or youngsters dropped from school because of the unmanageable nature of their disturbances in personality." Close working relations were established with a nearby school for the deaf, and hospital staff provided consultative work there.

Bottlenecks in the inpatient program and a growing awareness of preventable difficulties in childhood and adolescence led to the development of a rehabilitative and preventive psychiatric program for the deaf, including the reintegration of deaf psychiatric patients into the community and the provision of preventive mental health services in the community. This was made possible by the development of the special inpatient intensive care unit and the outpatient clinic on a permanent basis; the training of personnel in the psychiatric field and related personnel to work with the deaf; close collaboration with Vocational Rehabilitation; the use of a halfway house and various other community workshops and facilities; the program at a school for the deaf which included individual consultation and treatment, direct work with adolescent groups, and work with parents of students; and an active program of education and involvement of the community.

Among the unmet needs identified were the prevention and treatment of young deaf children and school age youngsters and special programs for the deaf who are mentally retarded. Significant findings for rehabilitation and social service workers are summarized in the final report.[7] Another key finding is that programs for the mentally ill deaf "must be designed and tried seriatim, and the concept of closure of a case is generally inapplicable."

St. Elizabeth's Hospital in Washington, D. C. is another place where deaf people who are mentally ill can receive psychiatric help in a residential setting. Out of a total of 3,400 beds, 70 are in a special unit for the deaf. The average outpatient load is 50. (This inpatient load, as noted below, includes patients from across the United States as well as from the District of Columbia).

In 1963 when the program for the deaf began at St. Elizabeth's, the total inpatient census there was approximately 6,000 and its outpatient census was approximately 1,200. By 1972 the average number of resident patients was 3,202 and the average number of outpatients was 2,695. The target deaf population represented 0.1 percent of the total patient population. In general, they reflected the characteristics, except for deafness, of a cross-section of the whole patient population.

The special program for the deaf at St. Elizabeth's began without awareness of the New York studies. Initially it consisted of group psychotherapy for deaf patients at the hospital. It concentrated on patients who had been deaf since birth or early childhood, a group whose speech and language abilities varied considerably. The primary methods of communication in the sessions are manual - sign language and finger spelling.[8]

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[7] Ibid.

[8] Patients may use their voices if they are able to do so. Lipreading and writing are permitted.

The program has grown to be a comprehensive one in the field of mental health. It has a reciprocal relationship with Gallaudet College, an institution for the deaf in Washington, D. C. This not only strengthens the service program for the deaf but also enriches the training program for professionals and others working with the deaf. There is also a close working relationship with the Vocational Rehabilitation agency and much reliance is placed on it for services, particularly after the deaf leave the hospital.

Patients for the deaf program at St. Elizabeth's are accepted from all over the United States. Indeed they constitute the bulk of the population of the special unit. The greatest difficulty encountered in working with the patients from outside the District of Columbia is the difficulty of working with their families.

The average cost for all inpatients at St. Elizabeth's is $55 a day. No study has been made of the cost of serving the deaf, but it is presumed to be higher because the program has a higher staff-patient ratio. It should also be noted that the lack of resources for the deaf in their home communities results in a longer stay for the deaf at St. Elizabeth's.[9]

A third major program in mental health services for the deaf is at the Langley Porter Neuropsychiatric Institute in San Francisco, and another is at The Michael Reese Hospital in Chicago. Interest in other States is developing.

VOCATIONAL REHABILITATION OF THE DEAF

Deafness is not defined in the Vocational Rehabilitation Act, regulations, or statistical instructions. For statistical reporting purposes the deaf are divided into two classes: those able to talk and those unable to do so. In 1972, State VR agencies rehabilitated 6,412 deaf people, of whom 4,066

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[9] The longer stay for the deaf was also noted at Rockland.

(almost two-thirds) were unable to talk.

The 6,412 deaf people rehabilitated in 1972 were only 2 percent of the total number of people rehabilitated. Although the success rate[10] for the rehabilitation of the deaf is high, not nearly so large a proportion of the deaf are served as the proportion in some other disability groups.[11]

The services which can be provided to the deaf under the Vocational Rehabilitation Act include all the rehabilitation services authorized for disabled people under that Act. These range from counseling, diagnosis and evaluation, surgery and treatment, and training to a wide variety of supportive devices. Under the Act, rehabilitation facility programs for the deaf and other group facilities and services may also be provided.

A survey of services to the deaf and the hard of hearing was published in the State Agency Exchange, May, 1972. Thirty-eight of the 50 States responded. The survey showed that services to the deaf and the hard-of-hearing were unequal among the States and that within a State they were fragmented. Often they were nonexistent or unknown or restricted to certain target groups.

Hearing tests and hearing aids were the services uniformly available from agencies of the State. Other services usually available were counseling, surgical or therapeutic treatment, hospitalization, speech therapy, maintenance during rehabilitation, transportation, evaluation of ear condition, evaluation of rehabilitation, and post-secondary education. These services were provided primarily by the State Vocational Rehabilitation Agency, exclusively, or by the VR agency and some other public agency.

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[10] The number rehabilitated divided by the number not rehabilitated.
[11] Schein and Delk, The Deaf Population.

Half of the reporting State VR agencies indicated that they had arrangements for the provision of opportunities for learning and social experience, including such opportunities for young deaf children, and about two-thirds operated or utilized a rehabilitation facility for the deaf. Only seven State VR agencies reported maintaining a register of the deaf, and only 15 State agencies distributed captioned films or participated in the program of captioned films for the deaf. The services least likely to be available in States were: outreach, advocacy, and protective and other social and sociolegal services.

The survey indicated that the numbers served were not great and that in no case were there sufficient services, especially to young children or the elderly.

The unmet needs of the deaf and the hard of hearing as identified by State VR directors in the survey, ran the gamut from identification of those with hearing impairments to employment opportunities. The needs for social, psychiatric, and psychological services and for improved education and training programs were specified over and over again.

Almost universally mentioned was the need for better communication. This was expressed in the need for communication training programs for the deaf, the need for qualified interpreters, and for staff capable of manual communication.

The lack of services for the young and for the aged was emphasized. So were many aspects of the provision of hearing aids.

The vocational rehabilitation program has not only served deaf individuals but also has done much to enlarge and enhance the resources available for the rehabilitation of the deaf. For example, certain State VR agencies have established rehabilitation facilities for the deaf, and many have helped to establish speech and hearing clinics. A research and training center for the deaf has been financed through vocational rehabilitation research grants. As previously stated, a national center for the deaf-blind has been undertaken. Vocational rehabilitation has also assisted in improving educational resources through the establishment of a national technical institute for the deaf and assistance in establishing community college programs serving the deaf.

The research activities funded from vocational rehabilitation funds have been diverse and substantial. An annotated listing of such research projects is published periodically by the Rehabilitation Services Administration. Listings of research and demonstration projects and training projects funded under the auspices of the RSA and other auspices in the Department of Health, Education, and Welfare or elsewhere in the Federal Government are included in Deafness.

Both short- and long-term training grants in the rehabilitation of the deaf have been made under Vocational Rehabilitation auspices. Training has included training in manual communication for those working with the deaf, staff orientation to deafness, a national leadership training program, training programs for counselors working with the deaf, and many other aspects of the rehabilitation of the deaf.

Although the vocational rehabilitation program has made substantial contribution to the field of rehabilitation of the deaf, much remains to be done.

Priorities

In 1971 a small group of experts on deafness rehabilitation met in Tarrytown, N. Y., to ponder priorities in the rehabilitation of deaf people in the 1970s. Their discussions ranged over many issues, and their conclusions were summarized under seven major headings: Administration, Organization, Manpower, Facilities, Job Development, Communication, and Research.

Under each heading the problem is specified, the need identified and a recommendation made.

Action has been undertaken on a number of the recommendations. Many are incorporated in the "Model for a State Plan for Vocational Rehabilitation of Deaf Clients."[12] In November 1973, the RSA extended its approval to the Model State Plan for Vocational Rehabilitation of Deaf Clients, developed by a task force of the National Rehabilitation Association (NRA) and a committee of the Council of State Administrators of Vocational Rehabilitation (CSAVR). It has been endorsed formally by the NRA, the CSAVR, and the Professional Rehabilitation Workers with the Adult Deaf, Inc., as well as by the RSA.

The model plan was meant to provide suggestions and stimulate thinking about a plan to serve deaf persons. It was recognized that additional services not outlined in the monograph may be needed in a particular State. The plan also suggests the need for modifying some services and policies in order to make them effective for the deaf.

The model plan discusses manpower needs, qualifications, and functions, including rehabilitation counselors for the deaf, State coordinators of services for deaf clients, and counselor aides/interpreters. Outreach and advocacy and special considerations in communication, inservice training, and staff development are among the areas covered in the model plan. Particular attention is given to a State Advisory Council on Deafness and to interagency cooperation.

The importance of representation from deaf consumers and deaf groups is emphasized. So is the importance of staff support to the Council.

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[12] Professional Rehabilitation Workers with the Adult Deaf, Inc., "Model for a State Plan for Vocational Rehabilitation for Deaf Clients," <u>Journal of Rehabilitation of the Deaf</u>, November 1973.

A partial listing of other public and private resources to be considered in developing a plan for serving the needs of deaf persons in the vocational rehabilitation process is provided. Some specific mechanisms for developing fruitful relationships with public and private agencies are suggested: third-party cooperative funding, cooperative agreements, "establishment" authority, and the Vocational Education Act requirement of 10 percent expenditures for the handicapped.

Three other important areas are considered in the model plan: special facilities for the deaf, deaf community development, and a national-State-local communication system on deafness.

The model plan focuses on what State VR agencies can and should do. It takes into consideration the marshaling of resources within the State and the development of productive interagency relationships as well as internal operations. There are, however, certain priority areas beyond the capacity of any one State VR agency or of State VR agencies as a whole. Among them are:

1. Expanded staffing in the area of deafness in the Rehabilitation Services Administration and the other Federal agencies; e.g., the Department of Labor, Transportation, Housing and Urban Development, and the Federal Communications Commission.

2. Strengthening university training programs for manpower in the field of deafness through such means as the development of manuals and other training materials and media, cross-fertilization among university departmental programs concerned with different aspects of deafness, and the adequate funding of university programs to train sufficient numbers of rehabilitation workers for the deaf, including the funding of training programs for interpreters in conjunction with ongoing training programs for professional preparation in the area of deafness.

3. The accreditation of rehabilitation facility programs for deaf people, including, but not limited to, facilities offering comprehensive services, specialized vocational training, sheltered workshop programs, and programs for the multiply handicapped deaf.

4. The establishment and maintenance of community counseling and referral centers for the deaf in large cities.

5. Provision of mental health consultation programs and assistance to individuals on a systematic and routine basis, to deaf children and the adult community, through Federal funding for mental health facilities and outpatient clinics for deaf people on a regional or State basis, and the provision of mental health program support for large educational programs for deaf children.[13]

6. Job development within the main stream of the labor market, including research programs providing job development strategies, training of the deaf community so that they are aware of and knowledgeable as to employment needs and job trends and the acquisition of job-related skills.

7. New and revised communication approaches. The Tarrytown conference recommended that:

(a) instruction on manual communication be used throughout school and rehabilitation programs and in the community.

(b) a curriculum for teaching manual communication in schools for deaf children and in rehabilitation programs for deaf adults be developed and implemented.

(c) A curriculum for teaching total communication to teachers

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[13] Community Mental Health Centers could be used as a major vehicle for this recommendation.

of deaf children and rehabilitation workers with deaf adults be developed and implemented.

(d) until comprehensive programs in schools are developed, a curriculum for teaching manual communication to adult deaf persons be developed and implemented.

(e) a systematic study of interpretive processes and the role of interpreters in assisting deaf persons in communication be developed.

(f) a 24-hour emergency interpreter service be established in metropolitan areas.

(g) improved low-cost communication at a distance (through services such as TTY)[14] be made available.[15]

8. The pooling of research resources, ongoing studies of the deaf population,[16] and emphasis on vocational development and adjustment in research priorities. Other recommendations on research included the establishment and support of regional deafness research and training centers to conduct research on the problems and needs of deaf people within the regions, and give guidance to state services for deaf people within each region.

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[14] TTY can be made available to vocational rehabilitation clients under the Vocational Rehabilitation Act. Additional provisions are needed for non-VR clients.

[15] These recommendations for manual communication presume the continuation of efforts to teach and encourage deaf students, also to develop their skills in English oral and written communication, receptive and expressive. No presently available evidence has shown that learning manual communication interferes with other forms of communication. In fact, there is some evidence which suggests that learning manual communication will facilitate the oral and written skills.

[16] The NCDP was barely under way at the time of the Tarrytown Conference, it, of course, describes the size, characteristics and location of the deaf population at a given point in time. It recommends also a continuous survey.

Two other recommendations made by the Tarrytown conference should be considered at this time. One was legislation to fund an agency or organization for the establishment and maintenance of a comprehensive clearinghouse for information on deafness. Its functions would include the dissemination of information not only to professions but the general public and special target groups. Such a clearinghouse could be operated by an entity such as the Council of Organizations Serving the Deaf, but vital to its success would be the assurance of a system for permanent funding such as that accorded to the American Printing House for the Blind by annual Federal appropriations. The possibilities of affiliation of some sort with the central clearinghouse for information and resource availability authorized in Section 405(a)(5) of the Rehabilitation Act of 1973, should also be explored.

Another concerns facilities for low achievers. Because of the absence of appropriate training and adjustment services, large numbers of deaf people remain unemployed or grossly underemployed. They need comprehensive vocational rehabilitation centers. There is an equally important need for educators to give greater emphasis to innovative efforts to meet the needs of deaf children, who have special learning and adjustment problems.

HR 8395, 92d Congress contained special provisions for establishing, operating and financing comprehensive rehabilitation centers for low (under) achieving deaf youths and adults. Such provisions were not included in the Rehabilitation Act, although it does include in Section 304 provision for special projects and demonstration for establishing "programs and facilities for providing vocational rehabilitation services which hold promise of expanding or otherwise improving rehabilitation services to handicapped individuals (especially those with the most severe handicaps) including individuals with spinal cord injuries, older blind individuals, and deaf individuals, whose maximum vocational potential has not been reached." Unfortunately, so-called "project" funding is usually limited to short-term financing and makes the acquisition and retention of staff for a service program most difficult. A legislative mandate to authorize and fund efforts of a continuing nature for rehabilitation centers for the low-achieving deaf, and to fund special programs for multiply handicapped deaf children is still needed.

There are a number of other problems and unmet needs of the deaf. Some of them like driver training and licensing are discussed briefly in the report of the Tarrytown Conference. Other aspects, such as those related to courts,[17] were discussed at a forum in Chicago in February 1970, sponsored by the Council of Organizations Serving the Deaf, and its proceedings explored the legal rights of the deaf.[18]

Overriding other problems and needs of the deaf and implicit in them is the need for language development. Bronowski, in The Ascent of Man, points out how crucial language is to the learning process in man and how integral it is to the essence of humanness. He also points out that language must be learned in childhood if it is to be learned at all.[19]

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[17] For example, there are well substantiated incidents of deaf people being diagnosed as mentally ill rather than as deaf simply because psychiatrists and the courts with few exceptions cannot communicate with the deaf and mistake the significance of certain symptoms of behavior and their cause.

[18] Council of Organizations Serving the Deaf, "The Deaf Man and the Law," Proceedings of National Forum No. III, (Chicago: The Council, 1970).

[19] Language as a system for the expression of thought, rather than as as particular language such as English.

The learning of language, including abstract concepts and thinking processes, is one of the research areas important for all mankind, but particularly for deaf mankind. It is fundamental to understanding and improving not only the educational system but the realization of the human potential. The absence of the ability to use language distinguishes the deaf as most severely handicapped and most difficult to serve.

Chapter 20

OTHER DISABILITY GROUPS

There are, of course, a great many more disability groups about which one could write. In this chapter we present in much more succinct form some groups which highlight other speci[illegible] considerations. The spinal cord injured have been significantly assisted by the development of Regional Spinal Cord Centers and by developments in medical and rehabilitation technology. Autism is one of the most baffling and difficult of the mental disabilities, yet slowly methods for moving individuals out of institutions are being developed. The age-old fears about leprosy, Hansen's Disease, make it one of the most handicapping. That we have not included separate chapters on epilepsy, arthritis, multiple dystrophy, and all of the other disabling conditions is not to slight their importance, only to indicate our time constraints. The primary reason for inclusion of these groups is the development of treatment programs beyond the State/Federal VR program. Decisions on future program thrusts must decide on the degree to which these programs or a new configuration will be developed.

SPINAL CORD INJURED

The central nervous system consists of the brain and the spinal cord. Much like a complex telephone cable, the spinal cord carries "sensory" impulses to the brain and "motor" impulses from the brain. When accident or disease causes damage to the spinal cord, both feeling and movement messages are no longer transmitted past the damaged area of the cord.

"Paraplegia" can be defined as paralysis, or loss of sensations and motion, in both legs and the lower part of the body. The individual with paraplegia may refer to himself as a "para," being "paralyzed from the waist down." "Quadriplegia" is paralysis which involves both lower and upper extremities. The individual with quadriplegia may describe himself as a "quad," being "paralyzed from the neck down." The bulk of these individuals spend their lives in wheelchairs or in bed.

Generally, the further down the back that the damage to the cord occurs, the more functional potential remains. The loss of sensation and motion below the level of injury may be accompanied by a variety of complicating physical problems ranging from pressure sores and bladder infections to autonomic dysreflexia and thermoregulatory difficulties. And yet most of the following problems are avoidable if the spinal cord injured (generically used to mean paraplegics and quadriplegics) have good rehabilitation and practice preventive medicine.

Due to the loss of skin sensation, the person with a spinal cord injury is susceptible to pressure sores, or decubitus ulcers that can take months to heal. Since the normal warning signal of painful sensation is absent, the spinal injured can easily get severe burns or skin abrasions. Loss of voluntary bowel and bladder control may be overcome with a deliberate program of conditioning or training. On the other hand, bladder and kidney infections and complications are still the leading cause of death for spinal cord injured.

Several of the problems facing this group can constitute severe disabilities in and of themselves unless dealt with properly. Spasms (involuntary muscle contractions), if severe and uncontrolled, can actually throw a person from a wheelchair. The spinal injured with autonomic dysreflexia may experience blood pressure irregularities like headaches or fainting. Thermoregulatory difficulties may, particularly with quadriplegics, result from impaired internal body temperature control mechanisms and may preclude work in hot or cold environments.

The "severely handicapping environment" presents many barriers to paraplegics. Documented elsewhere in this report are the architectural barriers that confront wheelchair users in housing, transportation, education, and recreation. Attitudinal barriers can also be severely handicapping, whether presented by an employer unwilling to make modifications to the work place or a landlord who rejects such persons as tenants.

Several factors determine how successful the person with spinal cord injury may be in achieving independence. These include the degree of disability, dependency, financial resources, motivation, intelligence, community support, self-confidence, survival skills, and realistic expectations. The most obvious is the <u>degree of disability</u>. Some quadriplegics simply cannot get out of bed without assistance.

Depending on the source, incidence and prevalence rates of spinal cord injury differ, but they are within a range narrow enough to estimate the magnitude of the population. For example, on the basis of Census studies conducted in Nevada and Hawaii, Wilcox reported incidence rates of 50.0 and 26.6 spinal cord injured per million per year.[1] Other studies have found similar rates which extrapolate to between 6,000-13,000 new spinal cord injured a year out of the total population.[2]

Estimates of prevalence range from 125,000 to 300,000 paralegics in the United States population. While incidence rates are gradually increasing, mortality rates for spinal cord injured have dropped significantly.

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1. N. Elaine Wilcox, Harriet Kuwamato, and E. Shannon Stauffer, <u>Statewide Census of Spinal Cord Injured Persons--Hawaii</u> (Downey, Cal.: Ranchos Los Amigos Hospital, 1971): and N. Elaine Wilcox, <u>Statewide Census of Spinal Cord Injured--Nevada</u> (Downey, Cal.: Ranchos Los Amigos Hospital, 1970).

2. Quoted in Herbert S. Talbot, "Spinal Cord Injury," <u>Archieves of Surgery</u>, June 1971, p. 539.

Most spinal cord injured from World War I died within the first year of their injury. Since World War II and the advent of antibiotics and spinal cord injury centers, the mortality rate has dropped to a rate much closer to that of the general population.

Spinal Cord Injury Centers

Munro founded one of the first centers for the treatment of spinal cord injury at Boston City Hospital. Munro considered, "Nothing less than an active self-supporting wheelchair life is to be considered for a moment as an end result."

Guttmann found a similar center at Stoke Mandeville, England, built on the belief that the paraplegic is a "disabled but healthy independent person, with an independent future in society."

But Munro and Guttmann recognized that the most medically effective and economically efficient approach to treating spinal cord injuries is a comprehensive medical and rehabilitation service team working within a single organization; namely, the spinal cord injury center. As Talbot states,

> The great danger is fragmentation in any form--the tendency to break up the management of the patient into parts; the acute treatment and the chronic treatment, neurosurgical care, orthopedic care, urological care, and all sorts of other care;--or even a distinction between 'treatment' and 'rehabilitation.'[3]

In an effective system of spinal cord injury treatment and rehabilitation, the person who breaks his neck or back is immediately transported by trained emergency personnel to the spinal cord injury center. From the original surgery through discharge and follow-along services, the key element is the team of specialists. Just as the neurosurgeon needs considerable expertise

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[3] Talbot, "Spinal Cord Injury."

in the early stage, so do the other specialists involved in the prevention of bladder infections, pressure sores, bowel complications, contractures, and psychological problems. Effective rehabilitation nursing and physical, occupational, and recreational therapy help the paraplegic maximize his independence in activities of daily living. The rehabilitation counselor must be knowledgeable about a range of subjects, from car hand controls to architecturally barrier-free colleges and training programs.

The comprehensive approach of the spinal cord injury center has proven quite effective not only in saving lives and minimizing complications associated with spinal cord injury, but in restoring optimal functioning and reintegrating the spinal injured into society. The National Institute for Neurological Disease and Stroke estimates that the annual cost of care of spinal cord injury is $2.4 billion. Without a systematic approach to treatment and rehabilitation, estimates of the costs for a person with a spinal cord injury are consistently in the hundreds of thousands of dollars. Spinal cord injury centers reduce costs to a fraction of that. Each complication which is involved means a savings in terms of weeks or months in a hospital.

The cost to the individual can be substantial. The spinal cord injured individual and family frequently pay thousands of dollars for medical care. Without a program of national health security, the injured civilian is unlike the similarly impaired veteran. The service-connected veteran paraplegic, in addition to free hospital care and $784 a month income replacement, regardless of annual income, may receive free equipment and drugs, aid and attendence, money toward a house and car, mortgage insurance, annuity, property tax abatement and so forth. It is difficult for the civilian spinal injured to appreciate the major differences in treatment and benefits.

Since World War II the Veterans Administration has had a network of spinal cord injury centers, while only in the past 3 years has such an approach been federally funded for civilians. While the population of spinal cord injured veterans is one-ninth that of the civilians in size, there are currently 14 VA spinal cord injury centers and 10 civilian centers.

University- and Community-Based Programs

Another component of rehabilitation of the spinal cord injured focuses on post-hospital opportunities. For example, the University of Illinois Rehabilitation-Education Program and Rehabilitation-Education Center at Champaign-Urbana has made it possible for properly qualified individuals with severe, permanent physical disabilities to pursue a higher education and to benefit from experiences which are part of a college education and common to other students.

The comprehensive nature of the rehabilitation program includes ongoing efforts to assure students barrier-free access to all aspects of campus life. Over 100 ramps have been constructed to make old University buildings accessible for classes, study, activities, recreation, and residence. For the past 20 years all new buildings have been constructed to be accessible to and usable by the physically disabled. All new buildings under construction and planned for the future will independently accommodate wheelchairs. Each student is issued keys to elevators so that once in a building, the student has access to all floors. Ramps have made the churches of eight different denominations accessible to the handicapped.

The 150 students in wheelchairs have opportunity to be fully integrated on the campus of 34,000 students. They live in the 28 large barrier-free dormitories. These residence halls include specially designed or modified furniture, toilets, and showers, which allow students with physical disabilities to live in regular residence halls with able-bodied roommates, completely integrated into the residence hall system, and completely independent.

A week of functional training is required of new students who previously required attendant care. During an intensive crash course in independent living, "severely disabled" students are expected to perform all activities of daily living with no assistance. For the first time in their lives, the majority fulfill those expectations. Several quadriplegics who had been told by their previous rehabilitation center staff that they would require 24-hour attendant care discovered complete independence in activities of daily living by the end of the week and moved into their residence halls with no attendant care.

A few of the high-level quadriplegics who are not ready to live independently in the campus residence halls move into the Tanbrier halfway house program. Nugent describes those admitted into the halfway house as:

> Individuals so severely disabled that there was no possible way, at their respective admissions, they could be accommodated in the residence hall program according to our standards of performance. Many of these were acute bulbar polios, some in iron lungs as much as 17 years, some were traumatic quadriplegics even to the inclusion of a C3 quadriplegic, and very severe forms of dystrophy, sclerosis, etc. Of the 22 people we have put into the project house, 20 eventually progressed to the point that they could live in regular University residence halls, and apartments with every measure of security, success, and independence possible. All of these have gone on to accept professional positions throughout the United States commensurate with their college training.[4]

Tanbrier halfway house is located in a three-story house in which the upper stories provide apartments for able-bodied students who help with

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[4] Personal communication fro T.J. Nugent, 1973.

attendant care. Even in this transitional halfway house, the handicapped students maximize independence and control over their lives. The five severely disabled residents interview and hire the three staff members, a married student couple who assist in weekday activities of daily living and a student who is available on weekends. The five disabled students share costs of rent and maintenance and help manage planning and budgeting.

In addition to the University of Illinois wheelchair basketball team, the "Gizz Kids," is a recreation and sports program of swimming, bowling, football, archery, table tennis, and track and field. Many of the paraplegics on campus are active in the Delta Sigma Omicron service fraternity which promotes social, recreational, and advocacy activities.

Conclusions

Rehabilitated paraplegics, properly trained and placed, can participate in most activities in which others can engage. From the stereotyped jobs like watch repairman to a wide variety of professions too numerous to name, individuals with spinal cord injury have proved successful. Elimination of architectural and attitudinal barriers along with comprehensive spinal cord injury centers, university- and community-based programs, and self-help consumer efforts are basic to their rehabilitation. Additional numbers of spinal cord injury centers would be desirable to meet the needs of civilian paraplegics. Increasingly the problems of this group are less in vocational rehabilitation than in removing the barriers in the environment.

This group of disabled may well represent a program focus unlike any of those previously mentioned. The majority tend to be intellectually capable and more feasible of vocational rehabilitation than many others. Yet this group is almost the prototype of those faced with barriers to independent living regardless of employment status which an IRL program might address. Housing and other architectural barriers and limited transportation opportunities for those in wheelchairs constitute a major part of the "severely handicapped environment" in need of changes.

AUTISM

Autism is characteristically a severe disability which appears in early childhood. It was for many years, and most probably still is, confused with either retardation or with child schizophrenia. The term "autism" refers to the self-centered manifestations presented by the youth. Associated characteristics include rocking, head banging, lack of apparent language either in speaking or understanding, tantrums and violence, repetitive rituals with little purposiveness apparent, and lack of spontaneity. Self-damaging and self-destructive behavior is common.

As with most disability labels, those so afflicted exhibit a range of severity factors. While some autistic children do not talk at all, mildly autistic children may talk excessively. While the severely autistic may not understand what is being said at all, the less severely involved need some time to process remarks. Associated with this is the degree of literalness often exhibited by the autistic person. Little is known about those autistic persons who have been taught to function and who have reached adulthood outside of institution. What is known is that this group as adults have more than the usual number of problems of adjustment given the nature of the disability.

With limited ability to focus on more than one thing at a time, literalness and limited understanding of the nuances of language, the autistic adult may have difficulty distinguishing between minor frustrations and serious situations, in knowing what agencies or persons can be turned to for help, in explaining the nature of the problem fully, in being able to follow the suggestions for remedy. The primary need is for some community-based, long-term advocate who understands the individual and is trusted who can interpret the autistic persons to the persons with whom contact is made and who can explain the meaning of events to the person.

Based on a few studies of the incidence of autism, the National Society for Autistic Children estimates there are about 80,000 autistic persons in the United States.[5] Those not at home are in various sorts of institutional settings. The most successful services have been the structured residential treatment center based on programs of behavioral modification. Most of these programs are small, intensive and supported primarily by fees, with some limited Federal and State support under a variety of programs.

One program is that of the Behavior Research Institute of Providence, Rhode Island.[6] The program can accommodate 13. The school day program runs from 9 a.m. to 2:30, 5 days a week for 10 months at $7,000 per year. The full day program is 9 to 6, 6 days a week, 12 months at $14,000 per year. The staff ratio is 1.5 to 1. The Institute has begun a residential program as well.

One report focuses on a young autistic adolescent named Billy who was taken to the program from a State Mental Hospital where he had been in a locked ward without age peers or program.[7] His time was spent rocking, mumbling, screeching, and doing nothing. On admission to the Behavioral Research Institute program, over 70 percent of his time was spent rocking

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[5] Darold A. Treffert, "Epidemiology of Infantile Autism," Archives of General Psychiatry, May 1970, p. 431.

[6] The National Society for Autistic Children, U.S. Facilities and Programs for Children with Severe Mental Illness--A Directory (Rockville, Md.: National Institute of Mental Health, 1974), p. 342.

[7] Behavior Research Institute, Inc., Newsletter, July 1974.

or in aimless sitting and wandering. In one day he pinched himself 170 times, stuck his fingers in his ear 327 times, mumbled 1,816 times, and screeched 262 times. After 2 years on an intensive program which included behavioral modification, sheltered workshop experiences, various teaching techniques, and much supportive activity, he would work a full day on his own at the sheltered workshop. By the end of 2 years he could care for himself, prepare meals, wash dishes, work full time as an assistant maintenance worker, and spend leisure time alone.

The alternative was a lifetime of care in a State Mental Hospital with average bed costs between $10,000 and $20,000 per year.[8]

An experimental prevocational training project for autistic and neurologically impaired children, conducted by the Division of Vocational Education of the Connecticut Department of Education, included activities of daily living and service maintenance and production assembly tasks.[9] At the end of 10 months, all 16 had made gains.

Among the types of tasks taught were toileting, showering, toothbrushing, dressing, meal preparation, street crossing, and ability to move about work space. While all could feed themselves, none could prepare a meal and even the highest functioning child was ignorant of how to properly and safely cross a street.

Service maintenance tasks included vacuuming, mopping, sweeping, cleaning walls or table, operating a dishwasher, a clothes washer and dryer, and ironing. Production assembly tasks included hand-press printing, operation of Xerox and mimeograph, type setting, packaging, and several others.

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[8] Ibid.

[9] David F. Freschi, An Experimental Prevocational Training Project for Autistic and Neurologically Impaired Children (Hartford: Connecticut State Department of Education, Division of Vocational Education, Research and Planning Unit, 1973).

While the gains in the production aspect are only partly encouraging, the fact that nearly all showed major gains in the activities of daily living tasks suggest great promise.

In considering the program of independent living rehabilitation, Congress and the administration must make specific provision for the inclusion or exclusion of such programs for this most severely handicapped group of persons. While at present there is fragmented assistance to them and their families through various programs for handicapped children such as special education and development disabilities, a basic array of programmatic and predictable resources and long-term follow up does not exist.

HANSEN'S DISEASE (LEPROSY)

Hansen's Disease, or leprosy as it is popularly called, is not generally included in the classification of disabilities covered by vocational rehabilitation. Although other Federal statutes provide specifically for the treatment and care of leprosy patients, there are implications derived from work in leprosy which are germane to other severe disabilities.

Leprosy affects approximately 15 million persons in the world. It occurs most often in tropical countries, Asia, Africa, and South America have the greatest number of reported cases. In Europe, leprosy reached epidemic proportions during the Middle Ages. Residuals of this epidemic were seen in Norway until approximately 100 years ago. At present only small endemic foci exist in the Mediterranean area. Most patients with leprosy in this country are seen in Hawaii, Texas, California, Louisiana, and Florida.

Today there are some 3,000 victims of Hansen's disease in this country, most of whom are being treated by physicians in their own community. Owing to expanded capabilities in early diagnosis and the successful treatment through sulfone drugs, some of this number are never institutionalized and experience little or no functional limitations as a result. Yet the social stigma arising from Hansen's Disease continues to constitute a severe handicap for many.

Other individuals with this disease are living in a community as out-patients of the U.S. Public Health Service Hospital established exclusively for them at Carville, Louisiana. The hospital is located on the Mississippi River 25 miles south of Baton Rouge and 75 miles north of New Orleans. It was acquired by the U.S. Public Health Service in 1921 from the State of Louisiana, which had operated it since 1894 as a home for leprosy patients within the State. Today its primary purpose is to afford patients with leprosy a facility for complete evaluation, treatment research and training.

Any person with a confirmed diagnosis of leprosy made in the United States is eligible for admission to the hospital. Admissions most often are made through the referral of the patient by a State or local health offficer, or by the patient's physician. However, all admissions are voluntary and must be requested by the patient. Likewise, a patient may leave the hospital at any time he wishes, although the majority remain until discharge is recommended by the medical staff.

Finally, inpatients are also served at Carville. In recent years an average of 135 patients were admitted and 125 were discharged each year. Ages vary from 7 years to 92 years. The hospital, as a self-contained therapeutic community, has a vocational rehabilitation unit which provides a complete array of services comparable to almost any state vocational rehabilitation agency. This includes among others prevocational evaluation, physical restoration, counseling, work adjustment, and, most importantly, vocational training through work experiences. In addition, sheltered employment is provided for long-term residential patients.

After release from Carville, the patient declared free of the disease has the opportunity for employment and participation in society. Upon release through efforts of the Hospital Vocational Rehabilitation Unit, the

State VR agency is contacted and arrangements made for the new client. Assistance from the hospital regarding implications unique to the leprosy client are assured the agency and the counselor involved.

Since more and more Hansen's Disease cases now remain at home, it is important that they be afforded maximum opportunity for vocational rehabilitation services in a State agency setting. With the present state of the art in this country, there seems to be fewer problems for many with this disease insofar as physical handicaps are concerned. For those persons the social handicaps resulting from this physical condition are the most profound. On the other hand, there are a number of these persons who have experienced severe physical deformities and loss of limbs as a result of this disease. Since the Hansen's Disease impairment is profound, no vocational goal at all may be possible. In such cases, independent living rehabilitation services may be the only alternative if the patient chooses to live outside the confines of the hospital at Carville.

While the facility at Carville has served a most useful purpose as a service and treatment institution, one of its outstanding features is its affiliated research and training center. In addition to widespread training of professional medical, social and rehabilitation personnel throughout the world, the research activities have contributed greatly to the treatment of leprosy and to its care and rehabilitation.

Of particular note has been the development of a process to help in dealing with problems of insensitivity, particularly in hands or feet that result from damaged and deadened nerves which frequently occur due to this disease. The sores, lesions, or decubiti which develop from excessive unfelt pressure in the past necessitated amputation.

Through the development of the "Carville slipper-sock, glove, and stump sock" it has become possible to fit shoes and prostheses that virtually eliminate pressure-generated lesions. The "sock" is a simple constructed device in which tiny blue dye filled capsules are placed. When walking or moving upon these capsules, the dye is expelled, leaving a clear imprint of the areas of abnormal pressure. With this "blue-print," adjustments can be made either to the activity involved or to the shoe, glove, or prosthesis to be worn by the individual. This approach has been widely accepted.

There are, however, implications growing from this research with regard to other severe disabilities with similar problems resulting in insensitive skin surfaces. Patients with diabetes, hemiplegia, paraplegia, quadriplegia, burns, and the like, experience ulceration from pressure irritation. The research at Carville is now being expanded in these areas with apparent success.

Extensive research is being conducted in the detection of pressure-vulnerable areas of the body through the use of thermography; that is, through studies of temperature increases resulting from undue friction or pressure. By using highly sensitive heat probes and thermovision equipment, slight increases in skin temperature that are not detectable by the afflicted patient cannot only be detected but actually photographed. With such "graphic displays" or "blue-prints" corrective adjustments to functions of apparel can be successfully made.

Leprosy for ages has been the most dread disease in the world. Its program in this country stands off by itself. In any effort to develop comprehensive programs to rehabilitate the severely disabled, this small group should be considered.

Chapter 21

SURVEY OF PROVIDERS OF REHABILITATION

The answers to many questions posed in this study were raised with rehabilitation providers in public and voluntary agencies. These persons, who work with the severely handicapped daily, are a significant source of information on the needs-meeting system. When they were asked to cite sources for their answers, they most frequently responded "own experience". The responses described below represent the "informed opinion" of actual service providers.

The Questionnaire

The Questionnaire for Individuals Who Provide Services to Handicapped people, or provider survey, was the means by which we canvassed the views of a great number of agencies and facilities providing rehabilitation services to disabled. They were asked about: (1) the kinds of rehabilitation services severely disabled people need in order to enter or reenter paid employment; or (2) services needed in order to live more independently in their families or communities; (3) the extent to which these services are currently available and provided; (4) the legal and other barriers to services; (5) methods of coordinating at the Federal, State, and local levels all programs that can contribute to the rehabilitation of the severely disabled; (6) the adequacy of present facilities and programs; and (7) additional resources and programs that may be required.

The Sample

The total universe included all persons involved in rehabilitation of the handicapped, publicly or privately, in the United States between Fall 1974 and Spring 1975. From this universe of approximately 100,000 persons and organizations were selected the stratified sample of 2,223 persons or organizations to whom questionnaires were mailed. The two-phase sampling involved (1) selection of mailing lists for subpopulations (e.g., vocational rehabilitation agency providers), and (2) selection of subjects from the lists.

The universe included approximately 10,000 rehabilitation workers in State vocational rehabilitation agencies. Nearly one-tenth (987) of these vocational rehabilitation counselors, supervisors, and other professionals were sampled, utilizing the mailing lists from State VR agencies. Staff mailing lists were received from 46 of the 50 States. States were divided into three groups based on population size. From large States, 30 staff were selected; medium States, 20 staff; and small States, 10 staff. Half of the sample from each State were counselors, and half were other staff, including several supervisors and the State agency director.

The Department of Labor directory of 7,000 sheltered workshops was used to sample 193 workshops. The International Association of Rehabilitation Facilities' 1974 directory of 700 rehabilitation centers and workshops was used to sample 322 facilities. Most of the rehabilitation facilities and other providers are independent non-profit organizations, and many are local affiliates of national organizations concerned with problems of disability, such as the United Cerebral Palsy Association, National Easter Seal Society, National Association of Retarded Citizens, American Heart Association, the Arthritis Foundation, the Epilepsy Foundation of America, Muscular Dystrophy Association of America, the Jewish Occupational Council, the National Association for Mental Health, the National Kidney Foundation, National Tuberculosis and Chronic Respiratory Disease Association, and the American Cancer Society.

The mailing lists and directories were obtained from relevant voluntary health and rehabilitation agencies and constituency organizations. Included were organizations that focus on serving the "severely handicapped" as defined by Rehabilitation Services Administration regulations (e.g., blindness, cerebral palsy, deafness, mental retardation, mental illness, paraplegia, and end-stage renal disease).

The questionnaire was also sent to a small sample of self-help and consumer organizations of the disabled, such as the National Paraplegia Foundation, the National Association of the Deaf, National Federation of the Blind, and the American Coalition of Citizens with Disabilities. It was also sent to organizations representing professional workers in the field of rehabilitation, such as the American Physical Therapy Association, the National Rehabilitation Association, the American Association of Workers for the Blind, and the Professional Rehabilitation Workers with the Adult Deaf.

The sample included a number of recognized rehabilitation experts, State developmental disabilities staff, rehabilitation educators, and staff of private insurance rehabilitation programs. Table 21-1 shows the number of persons in each of the various subsamples, as well as the number of people who actually responded in time for their data to be analyzed. A total of 1,198 of the 2,223, or 54 percent, responded to the questionnaire. Of the total who responded, 49.9 percent were from VR agency staffs, 5.3 percent were VR directors, 22.5 percent were from rehabilitation centers or workshops, with the remainder from the other agencies cited.

Table 21-1

Sizes and Number of Respondents, Provider Survey

Providers	Sample Size	Number of Respondents
State Departments of Vocational Rehabilitation (DVR)	905	598
State DVR directors[1]	82	63
Sheltered workships	193	92
Rehabilitation centers	322	177
Voluntary rehabilitation agencies	378	149
Rehabilitation specialists	153	40
Developmental disabilities agencies	55	19
Educators	92	41
Insurance Rehabilitation Staff	43	19
Total	2,223	1,198

[1] Includes directors of State rehabilitation agencies for the blind where separate State agencies exist.

Format of Questionnaire

In addition to background questions at the start, the questionnaire is divided into three parts. Part I is concerned with the provision of services to those severely handicapped people who can be vocationally rehabilitated for employment. Part II asks about Rehabilitation for Independent Living (ILR). Part III relates to both groups.

Average Respondent

The average respondent was white, male, about 40 years old, with a master's degree, about 10 years' experience in rehabilitation, and about 4 years in his current position.

Two-fifths of the respondents reported that the main emphasis of their work was in administration, and another fifth were in supervision. Provision of direct services to disabled persons was the main work emphasis reported by 27 percent. One in twenty was involved in support activities--research, planning and training. The rest were engaged in a variety of activities, including teaching, information dissemination, and advocacy.

Vocational rehabilitation counseling was reported by 43 percent of respondents as a service they provided directly as a part of their normal duties. Other frequently mentioned direct services provided by respondents were: job placement services (38 percent), work evaluation (21 percent), social services (20 percent), work adjustment and other sheltered workshop services (17 percent), and vocational training (15 percent). Special transportation was provided by 14 percent though, as will be seen later, lack of usable, affordable transportation was seen as a major need.

About one-third of the respondents reported working at the local level; another third worked within a section of a State; one-quarter worked at the State level, about 3 percent at the regional level, and 5 percent at the national level. About half of those working in the local community served people living in large cities and another quarter served residents of small cities. Only 17 percent reported that most of the people they served lived in small towns or rural areas.

The following summary of results shows the proportion and number of respondents who answered the question.

WHO IS ACCEPTED FOR VOCATIONAL REHABILITATION

Rehabilitation has been accused of being arbitrary as to who is accepted and who is not. Given two persons with identical severe disabilities and functional capacities, one may be accepted for vocational rehabilitation and one may not be. To test that accusation and to determine what might make the difference we asked whether respondent agreed that this could be the case.

About 59 percent of the respondents believe that there are severely handicapped individuals who <u>would not</u> be accepted into the program even though their disabilities and functional capacities are identical with those of a severely handicapped person who <u>is</u> accepted into the program.

Those respondents who believed there are individuals who would not be accepted were asked to give examples of salient characteristics of those individuals. "Poor attitude/motivation" was the characteristic most reported, (44 percent), "no potential for employment," "too old," or "too young." Less frequent comments were: "degenerative medical," "lack of transportation," and "low level of education."

Following this open-end format, respondents were asked for degree of agreement on a list of characteristics that our consultants thought were significant. Specifically, they were asked to indicate the extent of their agreement or disagreement on listed characteristics of an individual which may actually influence most counselors' decisions to accept and provide rehabilitation services to that individual in the State VR program. The single most important characteristic appears to be the "apparent motivation of severely handicapped person for work." Agreeing or strongly agreeing were 95 percent of the respondents, with less than 1 percent strongly disagreeing. The three next most highly agreed-upon characteristics were "ability to leave home to make application, keep appointments, receive services, etc."; "realistic vocational goal preference," and "in younger age bracket".

Six characteristics were agreed upon by between 60 and 70 percent of the respondents. They were "longer life expectancy"; "successful work history or background"; "ability and willingness of family to assist in rehabilitation program"; "personable manner"; "specific job available upon completion of rehabilitation program"; and finally "ability and willingness to relocate". The respondents were about evenly divided on two other items: "high school or additional education" and "living in urban or semi-urban area as opposed to rural area."

There was strong disagreement among the respondents that five of the characteristics influenced a counselor's decision of acceptance. Those items were: "member of majority race" (only 14 percent agreed), "of male sex" (only 15 percent agreed), "no visible deformities", "cultural similarity with counselor", and finally "above average socioeconomic status". These responses suggest that race, sex, and socioeconomic status are not believed to be important factors in screening VR but motivation and mobility are.

SERVICE TO MORE PERSONS WITH SEVERE HANDICAPS

We sought to establish the extent to which the respondents were currently serving the severely handicapped as well as their capacity to serve additional numbers. Are agencies capable of expansion to serve more severely handicapped? Is expansion appropriate?

The study was conducted a little over a year after passage of the Rehabilitation Act of 1973, which placed priority on the severely handicapped. Over 71 percent of the respondents reported that as a result of this emphasis in the Act, their agency had made organizational, procedural, or other changes that have resulted or will result in improved or expanded services to individuals who are severely handicapped.

Among the myriad of possible changes respondents felt have been made to assist the severely handicapped, 213 of the 818 persons writing in comments responded with "empahsized treatment of the severely handicapped." Other frequent comments were "added specialized staff"; "instituted new programs beneficial to severely "disabled"; "expanded facilities or equipment"; and "gave further training to staff".

Next, the respondents were asked to discuss their agency's main accomplishment in working with the severely handicapped. Of the 973 commenting, 265 reported that their agency's greatest accomplishment was "giving the severely disabled some degree of independence or improved quality of life." Next in frequency were: "getting severely disabled employed, making them productive members of the community," and "opened up greater services for the severely disabled, placed more emphasis on serving the severely disabled".

When respondents were asked what percentage of disabled persons receiving services from them were severely handicapped, responses were very evenly spread from 0 to 100 percent. For example, one-third of the respondents, (319) reported that the percentage of severely handicapped was between 0 and 33 percent. Nearly as many (312) reported a percentage between 34 and 66 percent. Finally, 327 reported a percentage greater than 66 percent.

Respondents who serve clients were asked their average caseload size. Thirty-nine percent reported caseloads of between 76 and 150, followed by 27 percent having caseloads between 26 and 75, 18 percent having between 151 and 300, and 12 percent having between 1 and 25 per respondent. Five persons reported caseloads of more than 500 clients.

Two-thirds of the respondents believed themselves personally capable of serving additional numbers of severely handicapped persons. An even higher percentage (83 percent) were of the opinion that the State vocational rehabilitation program was capable of serving additional numbers of severely handicapped persons. The three most frequent ~~comments~~ were (1) additional funds are necessary; (2) additional staff are necessary; and (3) the emphasis on "26" closures must be changed.

Appropriateness of Vocational Rehabilitation for Serving Severely Handicapped

Four out of five respondents (81 percent) felt it is appropriate for the State VR program to focus the major portion of its attention on serving the most severely handicapped; only 3 percent thought it very inappropriate. Of the 803 persons commenting, 208 or 25 percent felt that mildly disabled persons should not suffer a reduction in services. One hundred eighty-three individuals felt that the severely handicapped have a right to receive services mainly because they need help the most. Another 95 believed that the quota system must be amended so that the severely handicapped can be served equally; and 72 called for more funds and/or staff.

The statistics taken together seem to indicate that the great majority of respondents deem it appropriate for VR to focus on the most severely handicapped. Before looking in depth at the possible roles of VR and rehabilitation for independent living, it seems appropriate to examine how they have responded to the mandate of the 1973 Act.

IMPEDIMENTS TO SERVING THE SEVERELY HANDICAPPED

VR agencies are in the process of developing new methods, resources, and relationships to implement the mandate to give the severely handicapped first priority. In order to determine how vocational rehabilitation services can be provided more effectively and made more accessible to indiviudals who are most severely handicapped, respondents were asked to indicate their agreement or disagreement that certain problems (resources, barriers, employment, and management) are impediments to effectively serving the severely handicapped.

First Choice Rankings of Impediments

When respondents were asked to rank the 5 most important items on the list of 29 possible impediments to the State VR agencies in serving the severely handicapped, the most highly ranked item, with 24 percent of the respondents picking it as their first choice, was "insufficient funds for purchase of rehabilitation services." The three items next most frequently listed as first choice were "heavy client loads," "inappropriateness of rehabilitation quotas (stated and implied) imposed on VR counselors," and "maximum number of rehabilitations to sustain appropriations." However, each of these three items was the first choice of less than 10 percent of the respondents. Thus, one out of four persons saw <u>lack of funds</u> as the impediment to serving severely handicapped. Since there were 29 possible "first" choices, it would appear that there is strong belief in the need for additional funding for vocational rehabilitation services to better serve the severely handicapped.

Composite Rankings of Impediments

The "composite" ranking which was based on the number of first through fifth choice rankings for each impediment also revealed that insufficient funds for purchase or rehabilitation was the most significant impediment to serving severely handicapped individuals. The composite ranking score for "insufficient funds" (159) is 53 points higher than the second highest item. In fact, this difference is greater than the numerical difference between the second ranked item (48) and the fourteenth ranked item (58). Table 21-2 presents the 14 problems which were listed in the top half of the 29 rankings. There was an empirical dividing line between the top half and the bottom half in that the gap in ranking between item 14 (58), and item 15 (41) was the largest numerical difference between item rankings with the exception of the difference between the first and second items.

Other clusters are obvious in the composite rankings. (The second and third items are the only others with a composite ranking over 100.) "lack of available jobs" and "heavy client load per VR counselor" are nearely equally ranked. The four items that follow are also clustered.

Table 21-2

Composite Rankings of Top Fourteen Problems Restricting State VR Programs in Serving Severely Handicapped Individuals

1.	(159)	Insufficient funds for purchase of rehabilitation services
2.	(106)	Lack of available jobs
3.	(103)	Heavy client load per VR counselor
4.	(95)	Resistance of the competitive labor market to the hiring of the severely handicapped
5	(94)	VR agency required to rehabilitate maximum number of disabled to sustain its appropriation and support
6.	(93)	Inappropriateness of rehabilitation quotas (stated and implied) imposed unpon VR counselors
7.	(89)	Insufficient funding of rehabilitation centers and workshops through the State/Federal vocational rehabilitation program
8.	(77)	Lack of usable transportation
9.	(72)	Limited knowledge of how to rehabilitate the severely handicapped
10.	(65)	Lack of knowledge on the part of VR counselors on how to rehabilitate the severely handicapped
11.	(62)	Lack of affordable transportation
12.	(61)	Lack of job development and placement specialists for the most severely handicapped within the state VR agency
13.	(60)	Lack of barrier-free employment settings
14.	(58)	Insufficient number of rehabilitation facilities and workshops

PRINCIPAL IMPEDIMENTS SEEN BY RESPONDENTS

The one item that respondents agreed on the most as an impediment to serving the most severely handicapped was "a lack of usable transportation." A total of 93 percent either strongly agreed or agreed that this was an impediment, with only 6 people out of 1,183 who responded strongly disagreeing. "lack of affordable transportation" was also highly agreed upon (87 percent) as an impediment to serving the most severely handicapped. Respondents were consistent elsewhere in the questionnaire in ranking affordable, usable transportation as a major barrier. For example, on a later item in which several difficulties or potential difficulties in finding job placements for people who are severely handicapped are listed, lack of affordable transportation is checked more than any other difficulty. Additional information on the transportation barriers of the handicapped, as well as options for eliminating those barriers, are included in the Transportation chapter of this report. Finally, it is interesting to note that even though "lack of usable transportation" ranked first in percentage agreement, it was ranked only eighth of 29 items in the composite ranking. This suggests that VR recognizes problems which may be outside its current service mandate.

Nine out of ten people also agreed that barrier problems in employment and housing were major impediments to serving severely handicapped. It is easy to understand why 90 percent of the respondents would see "lack of barrier-free employment settings" as a major impediment; if a person cannot get into an employment setting, it is not possible to work. "Lack of barrier-free housing," agreed upon by 89 percent of the respondents, is addressed in more detail in the section of this chapter on housing and architectural barriers.

The two major employment problems were next most highly agreed upon (88 percent of the respondents agreeing with each item). "Lack of available jobs" is particularly a problem during time of high unemployment. "Resistance of the competitive labor market toward the hiring of the severely handicapped" relates to the more general problem of attitudinal barriers and discrimination.

Three different management concerns were highly agreed upon as impediments to serving severely handicapped individuals. The first of these, with 86 percent agreeing, was "the lack of job development and placement specialists for the most severely handicapped within the State VR agency." Development of such specialists seems particularly important. As is noted later, the question on "more aggressive placement services" is highly ranked as the kind of service that persons with severe handicaps need most to improve their work capacities and to enhance their employment.

The two other management concerns that were strongly agreed upon as impediments are, first, "VR agency required to rehabilitate maximum number of disabled to sustain its appropriation and support" (83 percent agreeing), and second, "inappropriateness of rehabilitation quotas (stated and implied) imposed on VR counselors" (81 percent).

The "heavy client load per VR counselor" was a problem was agreed upon by four out of five (80 percent) of the respondents. Simply stated, if a typical VR counselor with a general caseload of over 100 handicapped persons has added to his caseload a large number of severely handicapped persons, that will probably mean that all, including the severely handicapped, will get little service. The other major resource problem was the "insufficient funds for purchase of rehabilitation services," to which 77 percent agreed. While "insufficient funds" was tied for eleventh in percentage agreement ranking, it should be remembered that it was first according to the composite ranking.

First Choice and Composite Rankings

The option of a weighted case closure system for VR agencies was the first choice of 20 percent of the respondents. Next were "intensive training program" (16 percent) and "reduced caseload size for counselors with specialized caseloads" (14 percent). In the composite rankings, presented in Table 21-3, the same three items were clustered at the top of the list.

POLICY OPTIONS

Four out of five of the respondents agreed that the first six options would lead to greater services for the severely handicapped. The option with the strongest agreement (94 percent) was "the implementation of intensive training programs for counselors and others serving the severely handicapped." If counselors are to better serve severely handicapped clients, additional training seems required. "Increased service capacity in facilities to serve the severely handicapped" was agreed upon by 93 percent of the respondents. "Reduction of caseload size for counselors with specialized caseloads of severely handicapped" would lead to greater services for severely handicapped was agreed by 89 percent.

Eighty-seven percent of the respondents agreed that "greater utilization of employed handicapped to extend employment opportunities to other handicapped in the same work setting, industry, or service" would realistically lead to greater opportunities for the severely handicapped. Particularly in view of the earlier perception of the resistance of the competitive labor market hiring the severely handicapped, the use of persons who have been successfully employed in different work settings could be quite helpful in developing new job opportunities for other handicapped who follow into their field.

"Greater involvement of the severely disabled consumer in planning, delivery, and evaluation of rehabilitation services" was agreed upon by 85 percent of the rehabilitation providers sampled as a way to improve services and opportunities. A growing number of agencies have realized that they can provide better services to their constitutency if they let the person being served and their organizations have a voice in making the decision. Finally, four out of five (85 percent) of

Table 21-3

Composite Rankings of Eleven Policy Options

1.	(98)	Implementation of intensive training programs for counselors and others serving the severely handicapped
2.	(92)	Reduction of caseload size for counselors with specialized caseloads of severely handicapped
3.	(92)	Implementation of a weighted case clousre system in VR agencies to provide greater incentive for working with the severely handicappped
4.	(61)	Increased service capacity in facilities to serve the severely handicapped
5.	(57)	Establishment of a separate program within VR agencies with specialized caseloads to promote more efficient services to the severely handicapped
6.	(45)	Implementation of an expanded outreach program to locate more severely handicapped
7.	(43)	Greater involvement of the severely disabled consumer in planning, delivery and evaluation of rehabilitation services
8.	(33)	Implementaiton of differential wage scale within VR agencies to encourage more professionals to work with the severely handicapped
9.	(30)	Greater utilization of employed handicapped to extend employment opportunities to other handicapped in the same work setting, industry, or service
10.	(26)	Establishment of a seaprate interagency coordinating office to promote more efficient services to the severely handicapped
11.	(21)	Implementation of a VR tracking system to keep track of rejectees to see if they later become eligible

the respondents agreed that "implementation of a weighted case closure system in VR agencies" would provide greater incentive for working with the severely handicapped.

JOB PLACEMENT OF THE SEVERELY HANDICAPPED

The ultimate goal of the vocational rehabilitation agency is to place in a suitable job each disabled person to whom it is providing rehabilitation services. With the increased emphasis on service to the severely handicapped, it becomes important to know what difficulties or differences might be expected in the area of job placement. The first question, then, is, "Is it more difficult to find job placements for those people who are severely handicapped than for those people who are less severely handicapped?" An overwhelming majority of 97 percent responded affirmatively. They were then presented with a list of 12 difficulties and asked to check those which applied.

Job Placement Difficulties

Heading the list of job placement difficulties was "lack of affordable transportation," with 55 percent of the respondents checking it. There were two other items that half of the respondents saw as greater job placement difficulties for severely handicapped than for those who are less severely handicapped, namely: "presumed poor risk (Workmen's Compensation)" (53 percent), and "inadequate physical facilities (architectural barriers)" (50 percent). Other highly rated difficulties were "high unemployment rate," "lack of work for the homebound," and "discrimination."

Pre-Placement Services for the Severely Handicapped

Just as it was important to know of difficulties in placing the severely handicapped, it is also important to know whether people with severe handicaps require more or different kinds of services to improve their work capacities and to enhance their employment placement from those services usually provided other disabled people. Here again an overwhelming 98 percent majority agreed that severely handicapped did require more of different kinds of services. Heading the list was "more aggressive placement services," which 73 percent of the repondents checked. This statistical result is consistent with the support for the earlier mentioned policy option of increasing the number of job development and placement specialists for the most severely handicapped within the VR agency. Five kinds of services were agreed upon by between 63 percent and 65 percent of the respondents; they were "more intensive and/or extended: (1) evaluations, (2) restorative services, (3) counseling sessions, (4) work training, and (5) follow-up." Sixty-two percent of the respondents checked "more active intervention with environment (e.g., house modification, job engineering)" as a service that severely handicapped require. Clearly, additional services are required to effectively serve individuals with severe handicaps.

ECONOMIC CONSIDERATIONS

We solicited the perceptions of rehabilitation providers of the relative cost of rehabilitating severely handicapped people as opposed to the less severely handicapped. The three items that better than nine out of ten respondents saw as costing more for the rehabilitation of severely handicapped individuals in comparison to those less severely handicapped were: (1) job finding and job placement services (95 percent); (2) physical and mental restoration services to treat conditions that are stable and slowly progressive, including activities of daily living (93 percent); and (3) overall counselor time (92 percent).

REHABILITATION FOR INDEPENDENT LIVING

A program of rehabilitation for independent living is one which would provide comprehensive rehabilitation services to improve the ability of severely handicapped people to live independently or function normally within their family or community without reference to vocational goal. A basic question is whether the rehabilitation providers feel it appropriate for the State VR program to serve as the vehicle for providing rehabilitation services for independent living. Seventy-six percent of the respondents felt that it was either "very appropriate" or "appropriate." In fact, 50 percent (585 of 1,167) considered it "very appropriate" for VR to do rehabilitation for independent living.

In the open-ended comments, 114 respondents felt that VR doesn't have the staff, money, or expertise to perform such a task; 85 observed that a program for independent living is not vocational rehabilitation. On the other hand, 199 commented that VR is the agency best prepared to handle independent living rehabilitation and can be extended to do so. A table of 107 respondents pointed out that severely handicapped individuals have a right to such services and listed benefits.

Services for Independent Living Rehabilitation

The scope of services that might be required for a comprehensive rehabilitation for independent living program are considerable. A list of 21 services believed to be required in such a program was presented and respondents were asked to indicate their agreement or disagreement that each of the services listed would effectively assist the severely handicapped in a rehabilitation program for independent living.

On all 21 services at least four out of five respondents agreed upon this contribution. Heading the list was "instruction and training in activities for daily living," with 99 percent either strongly agreeing or agreeing; not a single person out of 1,170 who responded to that item strongly disagreed. Tied for second on the list, at 98 percent, were "mobility training," "prosthetic and orthotic devices, braces, wheelchairs, etc.," and "physical therapy." Third in degree of agreement were "occupational therapy", "homemaker services", and "transitional living arrangements" at 95 percent. Tied for fifth, with 94 percent agreeing, "rehabilitation medicine services," "psychological therapy/counseling," and finally "identity building (role as family member, sex partner, consumer, etc.)."

CONSUMER INVOLVEMENT

Less that 2 percent of the rehabilitation providers checked "advocacy" as the main emphasis of their work. Less than 2 percent described their organization as a "consumer organization representing the handicapped." Yet 85 percent agreed with the policy option of "greater involvement of the severely disabled consumer in planning, delivery, and evaluation of rehabilitation services." An even higher number (87 percent) agreed with the policy option of "greater utilization of employed handicapped to extend employment opportunities to other handicapped in the same work setting, industry, or service." As a means for delivering comprehensive rehabilitation services for independent living, 90 percent of the respondents rated self-help consumer organizations as either "helpful" or "most helpful."

Respondents were asked about the role qualified consumers or representatives of consumer organizations can play in improving the delivery of rehabilitation services and/or in preparing the severely handicapped to qualify for vocational rehabilitation or independent living. Four out of five respondents checked "information resource" (82 percent) and "referral source" (79 percent). "Peer counseling" was checked by 65 percent. "Consumer advisory boards" was also highly indicated both for "the State VR agency" (72 percent and for "other rehabilitation service providers" (62 percent). The most frequent write-in comment in the last section of the questionnaire was "use of professionals, especially handicapped paraprofessionals."

SERVING SEVERELY HANDICAPPED AND PROVIDING ILR

Two basic questions relate to the appropriateness of VR both for serving the severely handicapped on a priority basis and for independent living rehabilitation. The responses to these questions could be influenced by a variety of factors. To determine whether five key factors affected the responses, group comparisons were made, summarized in Tables 21-4 and 21-5. The first group comparison looks at whether respondents working for a State VR agency, as opposed to those not working for VR, consider it more or less appropriate for VR to focus the major portion of its attention on serving the most severely handicapped.

The second group comparison, "urban vs. rural," is between respondents who presently serve a majority of urban clients as opposed to those who serve mainly rural clients. The third group comparison was made to determine the effect of length of respondents' rehabilitation experience on responses. The fourth group comparison examined the relationship of responses to the percentage of severely disabled in respondents' caseloads. The fifth and final group comparison focused on the percentage of severely disabled clients which respondents placed in gainful employment.

Table 21-4

Group Comparisons on "Appropriateness for VR to Focus the Major Portion of its Attention on Serving the Most Severely Handicapped"

Group	Very Appropriate		Appropriate		Inappropriate		Very Inappropriate		Totals	
	N	%	N	%	N	%	N	%	N	%
VR	233	35	300	46	102	16	22	3	657	100.0
Non-VR	187	36	233	44	87	17	17	3	524	100.0
Urban	90	35	108	42	44	17	15	6	257	100.0
Small City	39	35	54	49	16	14	2	2	111	100.0
Rural	21	28	36	49	13	18	4	5	74	100.00
Yrs. Experience										
5 or less	122	39	133	42	50	16	9	3	314	100.0
More than 5	294	34	395	46	138	16	30	4	857	100.0
Percent of Severely Handicapped in caseload										
0-33%	82	26	149	47	70	22	16	5	317	100.0
34-66%	111	36	139	45	52	16	8	3	310	100.0
67+%	149	47	131	41	32	10	8	3	320	100.0
Percent of caseload Placed										
25% or less	50	37	60	45	20	15	4	3	134	100.0
More than 25%	67	39	68	40	29	17	7	4	171	100.0

Appropriateness for VR to Focus on Most Severely Handicapped

As can be seen from Table 21-4, there was very little difference between VR and non-VR respondents as to whether it was appropriate for VR to focus the major portion of its attention on serving the most severely handicapped. In both groups, about four out of five thought it either appropriate or very appropriate.

A higher percentage of respondents serving clients in an urban area answered the question with "very appropriate" than did respondents with rural clients. But this difference canceled out when "appropriate" responses were taken account. The percentage of "inappropriate" plus "very inappropriate" answers was also the same for both groups (23 percent). The same general response pattern of little overall difference in "combined appropriates" versus "combined inappropriates" occurred with the group comparisons based on the respondent's years of experience in rehabilitation and on the percentage of severely handicapped persons the respondent was able to place in employment.

The largest difference was that respondents with a low percentage of severely handicapped in their caseloads were also less likely to believe it appropriate for VR to focus its attention on the severely handicapped than those serving a high percentage. Of those with a low percentage of severely handicapped, 73 percent thought it appropriate, compared to 88 percent of those with a high percentage.

The overall response is a clear majority from all groups believing that it is appropriate for VR to focus the major portion of its attention on the severely handicapped.

Appropriateness for VR to Serve as Vehicle for Rehabilitation for Independent Living

In Table 21-5, the overall consensus that VR was the appropriate vechicle was more-marked than the group differences. VR respondents (74 percent) were not significantly different from non-VR respondents (78 percent). One difference was between respondents with 5 years or less or rehabilitation experience (81 percent) contrasted with those with more than 5 years experience (74 percent). As before, the biggest difference was between those with a small percentage of severely handicapped on their caseload (72 percent) and those with a large percentage of severely handicapped (82 percent). In summary, the clear majority believes it appropriate for VR to serve as the vehicle for providing rehabilitation services for independent living.

Capability of Serving Additional Numbers of Severely Handicapped

Table 21-6 presents comparisons for the same five groups on two questions about service capability. The most significant difference was that a higher percentage of non-VR respondents (74 percent) as compared to VR respondents (59 percent) believed themselves personally capable of serving additional numbers of severely handicapped persons.

Table 21-5

Group Comparisons on "Appropriateness for VR to Serve as the Vehicle for Providing Rehabilitation Services for Independent Living"

Group of Respondents	Very Appropriate		Appropriate		Inappropriate		Very Inappropriate		Total	
	N	%	N	%	N	%	N	%	N	%
VR	311	48	171	26	103	16	62	10	647	100.
Non-VR	274	53	130	25	76	15	40	8	520	100.
Urban	128	50	63	25	46	18	18	7	255	100.
Small City	65	60	24	22	13	12	7	6	109	100.
Rural	33	45	23	32	13	18	4	6	73	100.
Yrs. Experience										
5 or less	156	50	97	31	42	14	17	5	312	100.
more than 5	421	50	202	24	137	16	85	10	845	100.
Percent Severely Handicapped										
0-33%	138	44	87	28	53	17	35	11	313	100.
34-66%	153	50	75	25	50	16	27	9	305	100.
67+%	182	58	77	24	40	13	16	5	315	100.
Percent Placed										
25% or less	74	55	27	20	15	11	18	14	134	100.
More than 25%	89	52	39	23	31	18	12	7	171	100.

Table 21-6

Group Comparisons on "Capability of Serving Additional Numbers of Severely Handicapped People"

Group Respondents	"Personally Capable"				"State VR Program Capable"					
	Yes		No		Yes		No		Total	
	N	%	N	%	N	%	N	%	N	%
VR	296	59	203	41	532	83	110	17	642	100.0
Non-VR	336	74	119	26	403	84	76	16	479	100.0
Urban	141	62	87	38	187	78	53	22	240	100.0
Small City	77	74	27	26	94	86	15	14	109	100.0
Rural	50	70	21	30	58	82	13	18	71	100.0
Yrs. Experience										
5 or less	193	67	95	33	244	81	56	19	300	100.0
more than 5	435	66	223	34	685	84	128	16	813	100.0
Percent Severely Handicapped										
0-33%	203	68	94	32	253	82	55	18	308	100.0
34-66%	168	61	108	39	244	81	57	19	301	100.0
67+%	217	72	84	28	257	85	46	15	303	100.0
Percent Placed										
25% or less	82	66	42	34	132	79	35	21	167	100.0
More than 25%	104	68	49	32	105	81	25	19	130	100.0

Percentage of Severely Handicapped Placed in Employment

Several important questions were raised concerning respondents who place a significant percentage of severely handicapped in employment. Of rehabilitation workers who are involved in helping severely handicapped find jobs, are there differences between those who place a greater percentage of severely handicapped versus those who place a smaller percentage in (a) experience, (b) attitude, or (c) knowledge?

Experience -- The results from persons who responded on both the questions about their years of experience and the question about the percentage of severely handicapped that they were able to place were cross-tabulated.

Comparisons were made between the respondents who reported placing more than 25 percent of the severely handicapped people they served, as opposed to those who reported placing less than 25 percent. According to Table 21-7, those respondents who had over 5 years experience in rehabilitation-related fields placed a considerably higher percentage of the severely handicapped they served.

Table 21-7

Respondents	Respondents having 0-5 years of experience		Respondents having 6 more years of experience	
	Number	Percent	Number	Percent
Respondents who placed more than 25 percent of severely handicapped	46	46	125	61
Respondents who placed less than 25 percent of severely handicapped	54	54	80	39
Total	100	100	205	100

Attitude -- For obvious reasons, respondents were not asked whether they themselves discriminate against applicants in making eligibility decisions. The socially desirable response would consistently be "no." However, respondents were asked to indicate the extent of their agreement or disagreement that several characteristics of an individual (age, race, education) actually influence most counselors' decisions to accept and provide rehabilitation services to that individual in the State Vocational Rehabilitation program. In the sense that a respondent projects his own experiences and biases into answering the question, the answers reflect the respondents' attitudes toward accepting severely handicapped for rehabilitation. For example, 78 percent of respondents reporting a larger placement percentage of severely handicapped (over 25 percent) agreed that a client's "ability to leave home to make appointments, receive services, etc." influenced counselors' decisions, while 89 percent of respondents reporting few placement percentage agreed. Similarly, "high school or additional education" as a factor was agreed to less by those having a high placement percentage than by those in the lower group.

Having a "specific job available upon completion of the rehabilitation program" influences acceptance decisions according to 55 percent of respondents having larger placement percentages and 63 percent of respondents having placement percentages under 25 percent.

Knowledge -- One measure of general knowledge of potential opportunities was the question that asked respondents if they knew of "any special programs for the severely handicapped, including those who are homebound, that help prepare them for vocational rehabilitation or independent living." As would be expected, those respondents having larger percentages were more aware of special programs (51 percent) than those respondents having smaller placement percentages (38 percent).

In summary, respondents who reported placing a higher percentage of severely handicapped individuals generally had more years of experience, a more positive attitude toward acceptance of severely handicapped for rehabilitation, and greater knowledge of special programs for the severely handicapped.

Geographic Location

Because a person's geographic location may determine the availability of resources (counselors, accessible facilities), several questions were raised concerning differences in answers of respondents from urban versus rural areas. Probably the most critical question relates to the influence of a client's location as a factor that might influence his acceptance into VR. Twenty-seven percent of respondents serving rural clients and 52 percent of respondents serving urban clients agreed that whether a client is living in an urban or semi-urban area as opposed to a rural area will influence most counselors' decisions as to whether to accept and provide VR services to that individual.

VR DIRECTORS

An important group among the respondents are the State agency directors themselves. Of the 82 directors, 63 or 77 percent responded to the questionnaire. Their responses were examined with respect to three questions that relate to the 1973 Rehabilitation Act's mandate to serve the severely handicapped first: (1) Have VR agencies made changes to improve services? (2) Is the State VR program capable of serving additional numbers of severely handicapped? and (3) Is it appropriate for the State VR program to focus the major portion of its attention on the severely handicapped?

On the first question 71 percent of the respondents overall reported that their agency had made organizational, procedural, or other changes within the past year that have resulted or would result in improved or expanded vocational rehabilitation services to individuals who are most severely handicapped. As would be expected, more of the VR respondents reported change than did non-VR, and more directors than their staffs.

Second, on the question of whether the State VR program was capable of serving additional numbers of severely handicapped people, the strongest affirmative opinions came from State VR directors and workshop staff, with 90 percent of both agreeing. Eighty-three percent of all respondents agreed.

Third, almost all State VR directors (95 percent) thought it appropriate (47 percent "very appropriate" plus 50 percent "appropriate") for the State VR program to focus the major portion of its attention on serving the most severely handicapped. Only 2 of 62 directors thought it inappropriate, and none thought it very inappropriate. Eight-one percent of all respondents agreed.

In that the specialized caseload was a strongly supported policy option, but one that may be more feasible in urban areas where there is more than one counselor, urban-rural differences were examined. Seventy-three percent of persons serving urban caseloads saw a need for specialized caseloads, while only 65 percent of persons with rural caseloads saw such a need.

Finally, urban areas have more rehabilitation facilities, housing alternatives, and places of employment. Presumably, the number of accessible facilities in urban areas in greater even though the percentage may be the same. Sixty-seven percent of rural respondents checked "inadequate physical facilities (architectural barriers)" as a difficulty in placing the severely handicapped, campared to only 43 percent of the urban respondents.

MAJOR CONSIDERATIONS IN THE SURVEY RESULTS

Six major considerations seem to stand out in the survey results: (1) specialized caseloads, (2) weighted cases, (3) increased funds, (4) rehabilitation for independent living, (5) consumer involvement, and (6) barrier elimination.

Specialized Caseloads

Several of the impediments and the policy options seem to have a common element. Two of the highly ranked impediments to serving the severely handicapped were "heavy client load per VR counselor," and "lack of job development and placement specialists for the most severely handicapped within the state VR agency." Three of the top five ranked policy options address these same impediments, but in the form of solutions. The top-ranked option, "Implementation of intensive training programs for counselors and others serving the severely handicapped," would spread the expertise that already exists. Corresponding, in a sense, to the "heavy client load per counselor" impediment is the second-ranked policy option of "Reduction of caseload size for counselors with specialized caseloads of severely handicapped." Also under the general rubric of specialized programs, is the fifth-ranked policy option, "Establishment of a separate program within VR agencies with specialized caseloads to promote more efficient services to the severely handicapped."

Small specialized caseloads seem to result in improved services to particular populations. For example, the blind, the deaf, and the retarded have all received more effective services as a result of having counselors who could learn and master in depth the specialized knowledge and techniques required to meet effectively the needs of the particular disability group. The general caseload counselor must have difficulty learning about automobile hand controls for paraplegics, mobility training for the blind, sources of interpreters for the deaf, and a myriad of other specialized services required by each of the different disability groups.

Several examples of vocational rehabilitation programs with specialized counselors are worth noting. George Washington University's Research and Training Program has developed a program for severely handicapped persons that includes not only counselors specialized in severe disability but in job restructuring and rehabilitation engineering. Several of the Spinal Cord Injury Centers funded by the Rehabilitation Services Administration have specialist counselors assigned by the State VR agency who have amassed considerable expertise about the variety of considerations (from neurological to architectural) involved in helping individuals with spinal cord injury to find physical and vocational independence. Several State VR agencies have already developed or are now developing specialty units for the deaf, the mentally ill, and other target group populations of the severely handicapped. To the extent that agencies are large enough to support such specialization efficiently, it appears that severely handicapped can be better served.

Weighted Cases

In the list of 29 potential impediments to serving individuals with severe handicaps, two highly correlated items ranked fifth and sixth. The fact that the VR agency is "required to rehabilitate the maximum number of disabled to retain its appropriation and support" is, in great part, what leads to the "inappropriateness of rehabilitation quotas (stated and implied) imposed upon VR counselors." To correct these major impediments, the third-ranked policy option entailed the "implementation of a weighted case closure system in VR to provide greater incentive for working with the severely handicapped."

Whether it makes more sense to "weight" the difficulty of the case at the end of the rehabilitation program, upon closure, or at the start of the program, upon acceptance and evaluation, is an open question. But the introduction of an objective measurement system that takes into account such factors as the client's employment history, economic status, physical functioning, psychological adjustment, and social competency, could properly weight the counselor's efforts.

To date, however, the research on weighted closures does not show major break throughs. Case difficulty which requires effort and severity of handicap are often confused.

Increased Funding

Three of the questions to which a large number of persons responded with comments related to the capability or appropriateness of the State VR agency to serve severely handicapped. One variation or another of the response, "with more staff and more funds," was the most frequent comment throughout the questionnai

A similar pattern showed up in the responses to other questions. For example, on the question about impediments to serving the severely handicapped, "insufficient funds for the purchase of rehabilitation services" ranked first, well above the other 28 problems. Individuals who are severely handicapped were perceived as requiring more resources (e.g., physical and mental restoration, counselor time, and job placement) in comparison to individuals who are less severely handicapped. Three-fifths of the respondents believe that there are severely handicapped individuals who would not be accepted into the program even though their disabilities and functional limitations are identical with those of the severely handicapped person who is accepted into the program. One wonders how many of the severely handicapped are persons who (a) are turned down due to lack of resources (even though it is not an acceptable reason on the R-300 form), or (b) don't even bother to apply because they have been discouraged by other severely handicapped who have been underserved due to lack of resources.

As shown in Chapter 28 , one of the options presented for improving services to the severely handicapped is increased funding for the vocational rehabilitation program.

Rehabilitation for Independent Living

Three points come through clearly in the response of the rehabilitation providers to rehabilitation for independent living. First, three out of four of the respondents felt it appropriate for the State VR program to serve as the vehicle for providing rehabilitation services for independent living. Second, a wide variety of services is required, ranging from "instruction and training in activities of daily living" and "mobility training" to "transitional living arrangements" and "identity building." And third, a wide variety of service delivery methods are viewed as helpful, ranging from services to homebound and institutionalized persons to utilization of families of the severely handicapped and self-help consumer organizations.

Elimination of Barriers

On the list of 29 problems, the largest percentage (93 percent) of respondents agreed that "lack of usable transportation" was a major impediment to serving the severely handicapped. And yet, a relatively small proportion of services are directed at alleviating or eliminating the barriers. Only 14 percent of the respondents reported that special transportation was one of the services that they provide. Since the VR program is time-limited, the issue of post-rehabilitation transportation may be what is reflected in the identification of this issue. Except where van lifts or automobile hand controls are provided, rehabilitation service providers apparently view the post-rehabilitation responsibilities in transportation as outside of their domain.

The same discrepancy occurred between barriers in housing as an impediment and home modifications as a provided service. Eighty-nine percent of the rehabilitation respondents agreed that "lack of barrier-free housing" was a significant impediment to serving the severely handicapped. Almost all respondents (96 percent) agreed that home modifications would effectively assist the severely handicapped in a rehabilitation for independent living program. However, only 5 percent of such respondents are actually engaged in providing home modification services.

Ninety percent of the respondents agreed that "lack of barrier-free employment settings" was a major impediment to serving the severely handicapped. However, rehabilitation service providers apparently do not see the elimination of architectural and other barriers as a part of their regular responsibilities. Funds allocated for the elimination of such barriers would facilitate access to rehabilitation services by the severely handicapped.

In a few States the VR agency has taken on the responsibility of eliminating some of these barriers. For example, the Massachusetts Rehabilitation Commission, has funded the purchase of wheelchair-accessible vans for group transportation, in addition to providing hand controls and driving training. The agency has also worked with local housing authorities to acquaint counselors with availability of barrier-free housing and has supported legislation that was subsequently enacted to provide $10 million for barrier-free housing in the future. With respect to the lack of barrier-free employment settings, the agency has set the requirement that, before any new leases are signed for rehabilitation offices, the new facility must be completely free of barriers to the handicapped; it is represented on the State Architectural Barriers Board, and it has supported legislation that was enacted to strengthen the compliance powers of the Board in enforcing accessibility in new construction. It is clear from this example that agencies can be advocates.

SUMMARY

In summary, 1,198 rehabilitation providers were surveyed to obtain their collective perception of the needs-meeting system for individuals with severe handicaps. The data for all respondents were summarized. Group comparisons and other analyses were briefly highlighted. Discussion centered around six policy options that received considerable support: (1) specialized caseloads, (2) weighted cases, (3) increased funds, (4) rehabilitation for independent living, (5) consumer involvement, and (6) elimination of barriers.

The clear majority of respondents consider it appropriate for the State Vocational Rehabilitation program both (1) to focus the major portion of its attention on serving the most severely handicapped and (2) to serve as the vehicle for providing rehabilitation services for independent living. Both in terms of vocational rehabilitation and independent living rehabilitation for the severely handicapped, the potential for improving services is clear. Realization of that potential will require more staff and money than are currently available.

Chapter 22

REHABILITATION FACILITIES AND WORKSHOPS

It is not possible to discuss rehabilitation of any type for the most severely handicapped without consideration of rehabilitation facilities and workshops. Facilities play a key role in evaluation and service provision. Workshops are often the major source of skill training and, too often, the only source of work in an economic system which allocates jobs by market principles.

The many types of rehabilitation facilities include the comprehensive rehabilitation center, the spinal cord injury center, the rehabilitation workshop, the vocation evaluation and work adjustment center, speech and hearing centers, optical aids clinics, halfway houses for the mentally ill and for the mentally retarded and the activity center. Some of the facilities are large; some, small. A single facility may serve all disability groups or only those in a selected disability category. Some are sponsored and operated by public agencies, but most are under voluntary auspices. Regardless of its size, sponsorship, program emphasis, or client population, each facility plays an important role in rehabilitation.

TYPES OF FACILITIES

Rehabilitation facilities draw upon many disciplines for their services. The range of services which may be found in a facility is reflected in the Rehabilitation Act of 1973, which describes a rehabilitation facility as providing "...singly, or in combination, one or more of the following services for the handicapped individuals: (1) vocational rehabilitation services which include, under one management, medical, psychological, social and vocational services; (2) testing, fitting, or training in the use of prosthetic and orthotic devices; (3) prevocational conditioning or recreational therapy; (4) physical and occupational therapy; (5) speech and hearing therapy; (6) psychological and social services; (7) evaluation of rehabilitation potential; (8) personal and work adjustment; (9) vocational training; (10) evaluation or control of specific disabilities; (11) orientation and mobility services to the blind; and (12) extended employment for those handicapped individuals who cannot be readily absorbed in the competitive labor market. These services are rendered with the common objectives of assisting the handicapped individual to function at his maximum physical, personal, and vocational level."

Rehabilitation centers and rehabilitation workshops both had their beginnings in the nineteenth century, preceding the establishment of the State-Federal vocational rehabilitation program by many years. One of the first to be established was the Cleveland Rehabilitation Center which dates back to 1889. In 1917 the Red Cross opened the Institute for the Disabled in New York. The first workshop was established in 1840 in Massachusetts to provide employment to graduates of the Perkins School for the Blind. From these beginnings there are today about 1,000 rehabilitation centers in the United States and 2,500 rehabilitation or sheltered workshops.

Rehabilitation Centers

Early proponents viewed the rehabilitation center as a special type of rehabilitation facility which would join the many evaluative and therapeutic efforts of medicine and important nonmedical therapeutic services, including adjustment training, social and recreational training, vocational counseling, job tryout and vocational training. This combination of services makes it possible to give simultaneous consideration and treatment to a wide range of problems presented by the disabled individual. The setting frequently provides stimulation for a higher and more sustained form of motivation within the client, a key factor in rehabilitation. The rationale is based on the conviction that severe problems call for intensive effort and specialized skills working in concert.

Rehabilitation centers exist in a variety of forms and are found in various administrative settings. They tend to be either medically or vocationally oriented. The medically oriented center is generally a part of a general hospital, medical school, or hospital center. As the term implies, it has a strong emphasis on medical and medically related services. Our survey of clients of these centers gave a flavor of how such a center works. Its counterpart is the vocationally oriented center in which medical services are supplemented in a major way by vocational counseling, testing and training. These centers are strong in prevocational services.

While the comprehensive rehabilitation center is thought of as being designed primarily with the severely disabled in mind, it can serve persons who have only moderately severe disabilities. The versatility of the rehabilitation center in meeting a broad range of rehabilitation problems from single to complex disability, from the moderate to the more severe, has meant the broad utilization of centers by increasing numbers of rehabilitation clients of State agencies.

There is also increasing evidence that there is value in centers that are both comprehensive in service and accept a broad range of disability problems. Many of the different disability problems have common elements of service need.

Workshops

Workshops are receiving ever-increasing attention and utilization as an important resource for handicapped persons who need the services they provide. Their usefulness may be attributed to the work evaluation services they offer as well as work itself.

The workshop offers services which can enhance the likelihood of success when the handicapped person seeks a job in the industrial world. Use of a sheltered work setting may be conceived of as a means of providing transitional or long-term work experience according to the abilities, interests, aptitudes, and needs of the individual.

There are the multi-disability workshops serving all disability groups, such as the Goodwill Industries workshops, and there are single disability workshops such as those for the blind, mentally retarded, cerebral palsied, emotionally disturbed, and the epileptic.

Workshops are located in all kinds of places. They vary from large bright factory buildings with modern equipment to a small room with people working around a single table. Although some may look like industrial establishments, they may also bear resemblance to an occupational therapy room in a hospital.

Three groups of handicapped people are generally considered to need the services of a sheltered workshop: (1) those who have never worked or have lost their skills and work habits as a result of injury or disease; (2) those who for some psychological or social reason are not acceptable to competitive industry without the development of proper work habits and productive skills; and (3) those who should have regular full-time or part-time work but are incapable of meeting regular industrial standards.

Workshops strive to provide a variety of rehabilitation services related to work experience. They are designed:

1. To provide prevocational evaluation, on-the-job training, and job tryout. Workshops are staffed and equipped, to varying degrees, to provide vocational training in job areas represented in the community. The development of job skills is important preparation for employment in industry.

2. To provide work hardening. Clients are often required to gradually

build up their work tolerance to the point of full-time employment. The workshop fulfills this need by gearing the daily work activities to accommodate the physical capacities of the handicapped person.

3. To provide therapy. Forced idleness is not conducive to the improvement of the handicapped person. The importance of work to the individual and to society has been clearly recognized and acknowledged by those who have made a study of the subject. Employment in itself is considered to have therapeutic value and is an essential ingredient of well-being. Although earning income may be considered the primary purpose of work, it also has a social function and is a means of self-expression.

4. To provide opportunities for personal adjustment. Many workers, both abled-bodied and disabled, lose their jobs as a result of the inability to get along with their fellow workers and supervisors rather than because of poor productive performance. These emotional problems are recognized and dealt with in the workshop with the assistance of social, psychological, and psychiatric services. One of the important and effective services of the workshops for the mentally retarded is found in the area of personal adjustment.

5. To cultivate good work habits. Proper work habits not only increase the employment potential but help to insure continuation on the job following placement.

6. To provide extended employment to those handicapped people who cannot readily find or be placed in employment in the competitive labor market. Many thousands of severely handicapped people cannot work in competitive employment and require the environment and supportive services of a sheltered workshop in order to earn money and to achieve the self-reliance and the self-fulfillment that can come through paid work.

Wagner - O'Day Act and Workshops

Lack of contract work on a sustained and regular basis is a major problem of sheltered workshops. A continuous flow of work is necessary to keep employees productively engaged and to maintain the workshop's rehabilitation services, since work, along with supportive rehabilitative services, is the means by which the workshop accomplishes its objectives. Inability to provide employment defeats the very purpose of the workshop's existence.

Most workshop directors, even those employing full-time salesmen, devote considerable effort to the procurement of contract work. Ever since 1938, when the Wagner-O'Day Act (P.L. 739-75th Congress) was enacted to provide employment opportunities for the blind in the manufacture of products to be sold to the Federal Government, leaders in the workshop field serving the nonblind have been hopeful that this same preferential treatment would be extended to facilities serving all types of disabled persons. It was anticipated that the vast resources and needs of the Federal Government would afford a solution to the "feast or famine" situation that many workshops face. With the Federal Government as a major customer and dependable purchaser, workshop directors and other key personnel would be able to devote more time to rehabilitation and management functions.

The Wagner-O'Day Act of June 25, 1938 made it mandatory for all government agencies to purchase certain items from qualified agencies for the blind. The Committee on Purchase of Blind-Made Products, created by the Act, selected the items, which were published in catalog form, known as the "Schedule." The Committee also established a fair market price for the items. The price could vary as market conditions changed. This Committee is now the Committee for Purchase from the Blind and Other Severely Handicapped.

A nonprofit agency, the National Industries for the Blind, was created in 1938 to deal with government purchasing offices and to distribute the purchase orders to the nonprofit workshops for the blind enrolled in the program. There are now 87 workshops in 36 States affiliated with the organization. They employ 500 blind workers and produce 435 items for the Federal Government. Gross volume sales have been over $30 million a year under U.S. Government contracts. (See preceding chapter, The Blind and the Visually Disabled, for further discussion of employment of the blind in workshops.)

Public Law 92-98, effective June 23, 1971, amended the Wagner-O'Day Act in two major aspects. First, it extended the special priority in selling products to the Federal Government that had previously been reserved for the blind to workshops employing other severely handicapped workers. Second, it expanded the category of contracts to include "services." Workshops for the blind will continue to have first preference in the sale of commodities and, until December 31, 1976, in the contracting of services. After that date, all nonprofit organizations serving the handicapped will receive equal treatment in the awarding of contracts for services, which will include such diverse activities as cleaning and maintenance, printing, automatic data processing, packaging, lettershop services, assembling, and any of the varied service functions now performed by workshops.

In April 1974 the National Industries for the Severely Handicapped (NISH) was created. NISH provides the means of extending the benefits of P.L. 92-28 to workshops serving the severely handicapped other than the blind. At the end of April 1975, NISH had certified 250 such workshops to participate in the program. As of that date 32 of the workshops were producing 17 products and 24 services required by Federal agencies.

Accreditation of Rehabilitation Facilities

There are three national agencies that accredit rehabilitation facilities as a means of assuring quality services in accordance with prescribed standards: the Commission on Accreditation of Rehabilitation Facilities (CARF); the National Accreditation Council (NAC), whose standards apply to facilities serving the blind and the visually handicapped; and Goodwill Industries of America, which accredits only Goodwill workshops. The State Administrators of Vocational Rehabilitation adopted a resolution in 1970 that requires all rehabilitation facilities used by the State VR agencies to be accredited by CARF or NAC or to have made plans for accreditation by 1976. In addition, the Rehabilitation Services Administration requires that rehabilitation facilities applying for Training Service Grants under the Rehabilitation Act substantially meet the standards promulgated by the Secretary of Health, Education, and Welfare. As of January 1, 1975, 20 States required rehabilitation facilities to be accredited in order to serve clients of the State vocational rehabilitation agencies.

Utilization of Rehabilitation Facilities

The significant role of rehabilitation facilities in the State VR programs is seen in the growing expenditures for rehabilitation facility services by State agencies and in the increasing number of State VR agency clients who are sent to the rehabilitation facilities for services. Data for the period 1964-1973 are as follows:

Table 22-1

Use of Rehabilitation Facilities by State Vocational Rehabilitation Agencies, 1964-1973

Fiscal Year	VR clients served in facilities	Percent of Clients Served	Case Service funds spent in facilities	Percent of case service funds spent
			$ 15	20
1964	38,000	9.5	19	22
1965	46,000	10.6	30	27
1966	57,000	11.6	42	26
1967	65,000	11.4	55	28
1968	101,000	14.9	62	24
1969	132,000	16.8	77	25
1970	142,000	16.2	97	28
1971	193,000	19.3	110	28
1972	199,000	18.0	114.6	28
1973	211,000	18.0		

Source: William H. Button, "The Role and Characteristics of Vocational Rehabilitation Facilities: Based on Data Generated by the RRR System," State Rehabilitation Facilities Specialist Exchange, September-October 1973, p.1.

In addition to providing services to the State VR agencies, rehabilitation facilities serve disabled people who are self-referred or referred by physicians, insurance carriers, Workers' Compensation, Medicaid, Medicare, welfare agencies, and other public and private human service agencies.

Many severely handicapped people could benefit vocationally from the services provided by rehabilitation facilities but are not receiving these services because the VR agencies have insufficient funds with which to purchase the services. For example, workshops are serving about 90,000 clients, whereas it is estimated that a million disabled could benefit by employment in sheltered workshops.[1] The

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[1] Committee on Government Operations, Operation of the Wagner-O'Day Act, House Report No. 93-1315 (1974).

facilities themselves cannot help because, relying as they do upon voluntary contributions for their basic support and capital needs, they are in a constant struggle to survive.

STUDIES OF WORKSHOPS

The literature indicates much controversy over the present and future value of workshops to their client-employees, particularly with regard to the question of "terminal" vs. "turnstile" shops. Terminal workshops are those which retain their disabled employees indefinitely, while turnstile workshops are those whose purpose it is to prepare their employees for competitive employment and to place them in a nonsheltered setting after a short time. A third kind of workshop, which has only recently appeared on the scene in this country, is the "competitive" workshop, which combines aspects of sheltered and competitive employment by paying competitive wages and attempting to achieve financial autonomy, yet providing working conditions specially adapted to disabled workers. The study of workshops now being funded by RSA is expected to clarify many of the issues.

Terminal Workshops

Defenders of the terminal workshops assert that their value lies in their ability to confer upon even the most severely handicapped the dignity and innate value of work.[2] Black asserts that workshops combine the valuable functions of rehabilitation, welfare, and business for the ultimate benefit of the client-employee.

More critical writers agree that terminal workshops combine a variety of social functions, but disagree as to their beneficial effects . For example, one speaks of the workshops as "a vague combination of the workhouse, the almshouse,

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[2] Bertram J. Black, "The Workshop in a Changing World: The Three Faces of the Sheltered Workshop," Rehabilitation Literature, August 1965.

the factory and the asylum, carefully segregated from 'normal' competitive society and administered by a custodial staff with sweeping discretionary authority."[3]

In the Gersuny study,[4] the authors agreed that workshop employee-clients are in a condition of servitude, rather than freely contracted workers. They cite examples of interventions into the employees' private affairs by workshop administrators--interventions beyond those found in the normal employer-employee relationship, such as the forbidding of marriage and sexual relationships. Secondly, they cite two National Labor Relations Board cases which denied workshop employee groups the right to organize and bargain collectively, putting them in a different legal category from freely contracted employees.

There is relatively little information on the legal and economic position of workshop employees, their powers and relationships to shop administrations, and their opinions and feelings about the shops in which they work. The only information discovered about disabled people's opinions and feelings about terminal workshops was found in Bachman.[5] The author reports that among the unemployed handicapped people whom she interviewed, none would apply for sheltered workshop positions. "Workshops were described as disgusting babysitters. Too routine, too boring and not meeting the needs of the severely handicapped." Scott [6] offers a supporting view when he observes that the work of blind beggars is often more stimulating and challenging (as well as sometimes more lucrative) than broom-making and other workshop activities available if they quit begging.

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[3] Jacobus Tenbroek, "Sheltered Workshops for the Physically Disabled," Journal of Urban Law, Fall 1966, quoted in Carl Gersuny and Mark Lefton, "Service and Servitude in Two Sheltered Workshops," Social Work, July 1970.

[4] Gersuny and Lefton, "Service and Servitude."

[5] Winnie H. Bachmann, "Variables Affecting Postschool Economic Adaptation of Orthopedically Handicapped and other Impaired Students," Rehabilitation Literature, April 1972.

[6] Robert A. Scott, The Making of Blind Men (New York: Russell Sage Foundation, 1969).

Sherman[7] believes that the production function of workshops takes away from the therapeutic function. He believes that for employees who need a therapeutic environment, production quotas have an adverse effect, and that the emphasis should be placed instead on the quality of work and of human relationships.

Some evidence has been reported that the majority of workshop employees can be prepared for competitive employment,[8] and that there is a tendency among workshops to hang onto their more productive employees (presumably contrary to the employee's best interests) in order to meet their production quotas.[9]

Nevertheless, there appear to be some people who are so severely handicapped that terminal workshops are one of the few alternatives to remaining completely idle. Rusalem[10] reports on a research and demonstration project to develop special workshop programs for multiply handicapped blind people, a group traditionally thought to be incapable even of workshop-type employment. The project design involved having the National Institute for the Blind (NIB) set up a laboratory in which products required for Federal Government contracts were tested to determine whether they could be produced by the multiply handicapped blind. When a production method had been designed successfully, it was tested by multiply handicapped blind people at any of a number of participating workshops. Production processes were set up in these workshops with the aid of specialists from NIB. When the testing went favorably, the product was retained by the workshop for multiply handicapped blind workers. More than 290 such

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[7] Anthony Sherman, "Industrial Therapy in the Sheltered Workshops," Journal of Rehabilitation, November-December 1969.

[8] Greenleigh Associates, Inc., A Study to Develop a Model for Employment Services for the Handicapped (Chicago: The Associates, 1969).

[9] Scott, The Making of Blind Men.

[10] Herbert Rusalem, ed., "Rehabilitation Research: A Capsule Research Review," Rehabilitation Literature, January 1973.

workers achieved employment through this program in the production of 37 new government-purchase product lines. To quote the author, "This research demonstrated that work conditions can be created that result in successful work experiences for members of this group. Thus, another myth concerning the employment potential of the severely disabled has been put to the test and found wanting. It would seem advisable to launch similar studies designed for other severely limited, multiply handicapped target groups..."

"Turnstile" Workshops

Greenleigh Associates[11] found that under increasing economic strain (and perhaps other pressures as well) many terminal workshops are either changing into turnstile shops or closing down entirely. They also concluded from interviews with workshop staff and other rehabilitation professionals that the great majority of those disabled people who are productive enough to be in the labor force at all (i.e., including most workshop employees) are capable of producing at least at minimum wage levels and can be prepared for competitive employment. They point out that under present circumstances whether these workers will actually find competitive employment is another question, depending on labor market conditions. Greenleigh Associates concluded that "the major role of sheltered workshops should be work evaluation, training, and work adjustment in connection with training or job experience." They add, "This does not deny the therapeutic value of work activity centers for those too handicapped to prepare for productive employment. However, the two functions are distinct and serve separate populations; work activity for primarily therapeutic purposes is not productive employment and is outside the labor market as such."

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[11] Greenleigh Associates, Inc., A Study to Develop a Model.

Competitive Workshops

A number of articles report on workshops that pay competitive wages, use management and production techniques borrowed from competitive industry and attempt to achieve financial autonomy (i.e. full reliance on sales).

The Project to Determine the Employability of Epileptics[12] study reports on such a workshop which developed by default. Originally, the workshop was intended to be of the turnstile type. However, when it was found to be impossible to place most of the clients in outside employment, the competitive workshop idea was developed. The cost of converting to a competitive shop, however, was to terminate workers who were unable to reach competitive levels of productivity. This seems to be a substantial disadvantage, particularly with regard to the most severely handicapped.

Viscardi[13] and Abilities Inc. of Florida[14] report on two competitive workshop projects in New York and Florida. Both projects use advanced industrial equipment and techniques plus equipment and work environment modification to provide competitive workshop settings for severely disabled workers. Each is operated as an industrial plant—the Florida project specializing in electronic parts production and printing. The Florida project includes substantial training programs for disabled workers in various skilled trades.

The great value of the projects is the way they show disabled workers how to adjust to jobs from which they are usually excluded and how to modify equipment to meet the needs of people with different kinds of disability. For example, it was found that a totally blind person could perform

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[12] EPI-HAB Phoenix, Inc., Project to Determine the Employability of Epileptics (SRS, DHEW, 1971).

[13] Henry Viscardi, Jr., "The Adaptability of Disabled Workers," Rehabilitation Record, May-June 1961.

[14] Abilities Incorporated of Florida, "Employment of the Physically Disabled in a Competitive Industrial Environment," pamphlet, 1966.

the role of Parts Assembler by feeling parts instead of seeing them. Yet, in the U.S. Department of Labor publication, Work Transit Requirements for 4,000 Jobs as Defined in the Dictionary of Occupational Titles, vision is listed as one requirement for this job. An example of equipment modification is the attachment of a simple hand lever to a foot pedal to allow a paraplegic to operate a drill press. Equipment modifications were made inexpensively and in such a way that nondisabled workers can perform many jobs which are usually denied them with little or no modifications of equipment and environment.

Wages, Financial Structure, and National Planning for U.S. Workshops

Button[15] reports on a 1967 survey of wage levels in 123 sheltered workshops of all kinds in three States: New York, New Jersey, and Pennsylvania. Mean hourly wages were $0.68 in New York, $0.48 in New Jersey, and $0.55 in Pennsylvania. In each State, more workshops appeared in the 25¢-or-less category than in any other. The average work week was 33 hours. A strong positive correlation was found between the extent to which a workshop supported itself through sales of its products or services and the wages it paid. Workshops with a high proportion of long-tenured employees tended to derive a high proportion of their incomes from sales of goods. In general, employees who were blind, had orthopedic disabilities or tuberculosis, were hard of hearing (but not deaf), or had cardiovascular problems had high wages (assumed to correlate with high productivity), while those who were mentally retarded, emotionally disturbed, or had cerebral palsy had low wages.

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[15] William H. Button, "Wage Levels in Sheltered Employment," Organization and Administration of Sheltered Workshops; Research Report Series No. 1, 1967.

Kimberly[16] reports on a survey of the financial structure of workshops. Workshops derive their incomes from their own sales, from charitable contributions, and from various government sources. Income from business activities accounted for 75 percent of the income for all workshops combined, but the median workshop income from business activities was only 50 percent. Findings similar to Button's showed that larger shops derived higher percentages of income from sales and generally employed cardiacs, orthopedically disabled, blind, and tuberculars. Smaller shops had lower proportions of income from sales and typically employed the mentally retarded, mentally ill, and neurologically impaired.

The National Association of Sheltered Workshops[17] reports on a study to determine the feasibility of national contract planning for workshops. The need for such planning stems from the fact that many workshops can no longer get enough contracts to keep their employees busy. (This is in part a result of increasing automation in competitive plants.) Some workshops reported up to 80 percent nonproductive time. Workshops generally lack staff people trained in contract negotiation and are too small or improperly equipped to handle contracts they could otherwise secure. In addition, contracting firms often play one shop off against another in order to get the lowest prices possible. Nevertheless, 65 percent of businesses surveyed reported that they had some work that workshops could do. Activities of workshops, in order of frequency among those surveyed were: assembly work, packaging, mailing, manufacturing, woodworking, sewing,

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16. John R. Kimberly, The Financial Situation of Sheltered Workshops, (Ithaca N.Y.: Regional Rehabilitation Research Institute, Cornell University, 1968).

17. National Workshop Contract Planning (Washington: The National Association of Sheltered Workshops and Homebound Programs, 1970).

painting, electronics, and furniture repair. Regional central contracting associations have been set up in a number of areas to help shops in contract procurement and to enable them to handle contracts that no one shop could handle alone. The author reports that these organizations have been successful and concludes that a similar effort is needed on the national scale.

Workshop Reform

It is obvious that workshops have filled an important gap in training and employment services for the most severely handicapped. As Conley puts it:

> The critical question is not whether sheltered work is needed, but whether it should be provided--in sheltered workshops or in regular employment channels.[18]

The future of such resources is thus a question of whether they should remain separate or somehow be incorporated into regular business channels.

Expansion of workshop capacity was made possible, in large part, by facility construction and improvement grants over the last decade. These funds were authorized by the 1965 amendments to the Vocational Rehabilitation Act. However, the general cutback in project grants, especially those for construction and other capital outlays that occurred in 1970, peaked this special allocation at $4 million in 1969. Such allocation must now compete for funds from the State's generic VR grant and general State authority.

Conley cites three conditions which may be essential for a workshop to be efficient: a source of profitable work, continuous flow of work, and a variety of work types.[19] While prime manufacturing meets criteria 2 and 3, it requires marketing, high working capital, and a wide range of skills among workers. To the extent that sheltered workshops can compete in prime manufacturing, they are

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18. Ronald Conley, The Economics of Mental Retardation (Baltimore: The Johns Hopkins University Press, 1973), p. 349.
19. Ibid., p. 340.

now mostly limited to the labor-intensive areas which have low profitability.[20]

Contributing to the criticism of inefficiency are (1) poor management, both of production and business, (2) size too small to benefit from scale economies, (3) production specialized in a particular disability and thus limited in the variety of contracts, and (4) undercapitalization, thus substituting manpower for more productive machinery.[21]

Stoikov, after studying 73 workshops in 5 States, concluded that all workshops with under 150 clients in average daily attendance were operating at a highly inefficient level.[22] The problem is not just small capacity but underutilization of what exists. Button reported a 70 percent utilization rate nationally;[23] a California survey found a 76 percent rate among its workshops.[24] The fact that the California workshops are somewhat larger, on average, than those in the country as a whole may explain most of the difference. Larger workshops, or workshops linked in an area management arrangement, are not as limited by such factors as absenteeism and the limited clientele they can serve. Both of these factors reduce capacity utilization.

Actually, while capacity management is a basic managerial problem for sheltered workshops, it may also be a solution to part of the problem of meeting future resource needs. While critics of workshops cite their inefficiency, viable alternatives are not readily available. No matter where located, sheltered work will retain its dual purposes, but its primary

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20. Ibid., p. 342.

21. Ibid., pp. 431-42.

22. Ibid., p. 343, citing Vladimir Stoikov, "Economics of Scale in Sheltered Workshop Operations," in W.H. Button, ed., Rehabilitation, Sheltered Workshops and the Disadvantaged (Ithaca, N.Y.: Cornell University Press, 1970), p. 66.

23. W. H. Button, "Sheltered Workshops in the United States," in W. H. Button, ed., Rehabilitation, Sheltered Workshops.

24. California State Department of Rehabilitation, California State Plan for Workshops and Rehabilitation Facilities. (Sacramento: Human Relations Agency, 1971), p. 138.

purpose for the client remains training and adjustment to work. On-the-job training in competitive industry is a high risk for the employer undertaking such sheltered work, even if subsidized. The availability of enough employers and resources to train the severely handicapped in competitive industry is also doubtful.

The alternative to sheltered workshops is sheltered work. The subsidy now going to run an inefficient workshop operation could be used, instead, to subsidize a specially constructed training unit in competitive industry.

More sheltered employment should be developed, if only to free more space in existing workshops for evaluation. Such development also will have impact on Vocational Rehabilitation. Presently, a VR counselor may use a sheltered workshop not only for training, but also as a closure. So long as there are long-term employment positions available in such facilities, the risk of an unsuccessful closure is reduced substantially, but so may be the attainment of full working potential by the client.

Rural areas and areas of small urban settlements such as Appalachia transportation services and trainers who are willing to travel distances to serve scattered populations. Such areas also face problems in funding sheltered workshops and in developing markets for their products.

A workshop serving a low density population must be more flexible in terms of the type of client it serves at any time than one in the more urban areas. Because of the problems both in production and market coordination, management must also be above average in capabilities.

All of these factors weigh against successful workshops in rural areas and point out the even greater need to develop alternatives such as sheltered work in competitive industry and training programs in area businesses. Actually, job site evaluations in area businesses are considered in many instances a more useful means for predicting future success and maximizing future job potential. Goodwill of Santa Clara (California) reports "...there is no substitute for extension of the assessment process into the actual industrial situation."[25]

It would be nice to say, as Conley does, that workshops do not have to be used, especially in the increasing numbers experienced over the last decade. Unfortunately, the hope for developing work sites in competitive industry sufficient to cover all the handicapped who should and will be served by the VR program overrates the ability of the competitive sector to find places for the severely disabled now served in workshops. While increased concentration should be placed on locating places in competitive business, the concurrent upgrading and expansion of workshops will have to occur if there are to be sufficient work places for the severely handicapped. One objective of this expansion would be to provide reasonable pay for the maximum number of severely handicapped at the minimum possible annual subsidy per worker. Since many of the severely handicapped have full intellectual ability, workshops might be developed to operate in such areas as information retrieval, referral services, and other activities requiring use of computer capability.

One project at the Regional Rehabilitation and Training Center at George Washington University suggests that with proper training the severely disabled who are homebound can be economically productive in computer programming, microfilming, and computer data processing.

A rough estimate of the public costs of operating a workshop in 1966 is that approximately $2,170 was spent per client successfully placed in competitive employment and $763 per client who attended daily. The average hourly wage of workshop clients in 1968 was approximately $0.76 at a time when the minimum wage was $1.60.

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25. Cited by Joel Markowitz, "Central Policy Issues for the Evaluation of Sheltered Workshops," Working Paper No. 185/RSO 12, Institute of Urban and Regional Development, University of California, Berkeley, 1972, p. 23.

Inflating the 1966 figures for the public costs of workshops to 1974, the cost of creating positions for the 225,000 unemployed severely handicapped persons, ignoring other services in the noncompetitive labor force represented by workshop employees, would be approximately $1,130 per worker. The costs of placing those workers in the competitive labor market, assuming such a goal were feasible, would be $3,213 per worker. These figures should be increased to cover the additional cost of providing a minimum wage, volunteer time, additional supportive services, and unaccounted-for capital costs. In order to provide high quality work environments, the public might underwrite the costs of increasing the capitalization of workshops.

For purposes of comparison with the estimate of $1,130 subsidy per workshop worker, the cost of on-the-job training and institutional programs funded under the Manpower Training and Development Act was $1,000 and $900 respectively per client in 1971, showing that the differences in supporting severely disabled workers are excessively more expensive than programs for the nondisabled.

NEED FOR ADDITIONAL FACILITIES AND OPERATING SUPPORT

The Rehabilitation Act of 1973 authorizes several resources for rehabilitation facilities. Among these are provision of grants and contracts: to assist in the construction and initial staffing of rehabilitation facilities; to improve their professional services and business management practices; to provide training services to prepare clients for gainful employment; and for technical assistance and consultation. In addition, the Act provides for a mortgage insurance program. While most of the required authority exists in the Act to aid rehabilitation facilities in achieving their full potential in serving all the severely disabled people who need their services, the funds appropriated to implement these provisions of the Act are limited. For example, funds for construction over the past 10 years have averaged $2.5 million per year. The Rehabilitation Services Administration conducted a national survey as to the needs for new and improved rehabilitation facilities through June 30, 1975. Its findings were:

> 1,829 new rehabilitation facilities, including 584 sheltered workshops immediately needed nationally.
>
> $282,000,000 required for their construction and initial staffing.
>
> 1,130 existing facilities of the 2,656 studied with known improvement needs.
>
> $41,000,000 required for their improvement.

In the survey of providers of rehabilitation services conducted for this study, respondents were asked to identify impediments to the State VR agencies in serving the most severely handicapped people in their respective States. Seventy-seven percent identified insufficient funds for the purchase of rehabilitation services; 77 percent, insufficient funding of rehabilitation centers and workshops through the State-Federal Vocational Rehabilitation program; 68 percent, insufficient number of rehabilitation facilities and workshops; and 69 percent, insufficient number of rehabilitation units within general hospitals, chronic disease hospitals and centers, and long-term care facilities.

Many other individuals and organizations feel that increased numbers of rehabilitation facilities and added support to these facilities are essential to the provision of service to all of the severely handicapped people in the Nation who could be rehabilitated vocationally. Should there be a State-Federal program of rehabilitation for self-care, the rehabilitation facility need will become even more pressing and urgent than it is at present.

Specific recommendations have been made by various people and organizations with respect to added support to workshops to enable these facilities to fully serve the severely disabled people in our population. Secretary of Labor Wirtz in the 1967 Sheltered Workshop Report from the Department of Labor to the Congress recommended:

-- wage supplements for eligible clients

-- additional financial support for the workshop for training, including material, equipment, and supervision

-- opening of new markets for products of workshops

-- additional financial support to enable workshops to modernize facilities and methods consistent with the needs of the clients

-- a technical assistance program to the workshop, including management assistance, and

-- new out-placement services for workshop clients

Wirtz added:

> We must at the onset face up to the fact that the achievement of a full minimum wage for handicapped clients of sheltered workshops will require outside financial support. This will mean a basic shift away from basing wages on what the handicapped worker can 'produce.'
>
> A wage supplement granted to handicapped clients could be fashioned so as to insure that the incentive to work and produce is increased. The pattern of wage payments could be established in a manner best designed to enhance the work incentives and human dignity of the sheltered workshop system...

In addition, consideration should be given to legislation providing for unemployment compensation, Social Security, and health insurance coverage for all employees in all sheltered workshops, as well as inclusion of workshops within the National Labor Relations Act. Finally, there is need to consider amending the Social Security Act so that Disability Insurance and Supplemental Security Income payments are not affected by earnings in sheltered workshops or in competitive employment until earnings exceed a level that provides an incentive for rehabilitation. Of equal importance is continuation of health coverage under Medicare or Medicaid for the beneficiary who is rehabilitated until such time as adequate health coverage under another program is provided.

Chapter 23

TECHNOLOGY

The current state of knowledge about the rehabilitation of the severely handicapped is closely related to the status of the technological advances in service modalities and in methods of utilization. Major breakthroughs in medical and biomedical research can have widespread implications for the severely handicapped. For example, the discovery of the Salk vaccine has profoundly reduced the number of persons with disabilities resulting from polio. If a means for spinal cord regeneration or reduction of certain physiological causes of retardation were found, the nature of the severely handicapped population would drastically change.

Developments which would reduce the incidence of severe handicaps were, we felt, outside the areas of investigation in this study, although their contributions are obviously of major importance. In this study, we will restrict our discussion to the hard technology which directly affects rehabilitation. Breakthroughs in technology have major payoffs in changing the nature of who is disabled, how severely people are handicapped by their disability, and in major social problems.

The concept of "hard" technology relates to biomedical or rehabilitation engineering, which develops devices for use by the disabled that assist in some area of their functional limitations. These include prosthetics and orthotics, wheelchairs, traffic lights with buzzers, and the like.

The basic problem addressed by hard technology is the fact that the impaired organism has suffered loss of function. Nerves, muscles or bones do not work properly, and breakdown in one may cause problems in another. When the spinal cord is injured and legs do not function, the individual is limited to sitting or lying down, which may result in pressure sores. Because of injured nerves, however, the person cannot feel the pressure. How does one compensate for lack of sensation? How does one know when to shift position? The technological problem is how to bypass damaged nerves to create sensation that permits some semblance of the usual function. Other disabling conditions pose other technological problems. For example, what sort of joints and sockets are best for a shattered leg? How can a person with cerebral palsy communicate with those around him?

We are far from having such desirable developments as replacement nerves or spinal cords. A recent development, however, is a small, portable kidney dialysis machine that could be used more frequently and thus tire the patient less than going to the standard clinic installation. Improved wheelchairs and various types of canes are now in existence or well along in the development state.

In the pages to follow, we draw heavily on documents of the Rehabilitation Services Administration (RSA), the National Academy of Sciences (NAS), and related sources to try to give a flavor of the developments in the field of rehabilitation engineering.[1] We conclude with a critique of the field from the consumer and marketing perspectives.

REHABILITATION ENGINEERING

Rapid technological development in the United States during the past 30 years, coupled with rehabilitation research, evaluation, training, and service programs, has made technology available to assist the severely disabled in the rehabilitation process. Technological devices for physical restoration can be considered as a core area in the rehabilitation process because they give the patient the ability to perform specific tasks related to rehabilitation.

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[1] The RSA 1975 Research Development Plan has state-of-the-art reviews which should be source documents for many interested in rehabilitation, in addition to those specifically mentioned in the section on Rehabilitation Engineering.

The field of Rehabilitation Engineering coordinates various concepts, techniques, and developments in engineering technology, systems information, medical and rehabilitation practice, and information regarding disease or handicap to assist the severely disabled person in the rehabilitation process. It is designed to help the disabled individual to be as independent as possible and to utilize his physical and mental functional capacities in adjusting to environmental conditions and to work activities. It is also designed to encourage necessary alterations to the environment so that the goals of the individual may be accomplished. Certain engineering techniques have been used for a long time--artificial limbs, for example--but the concept of total patient care has only recently been directed to many groups of disabled persons, including the spinal cord disabled, amputees, the deaf, the blind, and the neurologically handicapped.

In fiscal year 1972, the Social and Rehabilitation Service undertook a major commitment to a new program designed to combine the efforts of medicine, engineering, and related sciences to improve the vocational and self-care goals of severely handicapped persons. The following specific areas of interest were designated for work by the Biomedical Engineering Program of the National Institutes of Health and by the Rehabilitation Engineering Program of the Rehabilitation Services Administration.

Rehabilitation Services Administration

1. Artificial limbs - both internal and external prosthetic replacements.
2. Orthopedic braces - both internal and external orthopedic assistive systems.
3. Amputation and reconstructive surgery.
4. Mobility aids for orthopedically disabled persons - wheelchairs, automotive systems, etc.

5. Mobility and communication aids for the blind and deaf.
6. Architectural barriers for the severely disabled.
7. Fundamental studies directly goal-oriented to rehabilitation in the above areas.

National Institutes of Health

1. Life-saving devices--artificial hearts, renal dialysis machines, heart lung machines, etc.
2. Facility engineering - automated hospitals and patient monitoring equipment.
3. Surgical and medical instrumentation.
4. Implantation materials for vessel and organ synthetic grafts, coverings for electrode implants.

In the past year, similar working arrangements have been set up with the National Science Foundation and its Research Applied to National Needs (RANN) program, as well as with the Department of Transportation and the Department of Housing and Urban Development.

National System of Rehabilitation Engineering Research Centers

In 1971, the Rehabilitation Services Administration, following the advice of the National Academy of Sciences,[2] began the expanded program of Rehabilitation Engineering. The plan developed by the NAS calls for continuation of the project research grant program. In addition, it recognizes that certain schools of medicine and engineering, through their active rehabilitation service, research, and training programs, have demonstrated their capability in the area of Rehabilitation Engineering over the years. NAS recommended that

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[2] In the publication entitled, "Rehabilitation Engineering - A Plan for Continued Progress," in Research and Demonstration Strategy, FY 1975, Office of the Secretary of Human Development, RSA. DHEW, pp. 37-137.

these institutions be utilized to form a National System of Rehabilitation Engineering Research Centers, which would receive programmatic funding as a means of accelerating research progress and reducing the time between conception and practical application. This recommendation was adopted, and the first Rehabilitation Engineering Centers were funded in fiscal year 1972.

The need for the application of sound engineering principles to solve the pressing demands of vocational rehabilitation has been stressed by many experts. Use of engineering techniques to help the severely handicapped emphasizes the need for an approach to rehabilitation that strives to match the job to the capabilities of the worker, rather than the more traditional practice of making the worker fit the job requirements.

Centre Industries in Sydney, Australia is showing what can be accomplished by using this approach to meet the employment needs of the cerebral palsied. Through rehabilitation engineering, Centre Industries has been successful in employing over 200 severely physically disabled cerebral palsied workers in jobs normally considered "unsuitable" for persons with this disorder. This has been accomplished in part by intensive job training, in part by application of time-motion study techniques, using the Modular Arrangements of Predetermined Time Standards system (MODAPTS), to evaluate the capacities of their cerebral palsied employees, and in part by modifying hardware and methods to accommodate the remaining capacities of these individuals.

This country, however, still relies primarily on the sheltered workshop and token jobs or custodial institutionalization for the severely physically handicapped. While the sheltered workshop and the institution have served and are serving a valuable purpose, we may be overlooking the potential of those they serve to perform meaningful jobs that are productive for society and for the workers themselves. The overriding goal is to increase personal and economic independence of the handicapped, while decreasing their reliance on support from society. The Australian experience proves that this can be done, and moral and humanitarian as well as economic considerations demand that it must, if possible, be done.

The major goal of a new American project is to develop comprehensive competitive employment rehabilitation services for the cerebral palsied through a systematic series of phases:

1. To instruct physically handicapped individuals of varying degrees of severity in all aspects of competitive work through both job training and acquisition of other skills necessary to sustain them within the community.
2. To implement modifications of job hardware and methods to alert the physically handicapped person about his remaining capacities to perform a job.
3. To develop a placement program whereby a handicapped worker can be effectively and suitably placed in a job appropriately modified for him.

The grantee, United Cerebral Palsy of Kansas, is presently engaged in the design phase, to establish the data base needed to develop methods, materials and hardware critical to the employment of the cerebral palsied. The resultant data base will include: a client classification system with respect to remaining capacities; a hardware data base including a critical review of client appliances and of industrial modifications; a selection of possible job targets; a determination of nonhardware methods related to these job targets; a job matching system; and benefit-cost decisions. These accomplishments will provide a data base for the second, or research and development phase.

The research and development phase will involve using the job matching system to develop hardware for clients, mechanical hardware, and method modifications. The procedures to be utilized deal primarily with the application of classical industrial engineering principles in conjunction with human factors precepts to provide employment opportunities for the cerebral palsied. Specifically, the manual skills necessary to perform a broad range of industrial jobs will be analyzed and classified. Included in the study will be an analysis of the forces and displacements of standard machine tools found throughout American industry. After collection of this data, methods engineering principles will be utilized to modify existing jobs so as to allow performance by the cerebral palsied.

Upon completion of the laboratory phase of the research, clients will be placed on the job in Wichita industry to validate the laboratory results. It is anticipated that this "real-life" exposure will indicate any errors in methods analysis and client training not determined by the experimental process.

Results of this study should have broader implications to the engineering methods and principles which might be applied toward the vocational rehabilitation of persons with many other severely handicapping conditions.

Technological Systems for Persons with High-Level Spinal Cord Injuries--An increasing number of high-level spinal cord patients desperately need assistive systems to make their lives a little less difficult. The Northwestern Rehabilitation Institute is tackling this problem.

The objective is to develop the assistive systems in three stages: (1) call systems or signal systems; (2) comfort systems; and (3) interactive systems. Since these assistive systems are to be used during several phases of care, and eventually taken home with the patient, they must be designed so that they are readily adaptible to different environments.

Call systems have been winnowed to the point where only two types are presently being used and improved. These are the "sip and blow" system for the patient having almost no motor ability, and the "touch" switch for patients having some residual control of arm movement.

A completely solid-state "comfort and communication" system, developed for the patient who needs control of the environment about him, has eight channels designed for call, television, telephone, radio, room lights, bed control, tape recorder, and page turning. By "puffing" the category is selected. "Sipping" activates the device.

Rather than piecemeal expansion of such a system to handle a few more functions, it seems appropriate to jump to a minicomputer system. In this way it seems conceivable to build an interactive device which would make possible many more activities, including employment.

PROSTHETICS AND ORTHOTICS

Prosthetics refers to replacement of body parts by artificial items--plastic legs, artificial hands and the like.

Orthotics corrects defects of the skeletal system through surgical correction or insertion--such as shin or skull plates or braces.

The most difficult problem has been the clinician's inability to know the magnitude of force safely tolerated in both hard (bone and cartilage), and soft (skin and muscle) tissue. External pressure alters the metabolic and enhances the catabolic process in soft tissue. Disruption results in blisters, reduction of blood flow, or bruises. Recent advances in measurement techniques with force and pressure transducers, coupled with very sophisticated computer technology, offer an approach to solving these problems. Force and pressure measurements will be used to redesign the devices, both internal and external, in order to provide more efficient and effective rehabilitation of orthopedically disabled patients.

Patients with peripheral neuropathy, burns, paraplegia, and other conditions share the problem of tissue breakdown due to excessive pressure. By measuring tissue impedance it may be possible to predict potential breakdown. Devices now available to measure differential temperatures lack sensitivity and are difficult to interpret, expensive, and require excessive maintenance. Persons in the field hope to develop a device which will enable a clinician or patient to readily determine tissue changes with minimal equipment, thereby allowing prompt remedial action to the area immediately surrounding the affected spots.

Lower-Limb Prosthetics--Of all the areas covered by rehabilitation engineering, lower-limb prosthetics is probably the most advanced. Great progress has been made, especially in design and fitting of sockets and alignment of prostheses for all levels of lower-limb amputation; the design and development of more functional components such as hydraulic knee units; in emphasis on better surgery; and in perfection of immediate postsurgical and early-fitting techniques.

Lower-Limb Orthotics--Emphasis has been given to the development of devices and techniques that provide substitutes for lost functions but do not restrict residual functions.

Upper-Extremity Prosthetics and Orthotics--During the early days of the prosthetics program, a good deal of emphasis was placed on problems of the upper-limb amputee, and after significant improvements during the first 8 to 10 years, a plateau was reached. Since then, the major effort has been devoted to the application of external power. A review of clinical practice today indicates that: (1) a preponderant majority of upper-extremity amputees are being fitted much as they have been for the last 15 to 18 years; (2) innovation has been noted in the small but continually increasing applications of immediate postsurgical fitting techniques and in the use of direct-forming techniques in socket fabrication; (3) small quantities of externally powered components have been introduced randomly into clinic practice, mainly through the efforts of the VA; and (4) the potential value of recent developments in external power has heightened the interest of clinicians and patients in upper-extremity fitting. Control for Externally Powered Systems--There are now enough hardware designs available for fitting various types of upper-limb amputees. It is generally conceded that the advantages of external power, such as lower energy requirements, are mostly outweighed by its disadvantages--lack of feedback signals for control, high maintenance requirements, and high initial costs. Nevertheless, there are a number of devices and systems that should be evaluated clinically.

The development of devices and techniques to provide function to paralyzed upper limbs is a formidable problem because the human hand and arm together form a most complex system. During the past 15 years considerable effort has been devoted to the development of orthoses for the frail arm, but no one, including the developers, is satisfied with the progress made. Some highly motivated patients have benefitted from this work, but overall results have been discouraging. A number of patients seem to benefit from the devices but fail to use them soon after they leave the hospital. Yet, with the advances in acute medical care, the incidence of persons with frail upper extremities, especially quadriplegics, is increasing.

Needs for Prosthetics and Orthotics

RSA estimates that of the 3,681,000 persons who require orthotic and/or prosthetic devices, 92 percent require orthotic management. Moreover, 47 percent of the total need orthotic devices of the lower limbs. In spite of the fact that the number of persons who require orthotics is ten times greater than the number who require prosthetics, the state-of-the-art in orthotics is relatively poor.

Need for Practitioners

At present, anyone who needs prosthetic service can be provided with it. This statement sounds encouraging but is misleading. Most patients must wait from 6 weeks to 3 months for a prosthesis, and then travel over 100 miles for adjustments, repairs, or other service. Service is available, but, except for a few large metropolitan areas, it is marginal. RSA estimates that there are about 300,000 amputated patients, compared to 630 certified prosthetists, or a ration of about 500 to 1. The number having artificial limbs is estimated to be 203,000, or a ratio of about 300 to 1.

As noted above, many more patients require orthotic aids than prosthetic services. The rule-of-thumb ratio of 10 orthotic patients to each prosthetic patient appears to be a valid figure for this country and correlates with the figures from Great Britain. This ratio yields about 3 million orthotics patients in the United States, or about 15 patients per 1,000 population. However, the majority of orthotics patients have a temporary disability, whereas prosthetic patients have a permanent disability.

Services in orthotics are obviously and seriously lacking. Physicians often lack available services and must use a less preferable treatment. Patients are often in hospitals for unnecessary days or weeks because they cannot be discharged safely without an orthosis. The American Board for Certification reports that in 1973 there were 515 certified orthotists and 235 certified prosthetists/orthotists in good standing, giving a total of 750 orthotists. The ratio of potential orthotics patients to certified orthotists is 4,000 to 1, but the ratio of the number of orthoses actually provided to the number of certified orthotists is about 1,500 to 1.

Obviously the manpower shortage in both prosthetics and orthotics must be remedied if we are to come anywhere near meeting estimated needs.

Neuromuscular Control, Functional Electrical Stimulation

Functional Neuromuscular Stimulation--Electrical stimulation to modify functional behavior has recently received considerable attention by teams of engineers, biologists, and clinicians. Recent investigations indicate the potential use for the amelioration of pain, control of upper extremity movement, reduction of spasticity, etc. Development of new theory in the construction of mechanisms of pain has led to the development of implantable stimulators which ameliorate chronic incapacitating pain. If these reports are substantiated, a useful alternative to established surgical procedures would be available.

Various stimulating systems (e.g., the functional electrical peroneal brace) to control the foot of a semi-paralyzed patient are undergoing evaluation at a number of rehabilitation settings. Functional electrical stimulation of appropriate nerves to regulate posture and movement also appears to be an acceptable form of therapy for certain categories of patients with damage to the nerves which control walking.

The ultimate goal seen for functional electrical stimulation is functional bypass of damaged nerves with electrical devices which produce motor and sensory activities which approximate near normal function. Although considerable work is being directed toward application of electrical stimulation of paralyzed muscle, basic knowledge is still lacking on the reactions of tissue and materials to stimulation over a long period of time.

Electrical Block--Spasticity, one of the most debilitating features of spinal cord injury, places severe limitation on the functional use of the limb and contributes to frozen and painful joints. Surgical procedures to correct this problem have destructive and irreversible effects. The possibility exists for blocking a nerve with electrical current which can be maintained for an extended period followed by immediate recovery upon cessation of the blocking signal.

Electrical Stimulation--When the phrenic nerve is inoperative above the third cervical vertibrae because of spinal cord injury, breathing has to be supported by respirator. An implant for electrostimulation of the phrenic nerve is being tested by Yale University.

In spite of the long and complex history of the use of electrical stimulation, until recently there has been little well-documented research and knowledge available. In addition, the publications which have discussed the subject suggest that there is little evidence that the technique has been widely accepted in daily clinical work, although it is used in some rehabilitation centers. Its use has been particularly limited in the cases of upper-motor neuron disease. It is not known whether the low utilization of this method is due to imperfect technology, inadequate methods of application, or poor understanding of underlying mechanisms. All reports support the further investigation of electrical stimulation.

Electrical stimulation can be used by a significant proportion of the stroke population and those with spinal and brain injury. It is also useful in multichannel stimulation for gait control and knee joint activity, feedback control systems and spasticity control. It is less cumbersome than other devices, such as the foot-ankle brace, and provides therapeutic benefits by its ability to substitute an electrical signal for one previously sent by the brain. Actual muscle response is thus more comparable to normal physiological response. Moreover, it presents new possibilities for rehabilitation. This method could improve the chances of walking for those individuals who would normally be considered wheelchair candidates.

Mechanical Devices for Mobility

The manually operated wheelchair has been of great help to many handicapped persons, but there are many limitations to its use. Design changes could make the wheelchair useful to a wider range of disability groups. In this direction, the development of electric wheelchairs and other automotive devices as mobility aids have been significant breakthroughs.

Disabled individuals, especially quadriplegics, often need the help of an attendant to perform many activities. The manual wheelchair relieves the attendant of part of the physical burden required for moving an individual. But a true mobility aid for the quadriplegic, such as an electric wheelchair, permits substantial mobility, independent of an attendant, as long as some capacity for movement remains. One of the aids which does not require limb movement consists of a "transponder system which telemeters relative changes in the position of the jaws and uses these to derive control variables for the operation of a motorized wheelchair." The switches are housed in the mouth and the processing circuit may be worn on the person or installed in the wheelchair. The device conserves the user's energy and is nearly invisible.

Due to the physical strength and stamina requirements on the user, manual wheelchairs are commonly used for travelling only very short distances unless pushed by an attendant. Power wheelchairs, on the other hand, are often used for travel of up to several miles (a battery charge will last four to five miles). Only 8.3 percent of the wheelchair population now use power wheelchairs, but the proportion has been increasing as individuals in manual wheelchairs and other disabled persons discovered the convenience of power chairs and as the environment becomes more accessible (the need for ramps and curb cuts is more acute for those with power wheelchairs, since they require greater strength to lift).

Many individuals who previously used walkers, leg braces, etc., have switched to wheelchairs because they are less physically demanding. In general, however, the wheelchair has not made a totally successful transition from an indoor to an outdoor vehicle. Environmental barriers to wheelchair use which impede mobility abound. With the power chair, mechanical failures and the resultant immobility while waiting for repairs are commonplace. Exposure to the weather is also a continual problem for the user of any chair.

Recent research efforts have included attempts to develop a curb-climbing wheelchair and one that can be lifted into the driving position in an automobile. A wheelchair with curb-climbing capability would reduce the barrier posed by curbs and would improve accessibility to many unramped buildings, particularly if it had stair-climbing ability. However, the research results to date have not been promising. The results on wheelchair-automobile compatibility have been more promising, but prototype cost has been quite high.

Wheelchair Modifications--Because development of advanced wheelchair designs is in an early stage, reliable cost data do not exist. However, the development of one prototype in California indicates that curb-climbing capability would add about $2,000 to the typical $500 cost of a manual wheelchair. With the limited data available, it is impossible to determine how many individuals would benefit from such a wheelchair.

Automobile Modifications--As technology improves, modified automobiles and vans are becoming more common means of intermediate and long-distance travel for the handicapped. In areas where public transportation is inaccessible or non-existent, a personal vehicle is often the only means of transportation for those who have some upper body control and can transfer from a wheelchair. The usual modification is the installation of hand controls.

Those persons confined to wheelchairs are now limited to modified vans since, as noted, an automobile cannot be driven from a wheelchair. However, wheelchair technology is progressing to the point where this may soon be possible. The usual modifications to a van include a power lift, automatic door opener, hand controls, electric wheelchair tiedowns, floor and roof modifications, and a dual battery system.

For the handicapped who are confined to wheelchairs and unable to drive, an attendant operated van can be modified for wheelchair use by installing a power lift and mechanical wheelchair tie-downs, and making minor floor and roof modifications.

Due to the high cost of automobiles and vans, attempts have been made to develop smaller vehicles which retain the advantages of the larger vehicles. Thus far, these attempts have not been very successful. An automobile can be modified by installing hand controls at a cost of between $190 and $275. Installing a power door, a power lift and hand controls in a van costs approximately $2,800. For those individuals confined to a wheelchair who have limited upper body control, a van can be modified for $4,300 to $6,300, depending on the extent of upper body control.

For those unable to drive at all, and who have non-collapsible wheelchairs which are not easily lifted, such as power wheelchairs, or who are unable to leave their manual wheelchairs, an attendant-operated van can be modified to handle persons in wheelchairs for approximately $900.

SENSORY AIDS FOR THE BLIND, DEAF, AND HARD OF HEARING

The Rehabilitation Services Administration Research and Demonstration Strategy for 1975 noted that much of the literature on sensory aids shows that technology input to this area will be mostly "in improvements of environment sensing systems using ambient or emitted sonic or electromagnetic energy as the carriers of information about the surroundings" and to some degree in advances in long-cane design and practice.[3] In the case of the deaf, aids for speech training appear to be the most promising for the immediate future. The study of the Subcommittee on Sensory Aids concluded that because few demographic studies exist "to define and categorize sensory aid needs and to establish priorities for research on devices and systems to meet these needs, greater effort should be placed in assembling this kind of information".[4] Moreover, the report offered the following assessment of the field:

> Many sensory aids are ingeniously designed and earnestly applied but practical long-term utility is extremely limited. The primary reasons are that most designs are <u>ad hoc</u>, many perceptual requirements unknown and effective training and evaluation techniques are embryonic. Teachers and therapists working with the deaf frequently are not convinced of the value of devices, even when available and thus have not supported their use. Furthermore, we have only a rudimentary knowledge of the basic process of speech and language, and understanding of what is truly essential for effective communication is still lacking. 5/

This area of rehabilitation engineering will for purposes of presentation be subdivided into (1) sensory aids and (2) biofeedback. There will first be an overview of the rehabilitation engineering research centers dichotomized in the same way.

Overview of Sensory Aids

Sensory aids comprise devices aimed at helping people with sensory dysfunction(s) overcome the disabilities which usually ensue. Important also are practices, not always involving devices, which have the same aim. Aids for any of man's senses properly could be treated in an analysis of sensory aids. The areas of concern here are principally with aids for the blind (including the totally blind and the larger population having some vision) the deaf and hard-of-hearing, and the deaf-blind.

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3. <u>R & D Strategy</u>, p. 383.
4. <u>Ibid</u>., p. 7.
5. <u>Ibid</u>., p. 7.

The Federal Government has been supporting research on aids for the blind at least since 1944, when the Office of Scientific Research and Development and later the Veterans Administration gave support to the Committee on Sensory Devices of the National Research Council. A convenient guide to this early work, including citations to published results, can be found on pages 49-58 of the 1964 American Association of Workers for the Blind Annual, "Blindness."

The following are areas of sensory aid research:

1. Mobility Aids.

Technology probably will contribute relatively little in further developments of sighted guide techniques and dog guide methods, somewhat more in advances in long-cane design and practice, and most in improvements of environment sensing systems using ambient or emitted sonic or electromagnetic energy, as the carriers of information about the surroundings. Quite creditable attempts have been made to assess needs in this field and to recommend what should be done. Some current electronic mobility aids include:

Binaural Sensory Aid--This device, known also as the Kay Spectacles or Ultrasonic Glasses, has been produced in a pilot run in New Zealand. This device emits a sonar-like sound when objects are in the range of impulse. The sound warns the user. The first device proved sufficiently promising to lead to a production run of an improved version is the Mark II Binaural Sensory Aid.

Laser Typhlocane--Models of this device have been subjected to evaluation coordinated by an Advisory Panel to the Subcommittee on Sensory Aids, Committe on Prosthetics R&D. Production for general distribution began in 1974. The price is $1,500-$2,000, which is roughly half the cost for a guide dog.

Night Viewing Goggles--Preliminary work has indicated that small, handheld light-amplification viewers, developed to aid military men in low-light-level environments, might be useful to some persons restricted in mobility by "night blindness."

2. Devices for Independent Reading of Inkprint. For those with some useful vision, optical aids and closed circuit television (CCTV) magnification systems are currently being used with considerable success. A common body of knowledge in the CCTV magnification field is not now widely available. Information on specifications for such devices, selection criteria for clients, etiologies of visually impaired persons helped by the CCTV, training requirements and methods, gains achievable, and problems of production, distribution, maintenance, and deterioration (both of the devices and clients' vision), all need documentation.

For those without sufficient useful vision to permit using the eyes for reading inkprint there are a number of other possibilities. The Optacon, a tactile-output device and the Stereotoner, an audible-output unit, are now available. Continued deployment of these devices to appropriate members of the blind community, compilation of the experience resulting from the trials and evaluations, production of improved versions and follow-on later-generation devices are encouraged. It is expected that several reading machines will be required to satisfy the varied needs of different blind individuals.

3. Vision Prostheses. Two classes of devices are evident here: direct electrical stimulation of the visual cortex which produces image patterns and external skin stimulation in which stimuli suggest visual phenomena from a tactile input. Work has been in progress for several years in both areas with slow but steady acquisition of information, refinement of objectives, and increases in appreciation of the considerable difficulties with both methods. It appears likely that some form of visual prosthesis will be achieved eventually by these or similar methods.

A much more complex report on state of the art in sensory aids is the Report of the Sixth Meeting of the Subcommittee on Sensory Aids, available from the Committee on Prosthetics Research and Development of the National Academy of Sciences.

BIOFEEDBACK

Research attention in this area is on the human central and peripheral nervous system as the innate source of control, and on information feedback to and from the extremities and/or the sensory systems. The goal is to define and realize control concepts and feedback systems which will permit future hardware to function as augmentations of the human system. This approach is also directed toward gaining information from the parts of the body which still have some functional capacity in order to improve body diagnostic capability and therapy.

Biofeedback will provide to the human being information on the interaction between the prosthesis and the environment--essential to the operation of extremity prostheses and orthoses and to the interpretation of input for devices which substitute for sight and hearing.

Sensory feedback is also mandatory to the safety and long-term well-being of patients, particularly paralyzed persons with either natural or machine-supplemented motor control, who suffer the loss of sensory feedback as a result of spinal cord injury, hemiplegia, or other causes. Such patients can inadvertently overload their skin, muscles, tendons, and/or skeleton. Furthermore, they cannot detect the presence of hazardous heat, cold, or other potentially injurious environments such as sharp edges. Even the frames of an orthosis can abrade their skin and lead to ulcers in the absence of any sensory awareness on the part of the patient.

The effectiveness of any man-machine system depends upon sensory feedback to the person. In addition to the feedback provided by normal vision and hearing, biofeedback systems can augment the sensations from muscles, ligaments, and joints near the amputation or paralysis site. In a limb prosthesis, for example, related muscles can provide feedback from the prosthesis.

For the deaf infant, electrical or mechanical stimulation can direct attention to otherwise unsensed sounds, and provide cues to speech. In all cases, the usefulness of a biofeedback system and its acceptance by the disabled depends upon the speed and accuracy with which information can be perceived, the relevance of the mode of presentation to the individual, his ability to acquire or learn the use of the system, and the effects of stress or distraction,

Research Projects: Biofeedback

Limb Load Monitor (LLM)--The rehabilitation process for persons with neurosensory disorders (amputations, orthopedic problems such as fractures and total hip joint replacements, and hemiplegia or spinal cord injuries), often includes retraining in ambulation and sometimes in the proper weight loading of the affected limb(s). Weight bearing may be prohibited to avoid damaging sensitive tissue. The limb load monitor (LLM) consists of a force sensor (transducer) fabricated as an insert to a shoe, and an auditory unit worn on a belt, connected to each other by a coaxial cable. When the proper amount of weight is borne on the extremity a tone occurs with desired pressure preset by the physician.

Step Control Monitor--Problems of ambulation are manifested in such abnormalities as uneven step length and uneven timing, resulting in an asymmetrical gait pattern. A step length monitoring device, designed to measure and display to the patient information regarding the symmetry of gait while walking, consists of two sensor elements strapped just above each ankle. The distance between the sensors is measured by transmitting a short burst of ultrasonic energy from one sensor to another and measuring the elapsed time. The time element controls the pitch of an audible signal emitted from a loud speaker in a control box worn by the patient and powered by batteries. The audible tone increases from low pitch, at the point of smallest ankle separation, to a high pitch at maximum separation. The distance range is 2 to 24 inches. The effect of both asymmetrical step length and cadence obviously gives patient and therapist a constant immediate feedback of gait performance and allows the patient to practice improvement of his gait independently. Constant correct performance should reinforce the patient's learning and thus shorten time of rehabilitation.

<u>Knee Position Monitor</u>--Patients with neurosensory disorders as well as those with arthritis often experience difficulty in controlling the knee both during the swing and stance patterns of ambulation. The knee position monitor, under development, is to measure and display to the patient information regarding the position of his knee during ambulation.

<u>Treatment of Language Disorders of Central Nervous System Origin</u>--Patients who have sustained brain damage often present problems of language dysfunction. Between one and two million adults show some language disorders following damage from strokes, head injuries, and damage resulting from neurological disease and neurosurgical intervention.

Palate-like prosthesis evaluate lingual pressures during speech. Development has focused on pressure gauges, transducers in the palate prosthesis, intra-oral wiring and connections, coating of the prosthesis to be resistant to tongue abrasion and climate of the mouth, adhesion to the patient's palate, and backup testing and amplification systems. In another phase of the project satisfactory recording of mandibular motion has been achieved. Still to be ascertained are correlations between lingual function and jaw motion in sound production.

Sensory Feedback for Control of Powered Braces by Persons With Spinal Cord Injuries--Lack of sensory feedback is one of the major drawbacks to the wider utilization of externally powered orthotic devices by high-level quadriplegics. The usefulness of various sensory feedback systems has been amply demonstrated. These include "stereo" perception of a prosthesis between two vibratory stimuli applied to a stump, a matrix of vibrators by which a blind person can read ordinary type, vibrators on the back of a blind person presenting a "picture" of objects seen by a TV camera, low-frequency electrical stimulation as feedback to represent pressure in the Waseda-4 hand, and an implanted stimulator for the radial nerve of an amputee. A comprehensive study of electrocutaneous stimulation as a way of obtaining feedback information has led to the conclusion that it represents a feasible communication channel.

Detection and Prediction of Epileptic Seizures: Ambulatory epileptics able to work but still vulnerable to seizures have been subjects of a research program conducted by McDonnell Douglas Astronautics Company (MDAC), over the past five years under contract to the Social and Rehabilitation Service. The goal of this program was to develop an automatic system capable of alerting a subject to a pending seizure.

Advantages of such a warning system are:

A. The patient could lie down to protect himself against the forthcoming seizure.

B. There would be a psychological benefit in that the patient would know that he would have time to adjust to protect himself.

C. Opportunities for employment would increase. The patient would be less afraid to undertake employment, and prospective employers would be less reluctant to hire such persons.

D. Better understanding of preseizure and postseizure phenomena and of the effect of medication might be achieved.

Other Gadgets

A new prosthetic hand is now sold, which can approximate normal function, look normal, and be powered by the tiny amount of electricity generated during muscle contraction. The Bell System has developed and marketed a telephone communicating device for deaf persons which operates by using light signals and a predetermined code.

The Veteran's Administration Prosthetic and Sensory Aids Service is working with health facilities and private manufacturers on devices and systems, including:

-- A voice command system to operate environmental controls.

-- Hydraulic and electric window and door openers controlled by sound or radio signals transmitted from a wheelchair or bedside.

-- Miniature hydraulic piston cylinders to provide adjustable and variable resistance to pressure on knee and ankle mechanisms.

-- An electromechanical dialing device operated by pneumatic or chin controls, and connected with a conventional dial telephone unit.

-- A wheelchair-mounted radio for communication between patient and staff members at a nursing station.

-- A mechanical feeding device that would enable a quadriplegic patient to eat and drink certain foods without assistance from staff members.

-- External power units to permit paralyzed patients to move their braces.

-- Sensory feedback systems that will give an amputee a physical sensation of where his artificial limb is, what it is doing, and how much "fine" control is required.

A sound perception device for the deaf is now being developed. Also, a bionic ear has been developed which uses implanted electronic stimulators. Robert M. McLauchlin of the American Speech and Hearing Association suggests that bionic devices can give sight and hearing to those who have never seen or heard before.

Surgery

Amputation surgery in the United States is still being carried out predominantly by general and vascular surgeons who have varying levels of sophistication in this field. The general surgeon has not involved himself in prosthetic rehabilitation of the patient or, as a rule, in development of improved amputation techniques. Orthopedic surgeons are becoming increasingly interested in rehabilitation in general and in prosthetics and orthotics, both external and implanted.

MARKETING AND DIFFUSION

The prime objective of a Rehabilitation Engineering Program implies not only the advanced research and development which demonstrates the feasibility of a new concept in the clinical laboratory, but also making the devices available throughout the Nation, wherever the need may exist. The potential of such medical devices has not only promoted the growth of new industry but also deep concern of the Federal Government in the form of pending medical device legislation.

Such equipment is usually manufactured and distributed by private corporations, which must in the end recover their costs and profit through commercial sales. In the case of medical devices, which must be prescribed by the patient's physician and paid for by the patient or by a third party, the process leading to effective, safe, and commercially feasible distribution is long and costly. The problem is made especially difficult because emerging federal controls require demonstrated effectiveness and safety of any device which is to be cleared for general use.

Although devices may appear promising in a laboratory, many factors contribute to making them great commercial risks when considered as new products for industry. This dilemma is compounded by the fact that the market for many of these devices is relatively small. Since the potential manufacturer is unable to identify and quantify his market, he is discouraged by the (a) cost of design and production, (b) cost of special modification for each patient, (c) cost of adequate training and education of physicians and allied health personnel in their application, and (d) cost of marketing and subsequent maintenance. Consequently, there is a need for multidisciplinary interaction to overcome lack of communication among researchers, educators, social workers and to enhance mutual exposure and interaction among workers in different specialties; development of evaluation procedures to determine the total impact of a device or technique on the functioning of the user; the evaluation of existing aids to determine which devices and techniques improve various skills and to identify the strengths and weaknesses of these aids so that improvements can be made; and a comprehensive analysis of the potential consumption market.

In P.L. 93-112, provision is made for funding the industrial development of devices which are not commercially feasible for manufacture and/or modification to meet the needs of various disability groups. However, money for this purpose has not been appropriated. Funds are needed to underwrite the costs of the field testing and distribution of instruments and devices where the unit cost is so high as to be beyond the fiscal capacity of the researcher, the ultimate user, or his sponsoring agency to assume. For example, each instrument that would enable the blind to read printed words by converting the printed word into sound or tactile stimuli will cost $5,000 or more. Subsidies are needed to field test such instruments and to make them available for use by the blind. The market for such instruments would be confined to the relatively small percentage of the population that is blind or severely limited in vision. Without mass demand and mass use, the cost of the individual unit will remain high and beyond the financial means of the people who could benefit from its use. The underwriting of renal dialysis costs through the Social Security Act for individuals covered under the program is an example of a subsidized service for a relatively small number of people who otherwise could not benefit from the service because of its high cost.

Many devices, some of great significance, are either in readiness for manufacture or soon will be. A serious concern must be raised to both extend the areas in which rehabilitation research is now being conducted and to manufacture and disseminate devices to the disabled. It is also important to consider the training requirements inherent in dissemination, both for professionals such as surgeons, prosthetists, orthotists and counselors, and for the disabled user.

CONSUMER INVOLVEMENT

Consumer involvement is a highly controversial issue. For some it is the key to quality rehabilitation services, whereas others see it as an unwanted obstruction. Some of the possible roles which consumers might play in furthering the rehabilitation process are presented, together with the advantages and drawbacks of consumer involvement.

Many definitions of "consumer" abound in the literature. Consumer involvement at the client-counselor level is already mandated in the Rehabilitation Act of 1973 through the individualized written rehabilitation plan. For our purposes, "consumers" are handicapped individuals and elected representatives of organizations of the handicapped. While this begs the question of the validity with which such representatives represent their constituency, they nevertheless represent an important point of view on the service needs for the severely handicapped.

Consumer Role in Rehabilitation

Two alternative roles for consumers can be suggested. The first is direct involvement with the VR agency in the vocational rehabilitation process. The second is consumer-run programs of community-based service delivery, which are described under programmatic options. Both approaches have their supporters and critics. For example, consumer involvement may be seen by agency staff as one more burden in an already crowded schedule. Consumer-run programs may be seen as unprofessional or threatening. Whatever the approach, the final criterion should be whether the severely handicapped are better served.

Interest in increased consumer involvement in the rehabilitation system surfaced in several different parts of the Comprehensive Needs Study, including the Center for Independent Living literature review, the National Rehabilitation Association Workshop, and the responses on the provider survey.

CIL Literature Review

In reviewing the literature, the research staff of severely handicapped persons of the Center for Independent Living in Berkeley, California, found a lack of understanding of the experiential realities of the lives of disabled persons. The single most important reason for consumer input into the planning and implementation of rehabilitation programs is to insure that the programs are authentically related to these realities. If rehabilitation researchers, administrators, educators, practitioners, planners, program evaluators, and counselors are not cognizant of how severely disabled persons experience basic life situations, the endeavors of these professionals will be ineffective.

In the same CIL report, it was suggested that workshops be conducted by articulate disabled persons with counselors and other professionals to reduce attitudinal barriers between the professional and the person with a severe handicap. Rehabilitation specialists could benefit considerably from client feedback about the way they relate to and work with clients. Some may consciously or unconsciously avoid the more severely handicapped persons, or they may be very uncomfortable in working with such persons, especially when they do not understand how severely disabled people experience life situations. There may also be more hard work involved which may require skills not learned in professional training programs. Some workers try to handle these situations by imposing a social distance which prevents them from every really understanding the human being who sits on the other side of the desk. Professional training in theories, knowledge, and techniques may not help to develop the kind of sensitivity to client experience that is required. Workshops conducted by articulate disabled persons can be an interesting and relatively painless way for rehabilitation specialists to develop a deeper understanding of their severely disabled clients. Since they are supposed to be the "experts," the realization that they do not fully understand their clients is the most difficult first step.

Training workshops are but one of many examples of how consumers may be involved in rehabilitation. Other roles include involvement in planning, delivery, and evaluation of rehabilitation services, from reviewing research proposals to peer counseling. Certainly one relatively untapped resource for rehabilitation agencies that are interested in implementing meaningful consumer involvement is the large number of organizations of, by, and for the severely handicapped. Advocacy and political activity, both within and outside of the formal rehabilitation system, are other examples of possible consumer involvement.

Provider Survey Results: Consumer Roles

In our survey of rehabilitation service providers, less than 2 percent of the rehabilitation providers checked "advocacy" as the main emphasis of their work. Less than 2 percent described their organization as a consumer organization representing the handicapped. Yet 85 percent agreed with the option of "greater involvement of the severely disabled consumer in planning, delivery, and evaluation of rehabilitation services." Eighty-seven percent agreed with the policy option of "greater utilization of employed handicapped to extend employment opportunities to other handicapped in the same work setting, industry, or service." As a means for delivering comprehensive rehabilitation services for independent living, 90 percent of the respondents rated self-help consumer organizations as either "helpful" or "most helpful."

Respondents were asked what role qualified consumers or representatives of consumer organizations can play in improving the delivery of rehabilitation services and/or in preparing the severely handicapped to qualify for vocational rehabilitation or independent living. Four out of five respondents checked "information resource," and "referral source." Peer counseling was checked by 65 percent. "Consumer advisory boards" were also highly indicated both for "the State VR agency" and for "other rehabilitation service providers." The most frequent write-in comment was "use of paraprofessionals, especially handicapped paraprofessionals."

Consumers and VR

The State VR program may benefit from increased consumer involvement by (a) better working relationship between counselor and client, (b) greater awareness of the needs of the handicapped, (c) feedback from those being served as to program strengths and weaknesses, (d) clearer understanding of the mission of VR, and (e) increased advocacy for VR programs and needs.

The Rehabilitation Act of 1973 provides for the involvement of consumers in the State VR program in a number of ways. The major ones are serving in the development of their individualized written rehabilitation programs and in the development and implementation of the State agency policies. In response to the latter, the Act specifies that the State Vocational

Rehabilitation plan shall provide that the State agency will take into account, in connection with matters of general policy arising in the administration of the plan, the view of individuals and groups thereof who are recipients of vocational rehabilitation services (or in appropriate cases, their parents or guardians).

Active consumer participation keeps public service programs responsive to the needs and priorities of the constituency for agency services. State VR agencies have been slow to implement this section of the Act. One reason for this may be the lack of specificity as to the role of consumers. Such roles could include comments on proposed research, the establishment of new rehabilitation facilities, the development of program priorities, and the annual evaluation of the effectiveness of the program required by the Act.

Consideration should also be given to establishing a committee to advise the Commissioner of the Rehabilitation Services Administration on matters affecting the Vocational Rehabilitation program.

Other roles for consumers include client assistance and advocacy with the agencies responsible for services like attendant care, transportation, housing, and recreation. Consumer organizations have already taken a lead role in the elimination of architectural barriers and in organizing other self-help activites. Consumer self-help groups can play a major role, both in assisting persons with severe handicaps in independent living rehabilitation and in preparing them for vocational rehabilitation.

A Consumer Perspective in Technology Development

Technological advancements in rehabilitation are an important need for the severely handicapped, both for those with vocational potential and for those with independent living as the goal. Much of what has been accomplished to date, although helpful to some severely handicapped individuals, has little widespread utility among consumers. Many of the assistive devices which have been developed are the product of biomedical engineers in clinical settings, who have not had the consumer input to fully consider the total needs and real constraints of the user. Many times the cost of such devices is prohibitive, usage may require trained attendant care, or environmental constraints may prohibit widespread useage.

Examples are readily available. We shall mention only a few.

The Optacon, developed for the blind, is a machine designed to change written materials into tactile material. Such an innovation clearly would be of great assistance to most blind individuals. Howeer, the price of $3,450 per unit is prohibitive for the private consumer and poses a high fiscal burden on the budgets of service delivery agencies for the blind. Thus, the primary use has not been consumer oriented but has been adapted to computer programming for activities totally unrelated to services for the handicapped.

Biomedical engineers, through the application of advanced neuromuscular and mechanical technology, have been able to develop mechanical limbs. Again, such unique aids for the amputee would offer great opportunity for overcoming handicaps resulting from impairment. Although the engineering accomplishment must be a delight to the technologists involved, the prohibitive costs of development, estimated to be millions of dollars, the unit cost of thousands of dollars, and the maintenance problems and costs render this innovation of little practical utility to most handicapped individuals.

Again, consider some of the devices developed for children and adults afflicted with cerebral palsy, including items ranging from button hooks to long braces, special wheelchairs, and elaborate voice control apparatus.

There is no question that these assistive devices are important to and needed by those with cerebral palsy. In many cases, however, the real needs, perceptions and realities of the afflicted persons are not taken into account in the development of these items.

For example, Harris describes a device that helps the cerebral palsied child to learn to sit straight.[6] It was hypothesized that the reason the children do not sit straight is that improper sensory messages are issued from the head or limbs. Thus the child really does not always know where his head or limbs are. The device issues an "unpleasant" sound whenever the head or limb goes beyond a certain range, using a behavior modification approach towards changing the child's behavior. The authors state that some children may only use this device for a short period, but that some cerebral palsied children may have to wear it almost permanently. The device was tested on a total of seven children.

Obviously, a population of seven is not sufficient to test the reliability or usefulness of a product. A serious flaw in such a method is the questionable assumption that the reason the child could not hold his head up was improper sensory communition. The report indicated no consideration that poor muscle coordination, poor muscle strength, or any of a wide variety of other possibilities was considered. Furthermore, the device is rather strange in appearance, which might well be a drawback for the wearer. No discussion of the value of sitting up, compared to the psychological effect on the child of having to wear this strange-looking device was offered, nor was there any discussion of parental reaction to such a device.

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[6] Harris, Spelmin, and Agner, Therapy for Cerebral Palsy Employing Artification Sensory Organs (Carnahan Conference on Prosthetic Devices, 1972).

One could cite many more such examples, in wheelchair and power wheelchair design, in experimental work related to videoelectronic apparatus implantations for the blind, in telecommunication technology for the neuromuscular impaired, and many more. The fact still remains that although much is being done with all good intent by those involved, little consideration and input from the consumer is sought or included in the planning and developmental phases of the effort.

There is probably some wisdom in establishing a workable means whereby the eventual consumer can participate in the policy planning and priority setting activities which determine the course of activities pursued throughout the rehabilitation and biomedical engineering field. Until the felt needs of the handicapped are considered, rather than simply the basic interests and concerns of the researcher, until research in rehabilitation engineering is infused with some practical concern for the utilization of the device and the cost to the consumer, one can be certain that some portion of the effort may have poor payoff. It is not realistic to expect that persons involved in basic research will always be aware of the factors affecting consumers. Rehabilitation technology requires the coordination of rehabilitation engineering and consumer involvement, a matter of practical benefit to both.

Problem Areas in Consumer Involvement

It is important to note one of the problems of consumer groups--competition among the groups. As ability to influence programs increases, differences within groups may take on the character of major power struggles. When resources are limited, competing organizations may develop, each claiming to speak for the whole. Administrators and sometimes legislators are in the middle when the groups seek resources for themselves or have vastly differing priorities.

A related problem of consumer involvement is that consumer groups tend to be advocates by nature and help little in assessing priorities under strict constraints. Their primary advantage is in making the case and gathering support for additional resources, not in assessing the relative seriousness and urgency of the various needs of the handicapped as a whole. It is not always clear, moreover, whether the representatives of consumer groups speak for the group as a whole, or whether the most articulate are the least representative.

Despite the drawbacks, ~~however,~~ the literature and experience suggest that consumer involvement can make vital contributions to the rehabilitation of the severely handicapped. Further research is needed to determine the beneficial or other impact of consumer involvement on such areas as technology, rehabilitation delivery systems, and transportation systems.

Chapter 24

A BENEFIT/COST ANALYSIS OF SERVICE TO SEVERELY HANDICAPPED INDIVIDUALS ACCEPTED FOR SERVICE BY VOCATIONAL REHABILITATION

There are many types of analyses which can be used to establish the value of certain program expenditures. Such analyses often focus on the "benefits" and "costs" of the given program, although they vary greatly in utility, assumptions, and conclusions. Vocational Rehabilitation is one of the few social programs for which benefit/cost analyses have been made. However, we have some reservations about the confidence that can be placed in their findings. While the technical aspects of the work have been very acceptable, the basic data are simply not available, and this necessitates innumerable assumptions.

The limitations of the benefit/cost calculations have not generally been recognized by advocates and critics of the Vocational Rehabilitation program. If Congress and the Department of Health, Education, and Welfare want to use benefit/cost analyses as important inputs to setting appropriations priorities, then the types of data necessary to develop accurate benefit/cost estimates must be collected. Alternatively, if Congress desires to set priorities on the basis of other considerations besides economic efficiency (e.g., directing the Vocational Rehabilitation program to serve the severely handicapped, a group of clients whom most providers of services believe require more services than the less severely handicapped), then the need to collect better data is not as important.

The most widely accepted benefit/cost model is the economists' social benefits model. The estimates provided in this chapter were developed from that model. In the pages that follow, we describe our methodology for estimating the benefits and costs of serving severely disabled people accepted by the Vocational Rehabilitation program.

SOCIAL BENEFIT/COST MODEL

For this benefit/cost analysis the definition of severely handicapped is presented in Table 24-1. The definition uses R-300 primary disability codes used by Vocational Rehabilitation agencies to classify individuals as severely disabled or nonseverely disabled. The critical point to remember is that the individuals who are the basis of this analysis have received services from Vocational Rehabilitation and have not been rejected as being too severely disabled, as was our survey population. Thus this benefit/cost analysis looks at a particular group of severely handicapped--those who were classified by VR as severe, based on disability type, and treated by VR. In essence, then, all those classified as 08, 28, and 30 who were rejected for severity have been screened out of the analysis.

While this definition has been utilized for the purpose of analysis, it has several limitations.[1] Only primary disability codes are used, with no reference to secondary disability. Several disability codes are not listed in the table, including 140-149 (other visual impairments) and 370-379 (orthopedic involvement of one or both lower limbs). Some codes listed in the table are not classified either way, especially 532 (moderate mental retardation) and 430-449 (loss of one or both major extremities), and some disability codes perhaps do not belong in the definition, at least in entirety. Diabetes (614), for example, may or may not be severely disabling.

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1. A more detailed discussion of the pros and cons of different definitions can be found in the chapter on Definitions.

Table 24-1

Data Used to Determine The Percentage of Individuals Served by VR Who Are Severely Handicapped

		U.S. total—all rehabilitations	
		Percent severely disabled (SD's)	Percent non-severely disabled (NSD's)
100—Blindness:			
00 to 19	Disability blindness	2.7	
19 to 29	1 blind eye, 1 defective	2.4	
30 to 39	1 blind eye, 1 good eye		5.5
200—Deaf:			
00 to 19	Deafness	2.[illegible]	
20 to 29	Other hearing		2.1
300—Orthopedic:			
00 to 19	Orthopedic 3 limbs or more	1.5	
20 to 39	Orthopedic 1 upper, 1 lower	1.3	
40 to 59	Orthopedic 1 upper	2.2	
60 to 70	Orthopedic 1 lower	6.2	
80 to 99	Orthopedic 1 lower		
80, 81, 91 to 97		.7	
83	Orthopedic, other diseases		.6
90	Other orthopedic		.5
99	Orthopedic, other accident		8.9
400—Amputations:			
00 to 19	2 limbs or more	.1	
20 to 29	1 upper	.6	
30 to 39	1 lower		
40 to 49	Other		
40	Amputation other malignant		
42 to 49	Amputation other		
500—Mental, psychotic, personal disorders:			
00	Psychotic	6.0	
10	Psychoneurotic		4.9
20	Alcoholic	5.1	
21	Addict	.6	
22	Other Characteristic disorders (1)		10.6
30	Mentally retarded, mild (2)		7.1
32	Mentally retarded, moderate		
34	Mentally retarded, severe	.9	
600—Other:			
0 to 5	Malignant neoplasm (yes)	.2	
0	Colostomies, malignant (yes)		
1	Laryngectomies (yes)		
2	Leukemia, aleukemia (yes)		
5	Other malignant neoplasm (yes)		
9	Benign neoplasm (no)		.9
10	Hay fever, asthma (no)		.7
11	Other allergies (no)		.2
14	Diabetes (yes)	1.2	
15	Other endocrine (no)		.4
19	Avitaminoses (no)		0
20	Hemophilia (yes)	0	
29	Anaemia, etc. (no)		.2
30	Epilepsy (yes)	1.5	
39	Other nervous system (no)		.6
40 to 44	Heart (yes)	2.7	
45 to 49	Other circulatory condition (no)		1.0
50	Tuberculosis (yes)	.6	
51	Pneumonia (yes)	.1	
52 to 59	Other respiratory (no)		.6
60	Teeth (no)		5.8
61	Ulcer (no)		.4
62	Enteritis (no)		.3
63	Hernia (no)		0
64 to 69	All other digestive (no)		1.8
70	Genito-urinary (no)		3.1
80 to 89	Speech		
80	Cleft palate/harelip (no)		.2
82	Stammer/stutter (no)		.2
84	Laryngectomy, nonmalignant (yes)	0	
85	Aphasia from stroke (yes)	0	
89	Other speech impairment (no)		.2
90	Skin diseases (no)		.5
99	Other diseases (no)		.1
	Total	42.6	57.4

Note: Percent of clients severely disabled, 42.6.

SOURCE: U.S. House of Representatives, Select Subcommittee on Education of the Committee on Education and Labor, Vocational Rehabilitation Services: Oversight Hearings, pt. 1., August 3, 1973.

Utilizing this definition, a model was developed which includes on the benefits side:

-- Paid earnings

-- Homemaking

-- Unpaid Work

-- Fringe Benefits

-- Benefits Due to Change in Family Earning

-- Labor-Force Participation

On the cost side, the model includes:

-- Program Costs of the Agency

-- Program Costs Not Borne by the Agency

-- Research, Demonstrations, and Training Costs

-- Foregone Output

-- Client-Borne Costs

The model presented is a social model, incorporating social costs and social benefits. The data utilized to make the benefit/cost estimates draw on the R-300 data for FY 1970 and FY 1972, a reanalysis of existing computer programs developed for benefit/cost analysis of R-300 data at The University of California, Berkeley, the data of State followup studies, and national evaluation surveys.

Before detailing the specifics of the model and the results, it is important to look at the assumptions made and the concomitant limitations these assumptions impose on the results of the analysis.

First, there is no followup on available mortality data that are specific to the population analyzed. Thus, the same assumptions about benefit retention over time (length of stay on the job) are used for this population as for the overall rehabilitant population. If individuals change jobs frequently or leave the labor force, their benefit stream decreases.

Second, today's high unemployment conditions are not included. In a period of high unemployment, the probability of severely handicapped individuals entering the labor market is likely to be reduced. During these periods it is also doubtful that placing severely handicapped persons in jobs actually results in a net addition to the labor force--it may merely substitute some potential workers for others. There is no addition to social benefit from such substitution. The benefit stream attributable to the VR program is thus altered by labor market conditions.

Third, VR services may not be the reason why an individual has a particular job and retains it. In essence, there is no clear-cut cause and effect relationship and none can be determined without a control group. Furthermore, an individual may have received VR services but may have gone back to the job he held prior to disability. Unless the individual had lost the job and not been replaced, which is unknown, benefits are difficult to ascribe, since it is unclear that jobs following initial VR placement are related to VR services. Consequently, the lifetime earnings stream associated with these later jobs may not be benefits attributable to the VR program. In this study, we have attempted to make some provision for this phenomenon by using an "adjustment factor."

Despite these problems, the material presented in this chapter is interesting because it attempts to incorporate some of the more elusive benefit/cost items not usually included in analyses of this type.

COSTS

On the cost side, the model includes:

Variable Program Costs
-- case service expenditures

Fixed Program Costs (as budgeted by State agencies)
-- counselor salaries (variable costs over the long-term)
-- administrative costs
-- facilities and plant
-- research and demonstrations
-- training of personnel
-- services to nonrehabilitants (variable cost over the long term)

Costs Borne by Nonrehabilitation Agencies

Costs Borne by Service Client and Family
-- direct expenses
-- foregone employment

Future Costs of Sustaining Rehabilitation Gains
-- repeater costs to agency
-- deductible individual expenses

In allocating costs for disaggregated populations, reasoned but essentially arbitrary assumptions often must be made. In designing and calibrating the model, we routinely engage in sensitivity analysis to assess the impact of alternative assumptions and the variance of parameter and input data estimates.

The model also permits adjustment of basic program data to reflect its limitations as a measure of earnings. Benefit/cost studies in the past (with the notable exception of Conley's work) and the use of simple evaluation indicators like the change in earnings from acceptance to closure have generally made use of the R-300 figures (usually zero) of earnings at acceptance as the basis for their investment return estimates. Such practice greatly inflates the benefit/cost estimates for rehabilitation services.

The major costs of the VR program are of course the program costs. Here, however, several adjustments have to be made. Some components of program costs must be deleted; then some additional costs must be included. At the Federal level, program costs are the basic grants-in-aid under the Vocational Rehabilitation Act and expenditures under the Disability Insurance and Supplemental Security Income authorized by the Social Security Act. Program costs include both case services and overhead costs.

Costs that must be subtracted from program costs include carry-over and maintenance costs. Since an analysis is for a given year (with the rehabilitants closed in the year defining the frame for the analysis), some rehabilitants closed in that year incurred expenditures in the previous year, and some rehabilitants incurring expenditures in the year were not closed in that year. In a program in which the same number of rehabilitants were closed each year, the two departures from the 1-year accounting scheme cancel each other out. However, in an expanding program, fewer rehabilitants have cases closed with prior year costs than the growing number of cases incurring costs which will not be closed until later periods. "Carry-over" costs adjustment must be made, resulting in a carry-over adjustment estimated at 4 percent.

Maintenance costs are transfer payments and thus are not real resource or social costs.[2] Maintenance costs should be excluded. Using FY 1970 on maintenance payments results in a reduction of 7 percent to program costs.

Some services are provided under the rehabilitation plan for which the rehabilitation agency does not pay. However, these costs borne by parties other than the rehabilitation agency are part of the overall social cost

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[2] In economists' terms, transfers are not counted because the exchange or redistribution does not add to total GNP.

of rehabilitation. To include those services provided under the plan, we estimate an 8 percent increase in costs.[3]

Given that closures benefit from previous research, demonstrations, and training, we add certain R&D and training costs. Counselor training which benefits the rehabilitant is estimated at 25 percent.

This figure was based on Conley's observation that research and demonstration and training expenditures had averaged 25 percent of total program budget over a 5-year period.[4] Thus, a 5-year depreciation strategy and an annual ascription of total research and demonstration and training costs have been more variable as a percentage of total program budget in recent fiscal years, and the 25 percent relationship has been continued on the average. These adjustments to program costs constitute an addition of 22 percent of program costs to social costs.

For part of the rehabilitation process, the rehabilitants are without earnings. If the rehabilitant had earnings at acceptance, he may have foregone those earnings or part of them (by working fewer hours) to enter the rehabilitation program. In addition, although the rehabilitant may not have had earnings at acceptance, he may have been looking for employment and abandoned the search to enter the rehabilitation process. Moreover, these earnings are a loss to the economy and should be counted as a social cost of rehabilitation. The method used to estimate these foregone earnings uses average annual earnings at acceptance (rather than closure) for those with earnings, adjusted for pre-rehabilitation earnings base. In addition to paid earnings, fringe benefits are included. This earnings

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[3] Based on an Abt study of clients receiving services outside of VR during a VR plan. Abt Associates, Inc., "Cost-Benefit Analysis," in The Program Services and Support System of the Rehabilitation Services Administration: Final Report (Cambridge, Mass.: The Associates, 1974), Part IV, Section 8.2.

[4] Ronald W. Conley, "A Benefit-Cost Analysis of the Vocational Rehabilitation Program," Journal of Human Resources, Spring 1969, p. 242.

figure is further adjusted for the average time spent in rehabilitation without earnings. Time spent in rehabilitation without earnings is estimated as time from acceptance to closure minus 30 days. This time is expressed as a proportion of a year. For the entire population of rehabilitants, average time in process is 15.1 months for FY 1970. A final adjustment involves the number of rehabilitants who actually forego earnings. The Abt study[5] showed that only 1.5 percent of rehabilitants reported foregone earnings. To include those rehabilitants who give up the search for employment or worked fewer hours, a more conservative figure of 15 percent is used. In summary, total foregone earnings equals total annual earnings and fringe benefits at acceptance (including an adjustment for pre-rehabilitation earnings base) times the proportion of a year's earnings are foregone times the percentage of rehabilitants foregoing earnings. Note that the foregone earnings of nonrehabilitants are not included. Foregone homemaker and unpaid work are not included since few rehabilitants probably change this level of activity while receiving services.

Client-borne costs are simply those costs borne by the client (not by the rehabilitation agency) which are part of the plan and which contribute to the success of the rehabilitation. For years other than FY 1970 and for subpopulations, a ratio of \$421[6] to average case service costs for other years or subpopulations was established. Client-borne costs equal the proportion bearing costs times the average payment times the total number of rehabilitants. Client-borne costs for nonrehabilitants are not included.

The problem occurs when disaggregating costs by subgroups. While case service costs for the subgroup of rehabilitants are readily available, the problem comes in allocating counseling and administrative overhead costs

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[5] Abt Associates, "Cost-Benefit Analysis," Part IV, Section 4.2.

[6] Ibid.

to the subgroup. Some costs, such as counselor costs, are variable in the sense that subpopulations can receive more or less counseling time. However, counselor salaries for the program as a whole are fixed in a given year. Deciding how much of the overhead costs to distribute to the different subgroups is the difficult problem. Furthermore, since case service costs are less than half the total costs incurred in rehabilitating clients, the allocation of overhead costs assumes great importance in determining the benefit/cost results for client subpopulations.

The amount of overhead costs to allocate to a group could be based on a comparison of (1) the number of rehabilitants in the group to the total number of rehabilitants, (2) the total time in process for the group to the total time in process for all rehabilitants, or (3) the total case service costs for the group to the total case service costs for all rehabilitants.

The method chosen is comparison of case service costs. This method implies that the more case service costs a group has, the greater the proportion of overhead costs that should be allocated to that group. Of the three methods, in absence of administrative studies this method seems plausible and most practical. While the choice of the method can affect the results, a comparison of the three methods on seven disability groups showed that, despite different benefit/cost ratios, the ranking among disability groups was constant.

BENEFITS

The paid earnings are the major benefit in a social model. The increase in earnings computation is based on a before-and-after approach. Average weekly earnings of rehabilitants at closure are higher than average weekly earnings at acceptance. This difference is the increase in earnings attributed to the program. Nevertheless, the higher earnings of the rehabilitant at closure do not continue through time unchanged, nor do these increased earnings continue indefinitely. To get the total stream of earnings for all rehabilitants, the following modifications must be made to the increased earnings at closure:

- retirement
- mortality
- change in number with earnings
- changes in earnings
- time spent in rehabilitation, without earnings
- discounting
- pre-rehabilitation earnings base
- reduction in benefits attributed to services

The earnings stream of a rehabilitant stops at retirement. For the purposes of this study, 65 was assumed to be the age of retirement.

The modification for mortality recognizes that the earnings stream of a rehabilitant might be cut short by death. To calculate the number of surviving rehabilitants at any time, the cohort-survival method of population studies was used. To perform such a calculation the ages of the rehabilitants at referral and the probability of surviving from one time period to the next for each age group must be known. (The probability of surviving is one minus the mortality rate.) Age groups consist of 5-year intervals, starting at and ending at 60-64. Mortality data are from the Society of Actuaries for the period 1955-1965.

To get the total lifetime earnings stream, the number of rehabilitants who have earnings at a particular time must be known. Some clients closed in status 26 do not have earnings at closure. Of those that do have earnings at closure, some quickly, within a year or two after closure, lose their jobs. These job losses can be considered to be an indicator of the failure of the program, failure in the sense that services were not sufficient in removing vocational handicaps so that the rehabilitant could continue to be employed, even though the rehabilitant had been employed for at least 30 days prior to closure.[7] Over a longer period of time, some additional rehabilitants will drop out of the labor market; for example, on account of worsening disability or changes in family situation. To estimate the number of rehabilitants who lose their jobs fairly soon after closure, followup studies were used. A review of several State and national studies suggests that 1 year after closure 85 percent of rehabilitants with jobs at closure still have their jobs, while at the end of 5 years 80 percent still have their jobs.

The earnings of rehabilitants may change owing to any of three factors: learning, secular increases in wages, and age. The younger rehabilitant or the rehabilitant entering a new profession may show sharp increases in wages due to mastering the new job. Based on followup data, the earnings of the rehabilitant are increased 25 percent from closure to 5 years after closure. In addition, wages in general increase in the economy. A growth function with a constant rate of growth of 2.5 percent is applied to earnings after other adjustments are made. Age also affects earnings. Over the lifetime of the individual, wages increase rapidly, reach a peak, and may decline somewhat before retirement. Thus, using closure earnings for a rehabilitant in the 15-19 age group and projecting these earnings over a lifetime would underestimate earnings, since earnings are usually low for those younger age groups. An adjustment factor is made.

An additional adjustment to the earnings stream recognizes that the time spent in rehabilitation is also time spent without earnings. The amount of earnings that would have been received in the period during rehabilitation without earnings (during the last few months of rehabilitation the clients

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[7] The period of employment prior to closure has been expanded to 60 days. The 30-day period was in effect for the data period under analysis.

often have earnings) must be subtracted from the earnings stream. This adjustment is similar to the calculation for foregone earnings. Note that this adjustment is made for before earnings also, to prevent double counting.

Furthermore, the earnings stream must be discounted. The concept of a social discount rate is very important in benefit/cost analysis. Use of discounting reflects two facts. On one hand, a dollar in hand today is worth more than a dollar in hand next week; so it will make sense to pay additional money--interest--to get a certain amount of money now and pay back the principal and the interest at a later time. On the other hand, one can put the money in the bank now and get more back for it at a later time, through the addition of interest on the deposit.

The social discount rate is similar to the interest rate but applies to the society as a whole. The future costs and benefits of a program are brought to the present (expressed in their present value) because that is where the decision is to be made. In addition, the social discount rate can be viewed as having three basic components: time preference, opportunity cost, and uncertainty. The time preference component refers to the inclination of people to postpone present consumption for future consumption and vice versa. For example, some people are willing to put off buying a car and a home in order to continue their education, in the hope of payoff in higher earnings in the future. The opportunity cost of an action is the next best action that could have been undertaken but was foregone. Opportunity costs are involved in the social discount rate since opportunities change with time. Also, by undertaking a project in the public sector, a project in the private sector may be foregone. Opportunity costs, then, are revealed in a comparison of public and private investment. The third component, uncertainty, takes into account the risk of costs and benefits in the future. The uncertainty factor is especially crucial when costs and benefits are projected 20 years or more into the future, as is often done in cost/benefit analysis of programs.

The choice of a discount rate is important, since when one rate is used a project may seem acceptable, but when a higher discount rate is used it may not be justified. The social discount rate can be chosen on the basis of (1) the particular program involved, (2) guidelines from some central budget bureau for a governmental unit, or (3) examination of the three components of the discount rate. In any event, the choice of a proper discount rate is not an easy matter.

Several discount rates are used here: 0 percent, 4 percent, 7 percent, 10 percent, and 13 percent. They run the gamut from least to most conservative. Results will be reported for each rate, so that the variations can be seen.

To adjust for the fact that the average earnings in the week prior to acceptance often understates pre-entry earnings (due to unemployment) a pre-rehabilitation earnings base adjustment is made. The reported earnings at acceptance are increased 34 percent on the basis of comparison of acceptance average earnings to average earnings 3 months prior. Earnings 3 months prior probably reflect the earnings the rehabilitant would have had if he had not entered the rehabilitation process, since many clients are temporarily unemployed when they apply for services. This adjustment is not used for the benefit due to changes in family labor force participation, as explained below.

One major problem in identifying and measuring the benefits of a program is the problem of cause and effect. What does a program really change? For example, take the increase in earnings a rehabilitant experiences from acceptance to closure. Does the program bring about all of this change? Changes in general social and economic conditions could have occurred, such as a decrease in the unemployment rate or inflation. Would the rehabilitant unemployed at acceptance have lost even those earnings if he had not entered into rehabilitation? The problem is that time passes during the training process, often more than a year, and something might have happened to the client had he not come to the rehabilitation agency.

A before-after approach is used here. The differences between conditions after the program and prior to the program are assumed to be the result of the program. This assumption, as pointed out in the opening section, has important implications for the results of the model. However, a reduction of benefits attributable to the program is made. In this study we assume that 80 percent of the increase in paid earnings, as well as fringe benefits, homemaking, and unpaid work, is attributed to the VR program.

Homemaking is valued similarly to paid earnings. Adjustments for mortality, retirement, productivity, number with earnings, and discounting are made. A replacement cost approach is used to value normal population homemaking services. The tasks performed by a homemaker are described, as well as the hours spent in each task. Then the earnings of a replacement for the task, based on 1969 prices, are used to value the task. For example, general household clean-up is valued at the rate of a paid housekeeper. Summing the tasks and their respective values gives the average value of $5,139. Then to get the value of the disabled homemaker, the earnings of the disabled are compared with the earnings of the normal population. Thus, the assumption is that paid earnings have the same relationship to homemaking services for the normal population and the disabled. It is also assumed that the rehabilitant was unable to perform homemaking activities before receiving VR services and therefore the prerehabilitation value equals zero. The number of homemakers, including unpaid family workers, at acceptance and closure is taken from Characteristics of Clients Rehabilitated in Fiscal Years 1967-1971.[8] The inclusion of unpaid family workers, including farmers and those engaged in family-run businesses, should not bias the results, since the number of these rehabilitants is so small. However, their inclusion does allow the addition of their output. Note that sheltered workshop workers and the self-employed are included in paid earnings. Also note that those leaving paid employment are not added to the homemaker population. As such, homemaking is undervalued. Adjustments for changes in earnings and for changes in number with earnings are those made for paid earnings, except that the 25 percent initial increase in earnings is not applied.

Unpaid work is valued the same as homemaking, except that an unpaid work factor is included. This two-thirds (65 percent) factor consists of two components, one for women and one for men. The unpaid work of the full-time employed person was compared to the average hours of homemaking of a full-time homemaker. Full-time employed women devote almost two-thirds as much time to homemaking as do full-time homemakers. For men this figure is 18 percent. The proportion of male and female rehabilitants employed at closure gives a total unpaid work factor. The assumption is that homemaking and unpaid work can be valued at the same rate, and that the disabled and the normal population perform the same proportion of unpaid work.

Fringe benefits are valued as a proportion of the total discounted paid earnings stream. First, a ratio of potential fringe benefits, excluding

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[8] U.S. Department of Health, Education, and Welfare, Social and Rehabilitation Service, Rehabilitation Services Administration, Characteristics of Clients Rehabilitated in Fiscal Years 1967-1971 (1972).

payments for time not worked, to total earnings is calculated to be 19.6 percent, using Chamber of Commerce data. A proportion of fringe benefits for the disabled is developed. Realizing that the disabled work in sectors where fringe benefits are low and in secondary labor markets, and realizing the possible discontinuous work history of the rehabilitant, this proportion is assumed at 50 percent. The multiplication of these two proportions then gives the proportion fringe benefits is of paid earnings.

Benefits due to changes in family labor force participation include two trends. First, some family members may be released from caring for the disabled, due to the rehabilitant's increased capacity for self-care and homemaking. These family members can then find paid employment. Second, due to the entry of the rehabilitant into the labor market, some family members may find that they no longer need to work or to work two jobs. Rather than model these processes separately, an overall estimate of the combined effect is used--8 percent. This benefit will only be calculated for 1 year. Also, since the change in earnings is used solely as a comparative base, reduction for benefits attributed to services and prerehabilitation earnings base adjustments will not be made.

Repeater costs are included as a negative benefit. Repeater costs are future costs. Some rehabilitants closed in status 26 do come back for additional services. Although these costs may not be incurred in the year under analysis, there are costs attributable to the closures in that year. Of course, future repeater costs can only be estimated on the basis of past repeater costs, if the analysis is being made on the current year's program. Furthermore, these rehabilitants do not come back immediately, but most who are likely to come back do so by the end of 3 years. Thus, repeater costs are spread over 3 years and discounted. For FY 1970, 6.3 percent of rehabilitants had had a previous closure.

RESULTS

Two methods are used here to compare costs and benefits. The first is the benefit/cost ratio, or benefits divided by costs. The meaning of the benefit/cost ratio can be expressed as the rate of return per dollar invested. For example, a benefit/cost ratio of 5 (5/1) suggests that 5 dollars are returned for each dollar invested. The second method is the discounted net present value (i.e., the discounted difference between costs and benefits) and is expressed in dollars. Note that the number of clients in a group greatly affects this result, whereas the number of clients has no effect on the benefit/cost ratio.

The results are given in Table 24-2, Most Severely Disabled and Total Population. First, the ratio of social benefits to social costs is given. This ratio contains all of the costs and benefits discussed in previous sections. The ratio is given for values of the social discount rate, from 0 to 13 percent. At a social discount rate of 7 percent, the overall vocational rehabilitation program shows a return of $15.94 for FY 1972 for every dollar invested. The severely disabled accepted by VR had a return of $9.13 in FY 1972. Even when a conservative discount rate of 13 percent is used, the severely disabled show a return of $5.91 for FY 1972, if one accepts the assumptions and data used.

The second set of results uses a more traditional benefit/cost ratio. A ratio of paid earnings to program costs, excluding fringe benefits and homemaking, corresponds to early benefit/cost efforts and makes fewer assumptions, in addition to being less complicated. However, this traditional method results in higher returns, since the inclusion in the former

Table 24-2

Benefit/Cost Results for Total Rehabilitation Population and the Most Severely Handicapped for FY 1970 and FY 1972

	Social Discount Rate				
Social Benefits/Social Costs	0%	4%	7%	10%	13%
FY 1970 Total Rehabilitants	$43.30	$21.08	$14.12	$10.34	$ 8.08
FY 1970 Severely Disabled Rehabilitants	21.59	12.39	9.14	7.19	5.93
FY 1972 Total Rehabilitants	48.85	23.80	15.94	11.65	9.09
FY 1972 Severely Disabled Rehabilitants	21.73	12.42	9.13	7.17	5.91
Paid Earnings/Program Costs					
FY 1970 Total Rehabilitants	$57.64	$27.46	$18.11	$13.06	$10.07
FY 1970 Severely Disabled Rehabilitants	27.70	15.55	11.31	8.79	7.18
FY 1972 Total Rehabilitants	64.75	30.90	20.37	14.67	11.30
FY 1972 Severely Disabled Rehabilitants	27.46	15.34	11.12	8.63	7.03
Discounted Net Present Value[1] ($ Millions)					
FY 1970 Total Rehabilitants	$32,408	$15,381	$10,055	$ 7,155	$ 5,422
FY 1970 Severely Disabled Rehabilitants	6,113	3,382	2,415	1,838	1.464
FY 1972 Total Rehabilitants	45,734	21,790	14,276	10,180	7,730
FY 1972 Severely Disabled Rehabilitants	7,437	4,096	2,917	2,214	1,760

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1. Uses social costs and social benefits.

model of additional costs has a greater effect than the inclusion of social benefits relative to paid earnings.

The discounted net present value for the FY 1970 severely disabled under a social discount rate of 7 percent shows substantial returns, $2,415 million in FY 1970 and $2,917 million in FY 1972. Note this amount is 24.0 percent of the discounted net present value of the entire program for FY 1970, and 20.4 percent for FY 1972.

The differences in the results for the total population of rehabilitants and the severely disabled are due first to our more stringent mortality assumptions, and second, to greater average case services cost for them. The greater age of severely disabled reduces the length of time that benefits continue.

The benefit/cost results for selected disability groups (Table 24-3) indicate that the deaf (no speech) group has the highest returns, higher than the average total for the total severely disabled population, with blindness (both eyes) the lowest, and with the other four groups with similar returns. The high returns of the deafness-no speech group, especially in comparison with the deafness-have speech group, are based on several factors. The former group is younger, with higher earnings at closure, more change in the number with earnings and more with earnings at closure, and lower average case service costs. The blindness (both eyes) group has lower returns due to the combination of high average case services cost, lower number with earnings at closure, and lower earnings at closure than any other group except severe mental retardation. The severe mental retardation group showed returns comparable to other groups in spite of the low earnings of the group. However, the high number with earnings at closure, the lower

Table 24-3

Benefit/Cost Results for Selected Disability Subpopulations of the Severely Handicapped, FY 1970

	Type of Result		
Population	Social Benefits/ Social Costs	Paid Earnings/ Program Costs	Discounted Net Present Value: Social Benefits/ Social Costs (Millions of $)
Total Severely Handicapped Population	9.14[1]	11.31	$2,415
Blindness, both eyes (100-119)[2]	3.34 (.37)[3]	4.15 (.37)[3]	$ 94 (3.9%)[4]
Blindness, one eye, other eye defective (120-129)	5.08 (.56)	6.28 (.56)	$ 30 (1.2%)
Deafness, no speech (200-209)	11.34 (1.24)	14.59 (1.29)	$ 88 (3.6%)
Deafness, have speech (210-219)	6.60 (.72)	8.90 (.79)	$ 77 (3.2%)
Orthopedic impairment involving three or more limbs or entire body (300-319)	5.01 (.55)	6.05 (.53)	$ 99 (4.1%)
Severe mental retardation (534)	6.43 (.70)	7.71 (.68)	$ 46 (1.9%)

1. The results tabled use a social discount rate of 7 percent. Although different discount rates could affect these results, both absolutely and relatively, the number of results would obscure the basic patterns; as such, results only for the rate of 7 percent are presented. The comparative results do not change substantially under other discount rates, however.

2. R-300 classification of disabling conditions gives a more precise definition of the subpopulation.

3. This figure is the ratio of the cost-benefit ratio for the group to the cost-benefit ratio for the entire population. This ratio or index is similar to a price index.

4. Note that the number of clients in this group greatly affects this result, whereas the number of clients has no effect on the cost-benefit ratio.

Table 24-4

Benefit/Cost Results for Selected Disability Subpopulations of the Severely Handicapped, FY 1972

Population	Type of Result		
	Social Benefits/ Social Costs	Paid Earnings/ Program Costs	Discounted Net Present Value: Social Benefits/ Social Costs (Millions of $)
Total Severely Handicapped Population	9.13[1]	11.12	$2,917
Blindness, both eyes (100-119)[2]	3.39 (.37)[3]	3.91 (.35)[3]	$ 123 (4.2%)[4]
Blindness, one eye, other eye defective (120-129)	5.74 (.63)	7.19 (.65)	$ 47 (1.6%)
Deafness, no speech (200-209)	10.06 (1.10)	13.61 (1.22)	$ 81 (2.8%)
Deafness, have speech (210-219)	5.94 (.65)	8.07 (.73)	$ 98 (3.4%)
Orthopedic impairment involving three or more limbs or entire body (300-319)	5.81 (.64)	6.98 (.63)	$ 103 (3.5%)
Severe mental retardation (534)	6.26 (.69)	7.52 (.68)	$ 55 (1.9%)

1. See Table 24-3, footnote 1.
2. See Table 24-3, footnote 2.
3. See Table 24-3, footnote 3.
4. See Table 24-3, footnote 4.

Table 24-5

Benefit/Cost Results for Selected Disability Subpopulations of the Severely Handicapped, FY 1970

Population	Type of Result		
	Social Benefits/ Social Costs	Paid Earnings/ Program Costs	Discounted Net Present Value: Social Benefits/ Social Costs (Millions of $)
Total Severely Handicapped Population	9.14[1]	11.31	$2,415
15-19 years old	9.83 (1.08)[2]	11.89 (1.05)[2]	$ 751 (31.1%)[3]
20-24 years old	13.10 (1.43)	17.03 (1.51)	$ 556 (23.0%)
25-44 years old	9.00 (.98)	11.01 (.97)	$ 790 (32.7%)
45-59 years old	6.68 (.73)	7.58 (.67)	$ 322 (13.3%)
60-64 years old	1.08 (.12)	1.12 (.10)	$ 1 (0.04%)

1. See Table 24-3, footnote 1.
2. See Table 24-3, footnote 3.
3. See Table 24-3, footnote 4.

Table 24-6

Benefit/Cost Results for Selected Disability Subpopulations of the Severely Handicapped, FY 1972

Population	Type of Result		
	Social Benefits/ Social Costs	Paid Earnings/ Program Costs	Discounted Net Present Value: Social Benefits/ Social Costs (Millions of $)
Total Severely Handicapped Population	9.13[1]	11.12	$2,917
15-19 years old	8.97 (.98)[2]	10.80 (.97)[2]	$ 859 (29.4%)[3]
20-24 years old	12.69 (1.39)	16.27 (1.46)	$ 745 (25.5%)
25-44 years old	9.67 (1.06)	11.54 (1.04)	$ 940 (32.2%)
45-59 years old	6.90 (.76)	7.70 (.69)	$ 380 (13.0%)
60-64 years old	.76 (.08)	.69 (.06)	-$ 3** (-.1%)

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1. See Table 24-3, footnote 1.
2. See Table 24-3, footnote 3.
3. See Table 24-3, footnote 4.

average case services cost, and the much younger age distribution counterbalance the lower earnings.

The benefit/cost results for the age groups (Table 24-5) indicate the highest returns for the 20-24 age group, similar returns for the 15-19 and 25-44 groups, considerably lower returns for the 45-49 group, and the lowest returns for the 60-64 group. The low returns for the 60-64 age group can be explained mostly in terms of the 65 retirement age assumed in the model, though the 60-64 age group also has a low proportion employed at closure (and many more in the homemaker and unpaid work category). The returns to the 15-19 age group are high, in spite of the greater cost, both due to the longer time benefits will accrue as well as the low average earnings and proportion with earnings at acceptance. These lower figures result in a greater increase in benefits (attributable to the vocational rehabilitation program). These figures are lower mainly since this is the initial job entry for this age group.

CONCLUSION

Thus, the vocational rehabilitation services provided to individuals classified as severely handicapped and treated by VR show good economic returns, if one accepts the assumptions. Average earnings increase 10 percent from acceptance to closure. More importantly, the proportion of 26 closures with earnings increases from 18 percent to 83 percent in FY 1970 and from 17 percent to 81 percent in FY 1972. In addition, the proportion of homemakers and unpaid workers increases from 5 percent to 16.4 percent in FY 1970 and to 18.5 percent in FY 1972. These changes explain the favorable economic results.

Of course, the economic returns for the severely disabled are less than for the general VR population. In fact, the differences would be even more apparent if the severely disabled were compared to nonseverely disabled. The decreased returns are due to the higher average case services cost of the severely disabled, the older age distribution of the severely disabled, and the more stringent mortality assumptions.

Even though vocational rehabilitation services to the severely disabled show favorable results from an economic viewpoint, the benefit/cost ratio and discounted net present value are still not final bases for program judgments. Those results should be seen as but one more piece of information about the severely handicapped. Several points can be made about the analysis.

First, the benefit/cost analysis is descriptive. It describes the program at a point in time. A change in the population being served or a change in economic conditions in the future could greatly influence the evaluation of the program. For example, a high unemployment rate reduces the likelihood of a severely handicapped individual entering the labor force and consequently reduced the benefit stream. Thus, a continuance of present policies may not lead to the same high results.

Second, lower results do not indicate that services to a disability group such as the severely disabled should be decreased. If the legislature has given a mandate for the provision of services to certain groups needing them, then these services must be provided. Lower benefit/cost ratios indicate merely that new strategies for the provision of services (or even new services) should perhaps be considered if the program desires to increase benefits relative to costs.

Third, the evaluation is economic. While economic evaluations are very important, some other noneconomic evaluations might be useful. For example, a client evaluation of the usefulness and adequacy of services might be helpful in program analysis.

Fourth, the analysis is of the overall program in serving particular target populations. Nothing is said about specific services, policies, or individuals.

The most questionable aspect of this analysis is the definition of severely disabled. The benefit/cost results might have run lower with a different definition of severely disabled. The lack of followup data on retention of employment and earnings benefits specific to the severely disabled subpopulation is also a source of potential error. While almost all costs have been included and deliberately overestimated when there was any question, various types of benefits--some highly significant--have been omitted because of difficulties of measurement, lack of any reasonable data or basis for estimation, or inapplicability to a social benefit/cost model.

There are no national program data on the total number of rehabilitants who previously had been in institutions or who, in the absence of services, might have been regarded as having a high probability of entering institutions. A study by Michigan's VR program found that savings in institutional costs for mentally ill rehabilitation clients were sizable, about 3 percent of the projected increase in lifetime earnings and over eight times the projected decrease in public assistance payments for the mentally ill client population.[9] Moreover, the study only regarded benefits as the reduction in days of institutional care during the period between acceptance

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[9] Michigan Department of Education, Division of Vocational Rehabilitation, The Vocational Status of Michigan Rehabilitants of Fiscal Year 1969, Two Years After Case Closure (1971).

and followup interview. With the increasing public concern for deinstitutionalization, such data may need to be collected nationally in the future.

In addition to the benefits and costs described above, there are other true social benefits of the rehabilitation program which are almost impossible to quantify and measure but may be fundamentally important. Such benefits are often termed "intangibles."

Rehabilitating an individual to economic independence and self-sufficiency also will usually involve expanding his capability for doing many other things, thus greatly increasing the overall quality of the disabled person's life. How does one value a client's learning to read braille, or to dress himself or handle bowel movements, or to travel a city block in a wheelchair? Such accomplishments open a whole new life for many handicapped and form the basis for self-respect and dignity. Not every rehabilitant has needs requiring such a degree of accomplishment. But clients with such needs are not rare or even uncommon in rehabilitation programs.

The lives of other family members are also profoundly affected. The presence of a dependent disabled person in a household can be a trying situation for parents, siblings, spouse, and children as well as for the disabled. Helping the disabled person to achieve greater self-sufficiency and break patterns of dependency often dramatically changes the quality of life for everyone in the household. The consequences of this change in the stability and quality of family life can affect the growth and maturation and thus the later lives of siblings and children. These kinds of impacts are impossible to evaluate in hard numbers but may well outweigh the economic benefits of rehabilitation.

No one can say how much different taxpayers and members of society value the humanitarian benefits of the maintenance of rehabilitation programs. Economists talk of measuring the "option value" of such programs.

i.e., how much each member of society is willing to pay to insure the maintenance of such programs or institutions, lest some day that citizen become disabled and have need of such programs. Existing data do not permit such measurement.

Recognizing that nonmeasurable social value exists does not imply that public policymakers should cease looking for better strategies for serving the needs of disabled individuals or for ways to improve rehabilitation programs and make them more efficient and effective. However, in deciding whether to allocate more resources as between highways and rehabilitation, welfare and rehabilitation, private consumption (and lower taxes) and rehabilitation, the existence of such intangible social value should not be ignored.

Chapter 25

OTHER PROGRAMS ASSISTING THE HANDICAPPED

Section 130 of the Rehabilitation Act of 1973, which authorized the study being reported in this volume, calls for an examination of programs under the Secretary of Health, Education, and Welfare, to see how they may contribute to the goals of independent living or vocational rehabilitation, and how they may be coordinated. In our investigation of those programs we have found them to be extensive and varied, designed to serve different purposes and relying on different definitions of the concept of disability. Some programs are dedicated exclusively to the disabled; others utilize program earmarks or components for the disabled. Some are limited to specific disability groups, while others serve persons with any disability. Some focus on the severely disabled alone; others focus on all the disabled. All the programs in this melange impinge upon vocational rehabilitation (VR) as it presently works and on independent living rehabilitation (ILR) as it might work. Some impinge directly, some indirectly, while others do both.

In analyzing these programs, we have been unable to retain single consistent definitions of severity, since the program definition and the availability of data prohibit much precision. We are unable to make an unduplicated count of persons receiving these benefits, since the data are not there and analytic models for estimating the differentials and overlaps simply do not exist. We do know that some fair proportion of the most severely handicapped receive multiple program benefits in the sense that they at least get income maintenance and the concomitant health care coverage.

In this review of programs we found many not under the Secretary of HEW which have a vital influence on rehabilitation and the disabled. It makes little sense, for example, to discuss Supplementary Security Income without referring to Food Stamps, or to talk about Disability Insurance without referring to Workers' Compensation.

In the course of work on the other programs for the most severely handicapped, it has become increasingly clear that no overall, comprehensive look at the Federal programs and policies affecting the disabled existed before the Office of Handicapped Individuals surveyed the agencies. While few data exist in many areas, it does seem clear that programs are fractionated, sometimes competing, and often inconsistent. A recent study of programs for handicapped children concluded that the programs are inequitable, contain severe gaps in services, suffer from inadequate control, and are operated with insufficient knowledge and resources.[1] In our review we found the same problems, along with significant underdevelopment of community-based resources to support independent living strategies.

Most importantly, though, from our perspective, the major shortcoming in the design of programs for the disabled has been the preoccupation with the medical aspect, with emphasis on the <u>dis</u> rather than the <u>ability</u>, and underplaying of the most vital dimension of disability--the social aspects. If a problem faces a disabled person, that problem also faces many, perhaps more, of the nondisabled. The solution to a problem for the disabled will usually have spillover benefits for the nondisabled, possibly greater than for the disabled.

It is important to discuss some of what we believe are the conceptual ambiguities and underpinnings of existing programs for the disabled. We will try to discuss a number of problem and program areas, indicating what the existing programmatic response is and attempting to make some assessment of the adequacy of the response. Finally, we will try to present our perspective

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[1] S. Brown and J. Kakalik, <u>Improving Services to Handicapped Children</u>, The Rand Corporation, Report R-1420/1-HEW (DHEW, 1974).

on what could conceivably inform a strategy for Federal programs on behalf of the disabled.

A Question of Purpose

When one examines the range of Federal programs for the disabled, he is struck by both their scope and their diversity in both purpose and coverage. Early on, one notes overlaps and gaps, and one suspects considerable inefficiency such as loading benefits on some disabled while others go virtually without assistance. Then, too, some individuals receive cash when they could best use kind, and others get kind when they might best use cash. In still other cases, people get only part of what they require, with a cutoff in services or eligibility virtually mitigating the gains from what is provided.

In order to rationalize somewhat the current set of Federal programs and to suggest new considerations, it is necessary to conceptualize and articulate three broad notions: (1) Federal purposes as they seem to have developed; (2) a general concept of the disabled which is not conditioned by program concerns, so that one can design the program for the constituents' benefit only; and (3) a discussion of the problems and options available for examining the tradeoffs among Federal strategies.

It should be recognized that, in taking this somewhat Olympian view of the nature of the target population and the programs serving it, we are basing a good deal of the discussion not on data or consensus about values but upon abstractions.

The severely handicapped can be defined by the poverty of services they receive from private and public sources and by the low rates of social and economic participation they exhibit. On the other hand, almost no other minority group is the target of such an all-inclusive array of technologies conveyed by so many different professional and paraprofessional specializations.

For almost every conceivable aspect of human activity, there are individuals offering some set of skills or hardware designed to make that activity in some way accessible to one or more types of severely disabled people. The intimacy and pervasiveness of the interventions offered to at least some severely disabled people can be readily illustrated. There are physicians, counselors, and assistants who focus intensively on narrow ranges of impaired body functions, such as respiration and elimination. Sexual activity for physically impaired individuals is the concern of another group.

Careers are invested in the design and manufacture of prosthetic and orthotic appliances. Recreation for the blind, the deaf, and the wheelchair-bound, attract some people to training and employment. There are "international consultants" in transportation for the handicapped, and attorneys devoting their energies to rights of "access" for epileptics, the retarded, the blind, and others. Expertise exists in relationships between severely disabled adolescents and their parents and siblings, and there are persons called upon to mediate disputes between the blind and the wheelchair-bound on the placement of curb ramps and cuts.

All these and others are in addition to the expected collections of health professionals certified to detect, treat, and transform the sick, and injured into the disabled.

This suggests that national policies for the severely disabled have followed, rather than preceded, value and allocation decisions. Thus, in the areas of income maintenance, health care, and vocational rehabilitation, the Nation has tried first to decide what it can afford to spend and then to accept levels of participation which those funds will permit.

Income maintenance programs for the severely disabled tend to be explicitly subsistence in character and to embody requirements designed to stimulate recipients to enter the labor market along with other provisions inhibiting the incentives. Conversely, publicly financed health care benefits to the severely disabled, while under continual political and budgetary stress, reflect the widely held standards for care. However, to the extent that these benefits are tied to participation in welfare programs, the benefits contain major disincentives to labor force participation on the part of this medically high risk group.

Review Criteria

Before the problem of allocating expenditures to the severely disabled arises, one faces the equally difficult task of deciding which programs should be included. Any selection process for including some programs and excluding others will be to some degree arbitrary. Surely no program specifically excludes the disabled, so that one could argue that every public program spends some portion of its funds on the disabled.

Therefore, four criteria were used as the bases on which to decide whether or not to include a program. These criteria were: (1) the program deals exclusively with the disabled; (2) the disabled are a targeted population in the program; (3) the program is required to place special emphasis on the disabled; or (4) the program aims at alleviating consequences of disabling conditions, even if the majority of those served by the program are not disabled.

This last criterion is the most nebulous. Perhaps two examples will help to show how it was applied. If a disabled person received an income transfer, we have assumed the person to be poor as a result of his disability, and thus we allocated a portion of the income transfer program's expenditures in our calculations. On the other hand, a disabled veteran would receive educational support even if he were not disabled. Thus in this case, since the expenditure does not arise as a response to the existence or consequences of the disability, we have not included these direct service payments in our analysis. We wished to focus on actual allocations rather than budget authority or plans. The last year for which enough expenditure data are available was FY 1973. In a few cases, it was necessary to use data from FY 1972.

Following is an outline of each program, including information on how we decided to allocate a share of its expenditures to the severely disabled, and the actual amount thus counted. To clarify the differences in types of programs, we break them up into transfer payments, medical care and assistance, and direct services. A fourth category, indirect services, is excluded. These programs, such as research, staff training, and capital construction, generally have long-term and widespread benefits, making any allocation of the expenditures to one group useless.

While we have tried to clearly indicate how we made our allocations, we should point out that any summary over various programs not specifically designed for a single population, and not even using consistent definitions, must remain arbitrary.

It should be evident that there are few simple dimensions to the problem of investigating the programs for the disabled in terms of what is or what might be. There are disability-specific programs for special groups (e.g., blind and retarded); general programs for disabled only but nondiagnostic-specific (VR, SSI); and general programs in which the disabled participate, but not by virtue of their disability, although they may be treated differently by such programs than the nondisabled. Then there are concerns by functional area, such as the work effort of the disabled, medical care, or personal care. There are also concerns limited to depth of disability and not to diagnosis or function.

TRANSFER PAYMENTS

Introduction

The key part of any overall strategy of programs for the disabled will be the income maintenance system which sustains them. Even without defining impairments in a work related manner, we have pointed out that persons with severe handicaps tend to have lower incomes than persons without such handicaps. Many severely handicapped persons are perfectly competent, or at least as competent as the rest of us, to handle their own affairs. What they lack is the opportunity to achieve target income levels through their own efforts because of their impairments and/or because of various forms of labor market and other barriers. These persons need a purely cash system of payments of sufficient level for them to accomplish their needs.

Others of the impaired are not so well off, relatively speaking, but will have family or other persons available to assist them in their consumer decisions and self-care. For most of these persons a cash strategy is also appropriate, but it is complicated by the range of tastes and decisions about whether other family members should work or stay home and care for the individual, and when transfer payments should attend to such differences.

There are two other groups of the impaired who bear notice. The first is that large group of persons who work either full or part time and make a fair wage. Our examination of the available studies suggests that when an impaired person works, he works about the same hours and is paid about the same wage as his nonimpaired coworker on the same job. The effect of disability seems most onerous in terms of the availability of a desired job and in the types of jobs generally available.

Judging from the data, which are flawed, impaired persons tend to find themselves somewhat more educated, experienced, and older than their coworkers and to occupy beginning levels of low-level jobs. For example, where a certain occupation might be considered a suitable job for a young persons starting a working career, say an operative in a factory, these are terminal jobs for some of the impaired.

Conclusions must be tentative, in that the data are derived from surveys which asked the following work-related disability question: "Did your disability prohibit you from work or limit the kind or amount of work you could do?" An impaired lawyer probably would not have answered that question, and would not have appeared in the data as disabled at all, thus biasing the responses to the more severely disabled or to those unemployed or underemployed who use an impairment explanation.

The question of how to include in a transfer program the impaired with standard jobs paying standard wages is a vexing one. We know little about the costs of their jobs, or even if there are any costs. The technique used in most welfare reform designs of establishing a rate for the reduction of benefits could be designed so that fully employed disabled persons above a certain income are not covered, but this may affect the ability to give an adequate basic payment for those who cannot work. For the disabled as a class, it may be a lesser evil to establish a high guarantee and a high reduction rate.

The last group for whom serious cash transfer issues arise are those most severely handicapped. These include terminal cases, severe and profound retardation, the senile; and persons in institutions. The extent to which one wishes to make available to these persons professional judgment and placement or provide, where appropriate, cash which maximizes their individual choice is a difficult decision.

Two recent internal papers by the Social Security Administration provide an exceptional review of income transfer programs for the disabled in the United States: "Issue Analysis: Disability Protection in the United States,"[2] and "Disability and Welfare: A Review and Overview of the Data,"[3] are both key source documents in the area, and we will touch on only certain selected points here.

Each paper points out that for those who get coverage in one or more programs, benefits are fairly high, but for many the benefits are very low. They also indicate that many persons are not covered at all and, though not often saying it directly, they imply that many of the program rules have little underlying logic.

For example, in the social insurance program under Title II of the Social Security Act, if persons retired from the work force by age or disability have families, there is no special logic for treating families differently. Yet widows of workers who die while on disability are apparently treated differently than widows of workers who die after retirement. There was a time when the benefit was designed to bear some relation to wage loss. It now appears only to bear relation to the fiscal tolerance of the Congress and to whether one disabled group or another currently has a favored status.

Completely left out of such programs are persons with temporary total or partial disabilities or permanent partial disabilities (unless covered by workers' compensation or the few State temporary disability insurance plans). Some persons may be covered by Aid to Families with Dependent Children, General Assistance, or other programs if, in addition to their impairment, they meet other criteria.

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[2] Tom Moore et al., "Issue Analysis: Disability Protection in the United States," unpublished, SSA, 1973.

[3] Lawrence D. Haber, "Disability and Welfare: A Review and Overview of the Data," unpublished, SSA, 1973.

Of course, the financial catastrophe caused by a 5-month total disability, even if recovery can be complete, is significant. Workers' Compensation programs have been the subject of several studies [illegible] the past few years, and additional analysis is being started up both in the Department of Labor and the National Science Foundation. The shortcomings of Workers' Compensation programs are many, primarily in the long adversary process often necessary to achieve benefits. Despite the theory of Workers' Compensation, one wonders if a "no-fault" compensation program may be worth considering.

We will briefly describe the major programs later. Throwing political feasibility to the winds, we can make the following statement about how income maintenance might be coordinated for the disabled. If we assume that the impaired, without regard to duration, is the group in which social resources should be invested, then there is little logic underpinning the multiplicity of programs serving them at present. The most generous program in some sense is that administered by the Veterans Administration. One experienced analyst said, half jokingly (but only half) that we could get rid of much of the problem of how to get cash to the disabled if we made each disabled person an honorary veteran.

In the paper cited previously, Haber says:

> Although, from an analytical point of view, it may appear more elegant to incorporate these programs into a system of acute, extended, and prolonged incapacity programs, there are also strong reasons to argue for the singularity or uniqueness of these programs. One may question why workers injured in the course of employment are any more entitled to an adequate wage replacement than workers suffering from the natural decrements of aging or chronic disease; however, one must also accept the fact that these programs exist, and that they enjoy a certain amount of public acceptance and support. Considering the relative lack of development of wage replacement for extended sickness or illness, perhaps more planning should be directed towards the development of non-occupational extended sickness, leaving integration of the specialized work injury programs for a later date when the relative merits of the programs can be assessed. 4/

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4. Ibid., Attachment C, p. 29.

Haber raises many issues appropriate to this report. For convenience, we excerpt some of the significant statements at the end of this section. However, our exercise cannot at this point enter into all the practical issues and questions raised by such an intriguing possibility as the integration of disability, illness, and sickness programs into a coherent system, whether unitary in basic nature or not. Some of the practical considerations lie in the nature of the diagnostic technology, which is not consistent, and whether physicians are necessary for making the diagnosis (and if so, where to get the number who might be needed to operate such a program).

Other more basic philosophical issues on program purposes also exist. Some programs are predicated on culpability; some allegedly are not, as in Workers' Compensation. Some programs compensate beyond the economic effect of the disability because of a sense of gratitude, as in the veterans programs. Some compensate only for some portion of the wage loss as a proxy for a more rational way of defining income guarantees.

Some programs simply try to keep people from starving by meeting their basic "needs." A paper by Kelly pointed out the problems with trying to assess the "needs" of the disabled for income, primarily for the assessment of the subtle costs of disability in transportation, residential location, and other areas.[5]

The principle of disability payments in general is to compensate for lost earning capacity or lost income. It is, however, difficult for programs to do so consistently because of budgetary reasons, and because the economic effects of disability in individual cases often bear no relationship to the degree of physical impairment. For those programs which compensate for loss and pain, subjective decisions must be made about the value of a function to the individual,

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[5] Terence F. Kelly, "On Incorporating Differentials for the Disabled into Cash Transfer Programs," unpublished, The Urban Institute, 1974.

or compensation may have to be based on former income, unless there is a flat rate schedule for psychological and physiological impairments. Also, there are discrepancies in the impact of identical physical impairments on the general well-being and psychological condition of individuals.

The key to these programs will be the disability determination process. To the extent that this process is also key to all other components of this integrating strategy, hitting a screening criteria will open an array of benefits, including cash.

Disability and Welfare*

Acute and short-term sickness and injury are usually first seen within the work place, in relation to regular work activity. As such, sickness absence should be regulated by the employer or employer-union agreements and compensated at some level closely related to the current wage of the worker.

Policies on extended sickness and injury or temporary disability should attempt to maintain the relationship of the employee to the work place and to maximize the worker's opportunity for returning to the previous employment. Where impairment residuals develop, job restructuring and redesign, rehabilitation, restoration, and placement services should be most helpful in the early stages of incapacity.

Income maintenance obligations, while representing a limited liability, should not provide incentives for prolonging the period of work absence. This suggests that while eligibility should be relatively uncomplicated, review and followup should be extensive to insure that the worker returns to employment as soon as is reasonable and before a disability syndrome forms through a pattern of secondary gains.

Above all, a temporary disability program should act to deter self-definition of the individual as disabled until no other feasible alternatives exist. For this reason it is suggested that, in addition to the normal 6-month duration of benefits for extended illness or injury, special provisions should allow extension of benefits where diagnosis is still uncertain, possibly for as long as a year, prior to a determination of extended or chronic disability.

In both acute and extended illness, the income maintenance functions require prompt and expeditious decisionmaking, based on essentially medical

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* This section is taken Lawrence D. Haber, "Disability and Welfare: A Review and Overview of the Data."

evaluation of the condition or impairment. In the interests of equity, minimum standards should be established on a State and/or Federal level which could then be supplemented by State, local, or employer-employee agreements, contracts or legislation.

Sickness, injury, and disability support programs are intended to (1) maximize the continuation of stable work relationships, and (2) provide alternative mechanisms for maintaining economic and social relationships for those recognized as unable to meet regular role obligations because of a condition or incapacity beyond their control.

Illness, disability and disability designations, therefore, may be regarded as means of social control, which require alternative forms of behavior to provide economic and social goods and services for those unable to obtain them through the usual channels of gainful employment.

Restoration, rehabilitation, and job redesign represent efforts to normalize work relationships through recovery or adaptation of the individual or the situation. Earnings replacement and institutional care represent other forms of adaptation or normalization of the situation.

In the development of an income and rehabilitation strategy responsive to the problems of incapacity, we may view the identification process as a series of filters or gates through which the individual is progressively shunted. Initially, a limitation, disease, illness, injury, or impairment is expected to be acute or of short duration. The usual experience is that the worker will return to his place of employment within a period of a few days, with essentially the same capacities as before the illness or injury. While medical care may be appropriate, generally long-term rehabilitation guidance and counseling is not necessary unless the condition is recurrent or chronic.

The second dimension is that of extended sickness and injury, in excess of 2 to 4 weeks, involving wage losses for complications, convalescences, and conditions which may be of permanent, prolonged, or indefinite duration. In most cases, however, recovery is expected before 6 months, although residual impairment may continue.

The major problems should arise not in the initial allowance or certification of incapacity but in the prompt termination of benefits and exemptions from work. This would also suggest close contact with employers or the employment service, in stimulating and tracking return to work.

Income maintenance eligibility criteria should also emphasize the prevention or containment of impairment effects during the short-term or transitional stage of incapacity; this further suggests that evidentiary requirements should not be used in such a way as to weaken the commitment to work roles or to strengthen the psychological incentives for disability. The primary emphasis in this period should be on early vocational and referral contacts, in which the income maintenance serves the function of assisting the worker to maintain his normal economic and family obligations. The occupational criteria should, of course, be specific to one's present employment.

The third stage of the filter or screening process is the identification of prolonged or extended disability as a continuing or permanent loss or reduction of ability to perform expected work or other activities because of a chronic condition or impairment.

In addition to the temporary disability provided industrial workers, some protection is needed for workers in small firms and in casual employment, such as domestics, laborers and farm workers. Administration of this income maintenance benefit could possibly be organized through associations of employers or through a governmental insurance agency. A provision for temporary disability (extended sickness and injury) payments for those with, at best, a marginal relationship with the labor market should also identify persons and families in the early, more malleable stages of dependency. This presumably would require some form of means test to limit payments only to those lacking other adequate sources of income. State programs for General and Emergency Assistance may now fill part of this need.

We should also recognize that certain programs such as workers' and veterans' compensation and pensions fill special needs over and above that of income maintenance. Workers' compensation, for example, includes an emotional component, reflecting a perceived obligation to indemnify for the loss of physical integrity in the service of others. Veterans' programs, of course, also reflect the obligation felt by the Nation to those who served in its defense. The special objectives of workers' compensation also include sponsorship of industrial safety.

The long-term commitments of extended and chronic disability require and permit a more deliberate and extensive documentation and decisionmaking process, in which not only impairment but vocational and employability assessments may be considered. This process would take account of the residual capacities of the individual and of the economic and occupational setting.

The evidentiary and financial obligations involved in each of these levels of incapacity suggest that they appropriately belong at different levels of institutional or organizational responsibility. Short-term illness and injury is a day-to-day management concern, involving the productive operation of the plant or company, as well as an income maintenance problem for the individual. As such, the reporting requirements, supervision, and acceptance criteria

criteria should, within certain limits, be the responsibility of the employer, who should also have a responsibility for maintaining income at or around the wage level of the affected worker. Private sickness insurance and sick leave usually provides a maximum of 5 to 15 days a year.

FEDERAL TRANSFER PAYMENT PROGRAMS

The first major group of programs to be discussed are Federal transfer payments. The programs in this group are Disability Insurance, Aid to Families with Dependent Children, Black Lung, Supplementary Security Income, Veterans Administration compensation and pensions, Federal workers' compensation programs, Food Stamps, and various Federal retirement plans. We have estimated that the disability portions of these programs account for $16.7 billion or 19.7 percent of all expenditures for the disabled in 1973. Using the methods described below, we find that for FY 1973, the most recent year for relatively complete data, $13.9 billion or 83.2 percent of all Federal transfer expenditures on the disabled were to the severely disabled.[6] These and other expenditures are summed in the Appendix which follows this chapter.

1. HEW Transfer Programs

The <u>Disability Insurance</u> (DI) program provides monthly cash payments with unrestricted use to covered persons and their dependents when the covered person suffers a physical or mental impairment that has lasted, or is expected to last, 12 months or more, and prevents any substantial employment. On the basis of the requirements that gainful employment be unlikely and that the condition be expected to persist longer than 12 months, we take 100 percent of payments as benefitting the severely disabled. Inability to work because of a chronic disability appears to be a well-accepted definition of severe disability.

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[6] Our estimate of $13.9 billion from this report is for the federal expenditures only and does not include State and local government matching to those Federal programs. The figures reported in the program descriptions below will include both Federal expenditures and State and local matchings.

It could be argued that certain recipients are not severely disabled, in that they are capable of vocational rehabilitation and job placement. In 1972, for example, 6,883 persons receiving primary support under DI were reported rehabilitated by State vocational rehabilitation agencies.[7] In the context of DI, however, these rehabilitants represent only 0.4 percent of total recipients, a negligible amount. We therefore retain our estimate of 100 percent. Total DI expenditures on the severely disabled in 1973 under the DI and disabled spouse's program were $5,162,000,000.

<u>Aid to Families with Dependent Children</u> (AFDC) is a program to provide financial assistance to families with needy children, where that need is based upon incapacity, death, continued absence, or chronic unemployment of a parent. Turem has estimated that just under 15 percent of AFDC recipients are either receiving benefits because of the incapacity of at least one parent, or have an adult in the family receiving Aid to the Permanently and Totally Disabled (APTD).[8] Since eligibility for APTD implies the incapacity must have lasted over 12 months, we shall take 15 percent as our estimate of expenditures because of severe disability.

We must also assume that the mean family unit size of the severely disabled is not statistically different from the mean AFDC recipient's family unit size. This assumption is necessary since we are also assuming that 15 percent of program expenditures are received by 15 percent of the recipients. On this basis we arrive at $1,109,516,000 as an estimate of AFDC expenditures for the severely disabled.

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[7] Characteristics of Clients Rehabilited in Fiscal Years 1968-1972, Federal-State Vocational Rehabilitation Program (DHEW, SRS, 1974).

[8] J. Turem, "Adding Dependents of the Disabled to SSI: Effect on AFDC," unpublished, The Urban Institute, 1974.

"Black Lung" Benefits for Coal Miners is a program of direct payments to miners who are totally disabled by pneumonoconiosis, and to their dependents. The payment is intended to replace that portion of income lost because of their disability. With the programmatic definition again specifying "totally disabled," we take 100 percent of program expenditures as benefitting the severely disabled. Available data indicate that nearly all benefits are paid on behalf of workers who are unable to work because of, or have died from, pneumonoconiosis. The total payment to the severely disabled under the Black Lung Program in 1973 was $1,045,162,000.

Supplemental Security Income (SSI) is a program of direct payments with unrestricted use to persons over the age of 65, or blind, or totally disabled who, on the basis of their monthly income and some resources, are below a certain level of support. An estimate of the share benefitting the severely disabled can be calculated based upon the breakdown of program expenditures to the aged, the blind, and the permanently and totally disabled and the degree to which each group can be considered severely disabled. The details of the weighting procedure can be found in the following three programs. The resulting weighted average, 60 percent, was used as our estimate of Supplemental Security Income payments accruing to the severely disabled. Since SSI only began in 1974, we include the three separate program shares for 1973 in our calculations.

Aid to the Permanently and Totally Disabled (APTD) is a program of Federal grants to States for assistance to people who are substantially prevented from engaging in any useful occupation because of a permanent physical or mental impairment. Because of both the income-tested nature of this program and the requirement that the medically verifiable impairment must be judged "not likely to be improved by therapy," we have taken 100 percent of these payments as benefitting the severely disabled. For 1973, APTD payments allocable to the severely disabled were $1,447,469,000.

Old Age Assistance (OAA) is a program of Federal grants to States for assistance to people over the age of 65 who are unable to met their subsistence needs. A study by Saad Nagi reveals that 17 percent of all people over the age of 65 are strongly limited in performing their normal societal roles by physical or mental limitations.[9] Thus we use 17 percent of OAA payments as our estimate of the proportion of expenditures on the severely disabled under this program. Although we recognize the problems inherent in defining disability for those individuals outside the "normal" labor force market population--i.e., the aged, homemakers or children--we believe the 17 percent estimate to be a conservative one. Many of the recipients of OAA qualify for assistance (are below the income ceiling) because of lack of OASDHI coverage, which in turn may be partially correlated with disability-related lack of work history. Using the 17 percent figure, we estimate OAA payments to the severely disabled to be $302,793,000 in 1973.

Aid to the Blind (AB) is a program of Federal grants to States for aid to the legally blind, generally those with visual acuity of less than 20/200 in their better eye. Although some organizations use finer breakdowns of degrees of disability for the blind, we take 100 percent of the payments as benefitting the severely disabled. Given the income-tested nature of this program, we assert that nearly all (if not all) of the recipients of this program could meet an "unable to engage in any substantial employment" kind of test. Also,

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[9] Saad Z. Nagi, "R & D in Disability Policies and Programs: An Analysis of Organizations, Clients and Decisions," Columbus, Ohio, Ohio State University, Columbus, Ohio, 1971.

the Rehabilitation Services Administration considers blindness one of the sufficient conditions for severe disability. Thus $101,876,000 is our estimate of expenditures in AB on the severely disabled.

2. Non-HEW Federal Transfer Programs

Veterans Administration - Compensation for Service-Connected Disability is a program of direct payments to veterans with service-connected disabilities according to the average impairment in civilian earning capacity that can be expected to result from their particular disability. This program requires a more judgmental decision as to the percentage of its recipients who are severely disabled, since there are no income limits placed on the recipient. That is, a person could receive a 10 percent compensation for life and still be a full-time worker. It seems reasonable, all other things equal, that the higher the level of disability, the more likely a veteran will be unable to engage in labor market activities. A cursory examination of the definitions of various levels of disability leads us to consider 50 percent or more disabled as "severely disabled." From the Veterans Administration Annual Report for 1973 we calculate that 66 percent of total payments are provided to 22 percent of veterans with service-connected disabilities who are severely disabled (that is, 50 percent or more disabled). We therefore use 66 percent and 22 percent to weight the disabled expenditures and disabled recipients respectively. On this basis, we estimate $2,006,011,000 of veterans' compensation is for the severely disabled.

Veterans Administration - Pension for Nonservice-Connected Disability is a program of direct payments with unrestricted use to wartime veterans whose nonservice-connected disability is permanent, total, and prevents substantially gainful employment. Since recipients must be unable to pursue "substantially gainful employment," 100 percent is immediately suggested as the severely disabled percentage. However, a curious anomaly exists: we calculated, based upon the data from the Veterans Administration Annual Report for 1973, the following breakdown for payments to those with nonservice-connected disabilities:

Disability	Payments	Recipients
Tuberculosis	1%	1.5%
Psychosis-neurosis	25%	20.2%
General medical surgical	68%	71.0%
"No disability"	6%	7.3%

If we exclude those veterans classed under "no disability," we arrive at 92.7 percent of recipients and 94.0 percent of payments as reflecting aid to the severely disabled. Taking 94 percent of total Veterans Pension benefits paid in 1973, we estimate $1,353,055,000 as that allocable to severe disability.

We note that the 1966 Survey of Disabled Adults found that 38.8 percent of all "occupationally" and "severely" disabled veterans are "severely" disabled.[10] In this case, SDA apparently includes receivers of both "service-connected compensations" and "nonservice-connected pensions" in its universe of recipients. A weighted average of our separate estimates yields a comparable 44.9 percent of all recipients being severely disabled. Since the SDA was conducted in 1966, we could expect some differences simply on the basis of the time periods. Also, the SDA used a survey of veterans aged 18-65; our estimate is based upon expenditure data concerning all recipients.

Armed Forces Retirement is a program of monthly retirement payments to armed forces personnel, either after 20 years of service or as the result of disability. Retirement under disability can be either temporary or permanent.

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[10] Kathryn Allan and Mildred Cinsky, "General Characteristics of the Disabled Population," Social Security Bulletin, August 1972.

Data are reported separately for "total program" and "retirement under disability."[11] On the basis of these figures we estimate that 16 percent are unable to continue their career and are therefore considered severely disabled. We concede that this estimate may be a liberal one, since such retirement does not per se preclude the recipient from working full time on another occupation. However, we have been unable to obtain data relating to this phenomenon. The payment allocated to severe disability is estimated at $690,443,000.

Federal Civil Service Retirement is a program of retirement payments to Federal Civil Service employees, both after extended periods of employment and after disability if the latter is preceded by a minimum of 5 years of service. An analysis of data reported shows that 20 percent of total retirements under this program are because of service disability.[12] We have used 20 percent to weight our data for 1973 recipients and expenditures. Since it is unclear whether this program requires a disability preventing "any substantial employment" or preventing "the employee's regular employment at time of occurrence," we are using an admittedly weak allocation procedure. More information is needed to make an assessment as to how significant the error might be. The total share to the severely disabled under this program in 1972 is estimated to be $739,285,000.

Federal Employees' Compensation Act (FECA) is a program of income maintenance payments to Federal employees who are temporarily or permanently unable to work because of job-related injuries or illnesses. This program, one of three Federal workers' compensation programs, provides payments under several categories of "permanent" and "temporary" disabilities. Although an analysis of data of this

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[11] The 1975 Budget of the United States - Appendix (Office of Management and Budget, 1974).

[12] Social Security Bulletin Annual Statistical Supplement, 1972 (Social Security Administration, 1974).

particular program has not been possible, we can base our estimate on an analysis of general workers' compensation payments. The National Council on Compensation Insurance statistics for July 1974 concerning workers' compensation in 45 States allow an analysis of indemnity payments to the injured and their families. These statistics show that 43 percent of all payments and 6 percent of all cases are either "Permanent Total" or "Major" injuries. Since we expect that the money estimate is somewhat high, we use 40 percent and 6 percent respectively as our weighting factors for severe disability. We will use these percentage factors for other similar workers' compensation programs. Note the proportionally heavier cost of severe disability, in that 6 percent of the cases receive about 40 percent of the payments. For FECA this allocation formula results in an estimate of $82,579,000 in payments to the severely disabled.

<u>District of Columbia Employees' Workers' Compensation</u> is a program of income maintenance payments to employees within the District of Columbia who are temporarily or permanently unable to work because of job-related injuries or illnesses. This is one of the three Federal programs of workers' compensation, and we will use 6 percent of recipients and 40 percent of payments to determine the numbers and payments to the severely disabled. We have, however, been unable to obtain further data for this program.

<u>Longshoremen's and Harbor Workers' Act</u> is a program of compensation for disability or death from occupational injury or disease to eligible private longshoremen and harbor workers, both within the United States and overseas. In this, the third of three Federal programs of workers' compensation, we again base our weighting scheme for the severely disabled upon the National Council on Compensation Insurance data mentioned previously. Thus, 6 percent of recipients are severely disabled, and about 40 percent of total aid benefits those people. Unfortunately, we have been unable to obtain other data on this program.

Railroad Retirement is a program of unrestricted direct payments to retired railroad workers, after both extensive service and through disability. Retirement under disability is allowed after at least 10 years of service if the worker is unable to engage in any regular gainful employment because of permanent and total disability, and after 20 years of service if the worker is unable to engage in his regular railroad occupation. An analysis of data reported in the Social Security Bulletin, Annual Statistical Supplement, 1972 shows that 17 percent of all these retirement payments are linked to disability. Although we use this as our estimate of the severely disabled share, we again must note that this may be a somewhat generous estimate. Ideally, we would need to remove those "disabled retired" who, while "unable to engage in their regular railroad occupation," are able to work full time in another position. For 1973, Railroad Retirement payments for severe disability are estimated to be $417,654,000.

The Food Stamp Program seeks to improve the diets of low income households by supplementing their purchasing power toward food. In an attempt to measure the relationship between receiving food stamps and being severely disabled, we began with Saad Nagi's estimate that 21 percent of workers "unable to work" (therefore severely disabled by general standards) receive food stamps.[13] This 21 percent means approximately 1,500,000 families, or 4,500,000 recipients, since the mean family size for a severely disabled head of household is three persons.[14] Using 4,500,000 recipients, we can postulate that 36 percent of food stamp recipients are granted entitlement indirectly because of the severe disability of a family member. We therefore weight our 1973 data by this percentage, implicitly assuming that the average payment per recipient does not vary significantly

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13. Nagi, "R & D in Disability Policies."
14. Allan and Cinsky, "General Characteristics," p. 29.

between severely disabled families and nonseverely disabled families. Contrary data have not been found, although one might surmise that payments to severely disabled families would be higher than the mean payment, since families with the lowest income levels receive the highest levels of assistance. Our estimate of $798,120,000 may therefore be a lower boundary.

NONFEDERAL TRANSFER PROGRAMS

In the remainder of this section we will provide additional information on State and local transfer programs,[15] as well as some private transfer payments. Although these programs are not under the Secretary of Health, Education, and Welfare, they should not be ignored when considering plans to meet the objectives set forth by Congress. Since these programs also bear on societal treatment of the severely disabled, they must be incorporated in the formulation of future policy.

The public programs include Workers' Compensation, General Assistance, and transfers under State and Local Employees' Retirement. The private transfer payments include various insurance (whole life, Federal life, private health) and bodily injury payments. The total State-local transfer payments to the severely disabled are estimated to be $1.4 billion in 1973 and the private transfers for that group are estimated to be $3.3 billion in 1973.

1. <u>State-Local Payments</u>

All States and Puerto Rico mandate Workers' Compensation programs to provide income replacement payments for workers who are unable to work or have

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[15] These are programs which are purely State-local and do not involve Federal funds. To get total State-local expenditures benefitting the severely disabled, one would have to add to the purely State-local program expenditures the totals obtained by applying the percentages of aid allocated for the severely disabled to each of the State-local matching amounts presented under the Federal program listings.

suffered scheduled losses because of occupational injuries or illnesses. Payments are granted under temporary total disability, permanent total disability, and permanent partial disability. An analysis of data reported by the National Council on Compensation Insurance for July 1974 indicates that 6 percent of all recipient cases and 43 percent of all indemnity payments occur under "permanent total" or "major permanent partial" categories of injury. We therefore conservatively estimate the most severely disabled beneficiaries as 6 percent of all recipients, and allocate 40 percent of all transfer payments to them. We calculate these State programmatic payments to the severely disabled for 1973 as $970,400,000.

All States and many localities make payments under General Assistance to some needy people who are not eligible for assistance under Federally aided programs. Additionally, in some States payments are allowed to those whose needs are not sufficiently met by other Federal-State programs. Because of the wide degree of discretion practiced by the various States as to who receives payments under general assistance, it is difficult to assess what share of the program benefits the severely disabled. The problems are compounded by the difficulty in getting consistent data. As a conservative estimate, we have used the same weighting scheme used for another public assistance program, AFDC. Thus, we calculate that 15 percent of general assistance payments, or $111,150,000, benefitted the severely disabled in 1973.

State and Local Employees' Retirement is an estimate of payments to State and local government retired employees. Retirements are allowed under both traditional length-of-service programs and early retirement programs for disability. Statistical data are reported separately on "retirement under disability," thus allowing our calculation of the percentage of severely disabled expenditures. We must implicitly assume that persons retired "under disability" are generally "unable to engage in any substantial employment," and therefore are severely disabled in the usual sense. If significant numbers are allowed to retire only when "unable to perform their former occupation," our estimate of the severely disabled share will be overgenerous. Keeping this caveat in mind, we calculate that 8 percent of all retirements under State and local government retirement plans are benefitting the severely disabled. In 1972 this 8 percent represented $310,000,000.

2. Private Payments

Whole Life Insurance Disability Payments are income maintenance payments to people who are disabled while covered by disability riders under whole life insurance policies. We assume that such policies generally require the beneficiary to be "unable to engage in any substantial employment," and thus totally disabled by the usual definition. We therefore take 100 percent of these payments as benefitting the severely disabled; in 1973 this amounted to $316,600,000.

Federal Life Insurance Disability Payments are transfer payments to people who are disabled while covered by disability riders under Federal life insurance plans, which include U.S. Government Life, National Service Life, Veterans' Special Life, and Service-Disabled Veterans' Life. Again we assume that 100 percent of the recipients of those benefits are severely disabled in the usual labor force sense. These plans benefitted the severely disabled by $41,747,000 in 1973.

Private Health Insurance Disability Payments are transfer payments to people who are disabled while covered by disability riders under private health insurance policies. Once again we assume that 100 percent of the beneficiaries under these kinds of plans are severely disabled. Using this weighting of 100 percent, we calculate that the severely disabled benefitted by $2,127,741,000 through these plans in 1973.

Accidental Death and Disability Payments are income transfer payments to people who are disabled while covered under accidential death and disability policies. Assuming that 100 percent of these recipients are severely disabled, we calculate that this program contributed $270,725,000 to the benefit of the severely disabled in 1973.

Automobile Bodily Injury Payments are insurance payments made after litigation to injured and disabled persons as compensation for medical costs, pain, and suffering caused through automotive accidents. In estimating the most severely disabled share, we consider published data[16] which note that 9.7 percent of vehicle liability insurance payments are for "fatal" or "permanent and total disability" accidents. We therefore use 10 percent as our estimate of the share of "automobile" liability returns to the severely disabled, who benefitted by $406,499,000 in 1972 under this program.

Medical Malpractice and Miscellaneous Bodily Injury Payments are insurance payments made after litigation to injured and disabled persons as compensation for medical costs, pain, and suffering caused through medical malpractice and accidents other than automotive.

Separate estimates on levels of severity comparable to the Department of Transportation study previously cited are unavailable. We therefore use 10 percent again as our weighting factor in lieu of better information. This program benefitted the severely disabled by $86,502,000 in 1972.

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16. "Automobile Personal Injury Claims," Vol. 1 of Automobile Insurance and Compensation Study (U.S. Department of Transportation, 1970).

MEDICAL AND HEALTH CARE PROGRAMS*

Introduction

The medical and health care needs of the most severely handicapped typically begin with medical treatment and intensive rehabilitation, if available, until the patient's condition is considered "stabilized" by the physician or the patient, or until further intensive services become financially infeasible. Thereafter, routine preventive care, nutrition, hygiene, and minor medical treatment needs are similar to those of the well population.

Two conditions differ, however, in the fulfillment of medical needs for the most severely handicapped. First, they encounter unusual difficulties in meeting their needs as a result of their physical condition, their lack of financial resources, and societal attitudes toward the severely handicapped. Second, omission of care can be serious or fatal for the severely handicapped.

In addition, after initial medical stabilization special medical and health care needs also arise from the specific disabling conditions of the most severely handicapped, and from their activity or mobility limitations. The resulting needs for somewhat greater expediency, frequency, and reliability of medical and health care are traditionally met by family or long-term institutional care, but independent living is achieved by a growing minority and is viewed by many as a worthwhile goal.

Service Strategies

In looking at present medical needs of the severely handicapped, one must address the two components of these needs: restoration of the person to his/her highest level of functioning, and ongoing maintenance of general health. Restoration includes two phases. The first is acute care, an intense, inpatient medical

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* Florence Stroud prepared some of the background material used in this section.

regimen involving an array of medical, nursing, therapy, and support services. After discharge, a secondary phase begins which involves a period of outpatient visits and home care needed to continue the rehabilitation process. This secondary phase should enable the disabled person to achieve optimum functional capability and prevent physical deterioration.

Maintenance of health in general for those who are severely disabled involves attention to both acute conditions which require hospitalization, as well as to minor medical problems. Ongoing health problems may be related to the person's disability, or they may be common to all individuals, such as infections, malfunction of certain internal processes, and dental problems.

Both restoration and routine maintenance of health are carried on in a variety of settings. The conceptual model of the health care delivery system that is most convenient for the purposes of this report is one consisting of four levels including tertiary care, secondary care, primary care, and home care (which includes self-care).

Tertiary: Tertiary medical centers are regional facilities housing highly specialized personnel, such as Spinal Cord Injury Centers. Although everyone, including the severely disabled, may need the services of regional medical centers sometime in life for a severe illness, the disabled most often benefit from care in this setting at the onset of their disability or at a critical point in the deterioration of their condition. Medical rehabilitation centers provide an intense level of treatment either on a one-time basis or again on readmission for additional care and training. In addition to medical care and nursing, a variety of social services and therapies are provided for the purpose of evaluation and retraining, and to prepare patients for more independent status upon discharge.

Hospitalization in this kind of facility is extremely costly. Most severely handicapped persons will only need this level of care once.

Secondary Care: This level of care includes hospitalization in general hospitals, community psychiatric hospitals, long-term care facilities, and skilled nursing and intermediate care facilities. Treatment in these facilities includes the following:

(1) extensive diagnostic examination

(2) corrective surgery

(3) treatment of serious illnesses and disabling conditions

(4) moderate to severe emergencies

(5) long-term nursing and maintenance care

The handicapped, like the population as a whole, use these facilities routinely for the maintenance of health care. The disabled also require access to rehabilitation departments of general hospitals for ongoing therapy for their disabling condition. Although not equipped for a full range of services like rehabilitation centers, these units are adequate for followup, short-term inpatient stays to help prevent deterioration or to augment regionally provided services.

Long-term care facilities used by some severely handicapped who need 24-hour care and supervision could, if properly staffed and equipped, provide necessary shorter-term therapies for the disabled in a less expensive environment than a hospital. However, in most cases, these kinds of facilities do not provide more than the most rudimentary kinds of rehabilitative care.

Primary Care: Primary care is typified by routine office visits to a physician or dentist and can be provided in a variety of settings such as a physician's or dentist's office, an outpatient clinic, a health maintenance organization, a group practice, or a dentist's office.

Primary care is needed by the disabled both in maintaining or augmenting a rehabilitation program and for routine health care. Some conditions will necessitate more frequent physician visits than others. Age will also be a factor in determining the need for primary care. For instance, heart conditions tend to become more severe with age and are less amenable to medical control.[17] The increasing severity of disease may require additional equipment and drug costs.

Home Care (including Self-Care): Home care visits nurses, home health aides, physical therapists, attendants must also be available to the severely handicapped as needed. This type of care is especially critical to these individuals in order that they may maintain a degree of independence outside an institutional setting. Self-care generally includes acquiring the requisite information and performance skills to assume responsibility for daily personal services, such as meal planning around sound dietary principles, skin care, safety precautions, and oral hygiene.

Existing Service Patterns -- Barriers to Utilization by the Handicapped

Geography: Medical care for the severely handicapped is not always accessible. First, geography plays an important role in impeding delivery of care. Maldistribution of facilities and medical manpower means that persons residing in some locations cannot receive certain services. Table 25-1 shows, for 1968, how medical rehabilitation facilities are distributed, with some states showing only 0.001 facilities per 100,000 population (Idaho) compared to 0.66 facilities per 100,000 population (New Hampshire).

Hospitals and medical centers that provide rehabilitation services are also unevenly distributed, with some urban areas having an excess of inpatient

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[17] Coronary Heart Disease in Adults in the U.S. 1960-1962, NCHS Series 11, No. 10.

Table 25-1

Distribution of Rehabilitation Facilities[1] Among the States, 1968

State	Number of Facilities	Number per 100,000 Population (2)	State	Number of Facilities	Number per 100,000 Population (2
Alabama	5	.015	Montana	(3)	(3)
Alaska	(3)	(3)	Nebraska	3	.02
Arizona	7	.04	Nevada	1	.002
Arkansas	3	.016	New Hampshire	4	.66
California	46	.23	New Jersey	17	.024
Colorado	6	.027	New Mexico	4	.039
Connecticut	12	.04	New York	61	.334
Delaware	4	.007	North Carolina	4	.008
D.C.	4	.005	North Dakota	1	.002
Florida	8	.012	Ohio	31	.291
Georgia	9	.02	Oklahoma	3	.012
Hawaii	4	.005	Oregon	(3)	(3)
Idaho	1	.001	Pennsylvania	35	.297
Illinois	30	.27	Rhode Island	3	.003
Indiana	9	.017	South Carolina	(3)	(3)
Iowa	5	.018	South Dakota	2	.003
Kansas	3	.013	Tennessee	4	.01
Kentucky	3	.009	Texas	18	.16
Louisiana	10	.027	Utah	1	.009
Maine	2	.002	Vermont	1	.002
Maryland	9	.023	Virginia	7	.015
Massachusetts	19	.033	Washington	5	.015
Michigan	13	.015	West Virginia	3	.017
Minnesota	25	.068	Wisconsin	22	.05
Mississippi	(3)	(3)	Wyoming	2	.006
Missouri	14	.03			

1. Does not include units in general hospitals.
2. 1970 population figures.
3. No data.

Sources: 1968 Directory of Rehabilitation Facilities; Statistical Abstract of U.S., 1971.

beds whereas other areas have a real need for more beds.

The geographic maldistribution of medical personnel and facilities in the U.S. has been widely recognized. Shortages of even the most basic services, and particularly specialized rehabilitation services, exist in smaller cities, the South, and rural areas. As we have pointed out, a large number of the severely handicapped reside in such places.

Geographic constraints to medical care for the severely handicapped include the physical barriers in transportation, and architectural barriers, discussed in other parts of this report.

Institutional Barriers: The institutions which treat the medical needs of the severely handicapped pose operational barriers for adequate service to those individuals, such as lack of personnel trained in dealing with their unique medical problems. It is extremely important that certain physical and mental crises experienced by the severely disabled be handled with expert technical management. However, preventing deterioration of the disabling condition can many times be carried out by knowledgeable nursing care. Most training of medical personnel gives only cursory attention to rehabilitation medicine.

Regulations and traditional methods of handling patients sometimes impede optimum treatment and full rehabilitation of the disabled individual. Long-standing institutional rules tend to be inflexible toward the special needs of individuals with less common problems.

Cost Barriers: The high cost of medical care is felt by most Americans today, but for a person severely disabled it can especially limit access to such care. The severely handicapped, by and large, will qualify for either Medicare or Medicaid coverage to be described later.

Medicare under Part B Supplementary Medical Insurance (SMI) requires an annual deductible, after which the beneficiary is covered for 80 percent of the allowed charges. Certain prosthetic devices are also covered under this section Those enrolled in SMI must also agree to pay a monthly premium, or have this paid by a state welfare agency.[18] These charges often represent financial barriers to care, particularly in those States that do not pay the monthly premium.

For those who qualify by reason of their yearly income, Medicaid pays many medical expenses, but States' restrictions vary as to who is covered and what kinds of services are paid.

The additional "Catch-22" of Medicaid coverage is the deterrent to find employment of any consequence. Because the costs of health care for severely disabled persons are so much greater than the average, they find that only the most highly paying jobs can provide enough income to allow them to cover their own medical costs. Employment in lower paying jobs disqualifies them for Medicaid and does not provide sufficient income to cover their medical costs.

Attitudinal Barriers: Many of the people who deal with the medical needs of the most severely handicapped manifest insensitivity to their psychological and emotional needs. At the physician level, difficulties often arise over differing perceptions of the goals of care. Disabled persons may view care as helping them achieve some level of self-defined independent functioning. The physician may perceive the goals to be stabilization of the condition by prevention of complications and treatment of minor illnesses. Disagreement over goals can lead to the disabled person's withdrawal from medical care.

Program Options

Long-term strategies for the improvement of medical and health care are needed in order to resolve such issues as the geographic distribution of

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[18] Ralph Treitel, "Rehabilitation of the Disabled," Social Security Bulletin, March 1971.

services and the appropriate balance of investment in self-care, primary, secondary, and tertiary care. Medical care policy should be developed in the context of a coherent approach to the provision of other services such as housing, income support, transportation, and geographic mobility.

Before specific courses of action can be seriously proposed, further information is also required on the distribution of present and potential unmet needs, on the surplus capacity in the existing medical and health service delivery systems, and on the cost and effectiveness of alternative service models. A major factor in any long-term strategy should be greater involvement of the handicapped population in expressing their subjective needs and preferences.

In the short term, however, some incremental care improvements can be made without further study. Independent living rehabilitation is an option not all the handicapped would choose to exercise, but many who could benefit do not even consider this alternative. A number of informational and operational barriers could be reduced at small cost by more effective counseling at rehabilitation centers and medical institutions.

At little expense, the basic training of health care professionals could include education on the physical and emotional needs of the severely handicapped, and the development of greater sensitivity to the patients' goals in seeking care. Such training also could be provided to professionals already in practice.

Transportation and architectural design improvements discussed in other chapters could increase accessibility to adequate care.

FEDERAL MEDICAL PAYMENT PROGRAMS

This second major grouping of programs includes those Federal efforts to provide medical payments and services to the disabled. In this category we include Medicare, Medicaid, VA programs, CHAMPUS, Maternal and Child Health Services, Crippled Children Services, St. Elizabeth's Hospital, General Hospital and Medical Care (a group of programs described below), and Medical Vocational Rehabilitation.

Federal medical payments for the disabled have been estimated to be $16.0 billion or 18.9 percent of all expenditures on the disabled.[19] Using the allocation procedure described below, we find that $6.4 billion or 40 percent of all Federal medical transfers on the disabled are to the severely disabled.

1. HEW Medical Payment Programs

Medicare is a program of payments to cover the reasonable cost of hospitalization and medical care for eligible persons, including nonroutine services of doctors, nurses, outpatient clinics, rehabilitation facilities, and extended care facilities. Eligible persons include all those over 65. In addition, beginning in FY 1974, Medicare also covers disabled persons after 24 consecutive months of entitlement to Social Security Disability Insurance, and persons utilizing hemodialysis treatment (after an initial 3-month waiting period).

Although this is a large program both in terms of both total expenditures and recipients, data are not reported in terms that permit accurate calculation of payments to the severely disabled. As a first approximation, we have considered two facts. First, we have mentioned above the Saad Nagi estimate that 17 percent of all people above 65 years old can be considered severely disabled. Second, we could reasonably expect the severely disabled to have higher medical bills than their counterparts. Combining these facts allows us to conservatively estimate that 25 percent of Medicare expenditures benefit the severely disabled.

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[19] Again, for this page we are including just Federal funds, not Federal funds plus State and local matchings. See footnote 15.

Data problems hamper us from better estimation. For 1973, Medicare payments to the severely disabled were estimated to be $2,259,750,000.

Medicaid is a program of grants to states to provide financial assistance to meet the medical needs of certain eligible recipients. All Supplemental Security Income recipients and other "medically needy" (at each State's option) are the eligible population. Because of the discretion at the State level as to what services are allowed and what the "medical needs" of public assistance recipients are, it is difficult to analyze this program. However, we have made an estimate of the share benefitting the severely disabled, using the source of entitlement to benefits as our basis. Data obtained from the National Center for Social Statistics indicate the following breakdown of Medicaid payments by eligibility:

Eligibility	Payments (percent)	Recipients (percent)
OAA-type	38	22
AB-type	1	1
APTD-type	21	9
AFDC recipients	35	63
"Medically indigent"	5	5

We can construct a weighted average using the same conservative estimates for severely disabled shares as used before: 17 percent of OAA-type, 100 percent of AB-type, 100 percent of APTD-type, 15 percent of AFDC, and 50% of "medically indigent." The resulting estimates are that 34 percent of total payments and 24 percent of total recipients receive Medicaid assistance because of severe disability. This procedure yields an estimate of $2,924,000,000 as Medicaid expenditures on the severely disabled.

Maternal and Child Health Services and Project Grants are formula grants to support State agencies in the provision of treatment programs designed to reduce the incidence of infant mortality, to promote maternal health, and to help fund specific programs designed to reduce the occurrence of mental retardation. A wide range of routine health services, preventive medicine, and services for disabled children are encompassed in these two programs. Estimates of the portion of total expenditures that are attributable to "disability," e.g., assistance for congenital handicaps or mental retardation, are available and suggest that 9 percent is an accurate figure.[20] We have taken all of this 9 percent as benefitting the "severely disabled," although this may be somewhat of an understatement of the scope of these programs. The magnitude of aid for the severely disabled, derived using the 9 percent figure is $37,098,000 for 1973.

Crippled Children Services is a program of formula grants to provide medical and related state services to crippled children and children with crippling diseases; priority is granted to areas of economic distress. Lacking more specific information as to the range of severity in the disabled children treated, we have taken 100 percent of these payments as attributable to severe disability. Thus the full $129,800,000 of expenditures is included.

St. Elizabeth's Hospital provides treatment and care for mentally ill persons who are either beneficiaries of the Federal Government or residents of the District of Columbia. We have allocated 100 percent of these payments as benefitting the severely disabled. We base this estimate upon the presence of a mental limitation necessitating hospitalization, therefore preventing the patient's pursuing his or her normal societal role. Thus $37,721,000 is our estimate of the payments relating to severe disability.

General Hospital and Medical Care represents direct Federal payments for nonmilitary medical care through such agencies as State hospitals, community

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[20] J. Kakalik, et al., *Services for Handicapped Youth: A Program Overview*, The Rand Corporation, Report R-1220-HEW (DHEW, 1973).

hospitals, and Indian health facilities. Information concerning this program has been obtained from the Office of Research and Statistics, Social Security Administration.[21] Because of the aggregated nature of these totals, it is difficult to calculate a clear percentage related to severe disability. As these payments are heavily weighted toward long-term hospitals, such as community sanitariums or State psychiatric facilities, we have estimated that 70 percent of payments are attributable to severe disabilities. The aggregation of numerous services in this total would imply that we have at best a gross estimate. The magnitude of aid to the severely disabled, $563,290,000, should thus be considered in this light.

Medical Vocational Rehabilitation is a program of medical, surgical, and hospital treatment to remove or reduce disability. Based upon a study of the disabilities and characteristics of vocational rehabilitation clients of the Federal-State vocational rehabilitation program, we estimate that 41 percent of these payments benefit the severely disabled. (For a complete explanation, see the Vocational Rehabilitation section below.) The share of the severely disabled under Medical Vocational Rehabilitation is estimated to be $80,811,000.

2. Non-HEW Medical Payment Programs

The Veterans Administration has a program of care and treatment of eligible veterans in Veterans Administration Hospitals, other approved hospitals, and extended care facilities. The program also covers nonroutine outpatient services. Eligible in terms of descending priority are veterans with service-connected disabilities seeking treatment, whether related to their disability or not, and veterans with nonservice-connected disabilities who are unable to obtain or pay for needed medical services at private facilities. Our estimate

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[21] Data obtained from Nancy L. Worthington of that office, November 1974.

that 75 percent of these payments benefit the severely disabled is based upon a weighting scheme developed in previous research at Rutgers University.[22] For this scheme, Federal hospital discharge data were weighted by level of severity, using relevant ICDA diagnostic codes. The result was that about 75 percent of hospitalization payments were for chronic, long-term conditions. Applying this percentage to the VA medical program, we estimate that $1,915,425,000 was spent on the severely disabled in 1973.

Civilian Health and Medical Program of the Uniformed Services (CHAMPUS) is a program of payments for the dependents of both active duty and retired military personnel for hospital services and medical care related to illness and injury. Although it seems apparent that these payments are disability-related, those payments related to "severe disability" are not separately obtainable. The services covered by these payments are roughly parallel with programs like Blue Cross-Blue Shield. For this reason our estimate of the most severely disabled beneficiaries and payments is the same 16 percent for that program. (See description of Blue Cross-Blue Shield in the section on private programs.) We estimate that $64,360,000 of CHAMPUS funds are for the severely disabled.

NON-FEDERAL MEDICAL PROGRAMS

This final section provides additional information on State, local, and private medical programs. As explained in the section on non-Federal transfer payments, although these programs are not under the Secretary of Health, Education, and Welfare, but it would be arbitrary to exclude them from this discussion altogether.

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[22] Cost Burden of Disability and Effects of Federal Program Expenditures (New Brunswick, N.J.: Disability and Health Economics Research, Bureau of Economic Research, Rutgers University, 1974).

The public programs include Workers' Compensation, General Assistance, and General Hospital and Medical Care. The private medical payments include Blue Cross-Blue Shield and other forms of medical insurance coverage. The total State and local medical payments to the severely disabled are estimated to be $3.5 billion in 1973. Private medical care for the disabled is estimated to be $3.3 billion in the same year.

1. State and Local Medical Payments

Under Workers' Compensation all States and Puerto Rico mandate vendor payments for medical services for workers who are unable to work or have suffered scheduled losses because of occupational injuries or illnesses; the level of such support varies among jurisdictions. Data from the National Council on Compensation Insurance for July 1974 indicate that 30 percent of all medical payments are received by that 1 percent of cases classed under "Permanent Total" or "Major" injuries and illnesses. We therefore assign 30% of all medical payments to the benefit of the severely disabled. The fact that 1 percent of all recipients receives nearly a third of all medical payments reflects the grossly higher costs of severe disability both in terms of the longer duration of care per incidence, and the more intense nature of services provided per incidence. We estimate this program benefitted the severely disabled by $420,000,000 in 1973.

General Assistance programs provide State and local vendor payments for medical services to the needy who are not eligible for medical services under other Federal-State assistance programs. Because of State-by-State differences in the programs, little information is available as to how these vendor payments are stratified among various degrees of disability. We have weighted these expenditures by taking the same percentage used for the Federal-State Medicaid program, 34 percent. On this basis, we estimate that $36,694,000 was spent under General Assistance in 1973 for medical payments to the severely disabled.

General Hospital and Medical Care represents that portion of expenditures for general hospital services which are borne by State and local governments, such as funds to state and community hospitals. Aggregation of data again forces us to use a loose estimate that about 70 percent of these funds benefit the severely disabled. As under the Federal General Hospital and Medical Care program, these expenditures are mostly to long-term care facilities.[23] We therefore estimate that $3,030,440,000 benefitted the severely disabled under this program in 1973.

2. Private Medical Payments

Blue Cross and Independent Hospital Insurance Coverage provides payments for hospital care necessitated by illness or injury to persons covered under Blue Cross and independent group hospital insurance plans. It is estimated that 47 percent of Blue Cross and Blue Shield medical payments are made because of long-term conditions or illnesses, sometimes involving several short hospitalizations.[24] Although this 47 percent represents long-term conditions, it may not be suitable as a proxy for severity. As a conservative estimate of the share of payments that go to the severely disabled, we have taken 16 percent or .34 of the 47 percent of payments. Our weighting by .34 is based upon the general estimate[25] that 34 percent of all disabilities in the 18-64 age group

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[23] Private conversation with Nancy L. Worthington, Office of Research and Statistics, SSA; November 1974.

[24] Cost Burden of Disability.

[25] Kathryn Allan and Mildred Cinsky, General Characteristics of the Disabled Population, Report No. 19, Social Security Survey of the Disabled: 1966 (DHEW, 1972).

are "severe." An estimate of 16 percent implies that $1,231,840,000 of these payments benefitted the severely disabled in 1973.

Blue Shield and Independent Medical and Surgical Coverage provides payments for professional medical and surgical services necessitated by illness or injury to persons covered under Blue Shield and independent hospital group insurance plans. Assuming that 16 percent of these payments benefit the severely disabled (as explained before), we calculate that $621,440,000 was paid out in 1973 to their benefit by these programs.

Insurance Plans Hospital Coverage provides payments for hospital care necessitated by illness or injury to persons covered under individual hospital insurance policies. If we use our previously derived estimate of 16 percent, we can calculate that $862,720,000 of payments under these plans benefitted the severely disabled in 1973.

Insurance Plans Medical and Surgical Coverage provides payments for professional medical and surgical services necessitated by illness or injury to persons covered under individual medical and surgical insurance policies. Again using our estimate that 16 percent of such payments can conservatively be allocated to aiding the severely disabled, we estimate that $609,600,000 of payments under these plans benefitted the severely disabled in 1973.

Accidental Plans Medical and Surgical Coverage provides payments for professional medical and surgical services necessitated by illness or injury to persons covered under accidental death and disability insurance policies. If we use our standard estimate that 16 percent of these payments benefit the severely disabled, we conclude that these plans in 1972 contributed $4,524,000 to the medical well-being of the severely disabled population.

DIRECT SERVICES

A wide range of services is theoretically available to the disabled through the provisions in the Social Security Act, the Vocational Rehabilitation Act, and other Federal legislation, and as a result of the efforts of many State, local, and private initiatives. The objective of these services is to help the individual function effectively in the society. Some of these programs include Crippled Children's Services; public health programs; certain social services under the Social Security Act; Special Education; and programs for particular disability groups, e.g., the blind or retarded children. In addition, the Employment Service, Public Assistance agencies, and the Disability Insurance programs are designed by law to provide benefits and to assist State Vocational Rehabilitation agencies in providing rehabilitation services for disabled individuals.

Social services are generally linked to the receipt of income under a public assistance program, and include various activities performed for the client with the assistance of a social worker. The following definition, used by the public assistance program, is applicable to all programs providing services for the disabled. Social Services are

> those activities of social work staff and related specialists which are directed towards helping the individual client in one or more areas of functioning (i.e., economic, personal, family and social) for the purpose of achieving, to the extent possible, the objectives of stronger family life, social rehabilitation, self-care, and economic independence for each individual family or adult.

Because the categories of services are not precisely defined, there is considerable confusion in determining whether a tangible service has in fact been provided for the client. Many impaired persons, even under broad definitional interpretations, are not covered. In terms of social service expenditures, relatively little goes into programs for the aged and disabled.

Disability deprives the individual of the ability to compete equally with peers who are nondisabled. It is one of the important causes of dependency because it not only prevents the individual from working and receiving an income, thus contributing to the productivity and purchasing power of the community, but it also contributes to deterioration in basic skills, a loss of self-confidence, resulting in despondency, and the need for readjustments in family life. Traumatic amputation, the birth of a retarded child, or a stroke all create severe and major adjustment problems. Impairments are also often accompanied by financial catastrophe, leaving many disabled with less income for other than basic needs. Thus, the service components address a serious range of problems.

One of the basic needs of many disabled is to remove dependency through services which help the disabled person achieve gainful employment or self-support. The primary program which delivers these services is Vocational Rehabilitation, although the WIN program also can provide services to the impaired. Estimates vary from study to study of the number of disabled who need, want, and would benefit from services to make them capable of working in a competitive market or in their homes. However, it is certain that a similar percentage of the disabled with these characteristics are excluded from many programs or find their needs not satisfied.

HEW administers a large variety of service programs impacting on the impaired, ranging from VR and social services to nutritional programs for the aged and services for the developmentally disabled. Each has a constituency of worthy persons, but each fails to serve a significant portion of its potential clientele. Some, such as Crippled Children's Services, are highly medical and should be reexamined in light of potential health insurance plans. Others are largely oriented to custodial care (Developmental Disabilities Act, Medicaid, Social Services), and still others are limited to certain classes (e.g., VR--the employable disabled, and WIN--the AFDC Employable Disabled).

In terms of funds, the social service, VR, and educational programs carry the largest budgets outside of income maintenance, and we will mention these. The program for persons with developmental disabilities does not have a big budget, but has an organizational arrangement worth talking about. Some large special studies of the use of sheltered workshops and of the needs of the severely handicapped are in process; many questions raised about these persons will be answered soon.

FEDERAL DIRECT SERVICES

This major category of programs includes those which are mainly federally supported and provide various nonmedical services to the disabled: Vocational Rehabilitation, Social Services, Development Disabilities, certain programs for veterans and dependents, additional programs for alcohol and drug abusers, and special programs for the deaf and blind. Federal expenditures for the disabled in these programs amounted to $1.9 billion or 2 percent of all disability expenditures in 1973. Using estimates derived below, we find that $1.3 billion or 68 percent of Federal direct service program expenditures on the disabled are for the severely disabled.

1. Social Services

Various characteristics of social services have made it difficult to arrive at a precise definition of the term. Most social services are provided under the auspices of the Department of Health, Education, and Welfare, and can be identified in terms of fields and types of service. The former group includes health services (general health, mental health, and retardation); welfare services, education services; and vocational rehabilitation services. Within each field of service are particular programs which administer social services to the disabled, and these will be discussed shortly.

Although other agencies (e.g., the Department of Housing and Urban Development, the Library of Congress, the Department of Defense) provide some services in these areas, in most cases the programs are of narrow scope in terms of dollar expenditure, amount of service provided, and the number of disabled persons affected. Also, these efforts provide the same service whether the individual is disabled or not.

Social services are designed to perform the following functions: (1) counsel, guide, and inform individuals so as to enable them to use other private and public programs; (2) refer individuals to other resources in the community; (3) provide individuals with concrete and identifiable services (such as day care, homemaking, or meals-on-wheels) which will give them the opportunity to make use of other programs. These functions are performed by many programs and include the following types of social services:

1. Prevention
2. Information and referral (to identify the population in need and match individual needs and system capabilities as each changes)
3. Counseling (personal and psychological problems)
4. Medical treatment
5. Education
6. Special training (e.g., speech therapy, mobility training)
7. Vocational training and job placement
8. Sensory aids and other equipment (prosthetics, orthotics, canes, etc.)
9. Recreation and social activity
10. Personal care (e.g., visits by health workers)
11. Other activities performed by social agencies and social service workers (homemaker activities, day care, adoptions, legal aid, meals-on-wheels)

The types of service given a disabled person depend generally on the objectives of the agency administering the program. Regardless of the program's objective, the services offered vary and overlap, based on the skill of the staff. However, not all agencies provide or are concerned with every field of service, nor do they use the same method of providing the service. Also, the extent to which the services are provided varies among programs and handicaps. The two programs listed below are all under the Secretary of HEW.

<u>Social Services to Public Assistance Recipients</u> is a program of general financial aid to assist State welfare agencies in providing welfare recipients, or potential recipients, with comprehensive services designed to help them attain minimum dependence on public welfare. These services are provided under Title IVA and VI of the Social Security Act. Title VI, services to aged, blind, and disabled, will be superseded by Title XX in October 1975.

The aggregated nature of this program makes a definitive estimate of the most severely disabled percentage difficult to obtain. Congressional data[26] do give the following breakdown of categories of social services under this program:

Legal Aid to the Poor	5 Percent
Social Services to SSI Recipients	20 Percent
Social Services to AFDC Recipients	75 Percent

We assume that 15 percent of "Legal Aid to the Poor" benefits the severely disabled (a conservative estimate based upon our lowest estimate of the share of any program benefitting the severely disabled); that 60 percent of "Social Services to SSI Recipients" goes to those individuals (our estimate of the basic SSI program's severely disabled assistance); and that 15 percent of "Social

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[26] Subcommittee on Fiscal Policy of the Joint Economic Committee, <u>Income Security for Americans: Recommendations of the Public Welfare Study</u> (1974).

Services to AFDC Recipients" benefits them (our estimate of the basic AFDC program's severely disabled share). We can thus calculate a weighted average which demonstrates that 24 percent of social service expenditures benefit the severely disabled public assistance recipient. This amounted to $514,386,000 in 1973.[27] Note that this approximates the estimate of the Community Services Administration given to the Office of Handicapped Individuals (OHI) for FY 1975.

Developmental Disability Grants to States, Service Projects, and University Facilities are a group of formula grants to States, agencies, and organizations serving persons with substantial handicaps resulting from a neurological condition originating before age 18. The emphasis is on providing improvement in community institutional services for the developmentally disabled. It is estimated that funds are spent in the following distribution:[28]

Cerebral Palsy	7 Percent
Epilepsy	37 Percent
Mental Retardation	56 Percent

We must weight each of these categories to represent severe disability. Phelps[29] estimated that cerebral palsy victims can be classed into three levels of severity: 50 percent are "severe," needing custodial or home care continually; 33 percent are "moderate," needing some care; and 17 percent are "mild." We therefore take 50 percent of the cerebral palsy expenditures as benefitting

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[27] Again we have implicitly assumed that the average cost of providing social services to the severely disabled does not significantly differ from the average cost of providing said services to other public assistance recipients. The likely direction of the error in this situation is uncertain.

[28] David Pinder, "A Quantitative Study of Developmental Disability Services in Texas," unpublished thesis, University of Texas at Austin, 1973.

[29] W. Phelps, "Etiology and Diagnostic Classification of Cerebral Palsy," Proceedings of the Cerebral Palsy Institute (New York: Association for the Aid of Crippled Children, 1950).

the severely disabled. Similarly, the Epilepsy Foundation of America estimates that 50 percent of epileptics are "medically controllable," while 50 percent are at best partially controllable. Therefore, we take 50 percent of the epilepsy expenditures as benefitting the severely disabled. Finally, data from the SSA survey indicate that 78 percent of children suffering from mental retardation are considered severely disabled.[30] Thus, we consider 78 percent of the expenditures for mental retardation as benefitting the severely disabled.

Using all the above weightings, we calculate that 66 percent of all expenditures under the developmental disabilities programs benefit the severely disabled; in 1973 this amounted to $22,007,000.

2. Educational Programs

Much of the content of rehabilitation programs for the disabled is aimed at developing the physical rather than (or in addition to) the mental capacity of the individual. If the goal of rehabilitation is to provide the disabled with skills and the emotional or psychological strength to reach their highest levels of functioning, there is also a need to emphasize the importance and advantages of technical schools and institutions of higher education for those individuals capable of benefitting from them. The benefit to society of educating the disabled person to be productive and independent and to use his capabilities to the fullest is an accepted fact. Thus, to provide for equity and equality of education, the Federal Government sponsors a variety of educational programs for the disabled: vocational education, special education, and to some extent compensatory education for the disabled. The majority of these programs are

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[30] Lawrence D. Haber, Epidemiological Factors in Disability: I. Major Disabling Conditions, Report No. 6, Social Security Survey of the Disabled: 1966 (DHEW, 1969).

supervised by the Bureau of Education of the Handicapped, which provides financial assistance to educational institutions and also to programs providing training for special education personnel and research and demonstration grants. Table 2 summarizes the major Federal programs for education of the handicapped.

The Office of Education (OE) supports vocational education through the Basic Grants to States program and an assistance program to institutions of higher learning. The former provides for all aspects of vocational education including construction, staffing, and research and development. The latter program includes counseling, tutoring, curriculum development, and placement for low-income and disabled students. About 6 million persons are cited as having received some service under these OE programs in FY 1970.

Special Education programs, like Compensatory Education programs, were designed to serve the regular school population; provisions were made later for the benefit of the disabled. (They are sometimes targeted to a specific group, e.g., the blind, deaf, or mentally retarded.) Federal programs with the characteristics mentioned above include Title III, Vocational Education, and Headstart. The major burden of providing special education falls to State and local governments, which also determine how much should be spent on the program and the quality of services provided. As a result, the amount spent on special education varies across states and a large percentage of the handicapped needing education services are unserved.

a. HEW Educational Programs:

<u>Education for the Handicapped Programs</u> are those providing support or formula grants to preschools, schools, State departments of education, and universities for assistance to handicapped children through special educational programs, technical services to educators, evaluation and consultation services

Table 25-2

Summary of Federal Programs for Education of the Handicapped

Program	FY 1972 Budget ($ million)
Education	245.966
EHA-B	37.500
ESEA-Title I	
Local Education Agencies	28.000
89-313	56.381
ESEA-Title III	20.100
Headstart	33.384
Vocational Education Act	38.384
Higher Education Act	0.436
Federal Schools for Deaf	
Gallaudet College	7.888
NTI for Deaf	2.907
Kendall School	1.212
Model Secondary School	2.524
Special Target Groups	
Deaf-Blind Centers	7.500
Early Education	7.500
Learning Disabilities (EHA-G)	2.250
Instructional Support	57.906
Teaching Personnel	
EHA-D	35.145
Education Professions Development Act	6.100
Regional Resource Centers (EHA-C)	3.550
Media	
EHA-F	10.500
American Printing House for the Blind	1.580
Library of Congress	1.031
Research	10.994
Research (EHA-E)	10.994
TOTAL	314.866

Source: Kakalik, et al., Service for Handicapped Youth: A Program Overview, The Rand Corporation, Report R-1220-HEW (DHEW, 1973).

for deaf-blind children, and public information services. We take 100 percent of these expenditures as benefitting the severely disabled; a total of $81,152,000 was spent in 1973 for the benefit of severely disabled youth through these programs.

Educationally Deprived Children is a program of financial aid to States to extend and improve their comprehensive educational programs for the benefit of educationally deprived children enrolled in State-supported or operated schools. Many factors enter into an assessment of "educationally deprived children." Fortunately, data are reported separately for assistance to physically or mentally handicapped children under this program.[31] Of the $1,809,000,000 spent for educationally deprived children in 1973, $90,450,000 or 5 percent was spent on the handicapped. We assume that this entire 5 percent was to the benefit of the severely disabled.

Gallaudet College is an educational institution providing undergraduate higher education for the deaf, adult education, and graduate training in the field of deafness. The school also operates model elementary and secondary schools for the deaf children of Washington, D.C. We estimate that 100 percent of the Federal payments to this school can be considered to benefit the severely disabled because of the "special education" nature of this college. We therefore take $13,429,000 as the share for the severely disabled aid.

b. Non-HEW Federal Programs:

American Printing House for the Blind is a nonprofit institute created to supply materials and equipment for the education of the blind and visually impaired. Some organizations assess different degrees of severity to different blind persons, based upon the various levels of functional adaptation they

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[31] U.S. Office of Management and Budget, Catalogue of Federal Domestic Assistance (1974).

possess. Ideally we would use such stratification to develop our estimates of the percentage of severely disabled beneficiaries involved in this program, but we have been unable to find or create an applicable system. As a first approximation, we have taken 100 percent as the most severely disabled share. In 1973 this program added $1,697,000 to the total expenditures for the severely disabled.

<u>Books for the Blind and Physically Handicapped</u> is a program of library services to blind and physically handicapped residents of the United States, including braille books, talking books, and talking book machines. Although administered through regional libraries, the program is coordinated and directed by the Library of Congress. We also take 100 percent of expenditures under this program, or $8,874,000, as related to the severely disabled.

<u>National Technical Institute for the Deaf</u> is a residential facility for postsecondary technical training and education of the deaf. We again consider 100 percent of these expenditures as benefitting the severely disabled because of the "special education" nature of this program. Thus, $7,223,000 was spent by the Federal Government on the severely disabled through this program in 1973.

3. Alcohol and Drug Abuse Programs

The following four programs are all under the Secretary of HEW.

<u>The National Institute of Health Drug Abuse Community Service Programs</u> are for support to community centers designed to reach, treat, and rehabilitate narcotic addicts, drug abusers, and drug dependent persons. We estimate, based on our standard weighting of drug addiction, that 50 percent of these payments benefit the severely disabled. Thus, $54,137,000 was spent for the most severely disabled in 1973.

Drug Abuse Formula Grants provide financial support to assist the states in planning, establishing, implementing, and coordinating projects to develop more efficient drug abuse prevention campaigns. Utilizing our standard estimate that 50 percent of all "mental afflictions" are severe disabilities (this as a proxy for addiction), we calculate that 50 percent of $8,250,000 can be allocated as assistance to the severely disabled in 1973.

National Institute of Healt[illegible]ohol Abuse Grants are provided to help States plan, establish, maintain, coordinate, and evaluate effective prevention, treatment, and rehabilitation projects to deal with alcohol abuse. Again we use our standard weighting scheme for alcohol or drug abuse, and assert that 50 percent of the expenditures under this program benefit the severely disabled. Thus, $16,500,000 is attributable to severe disability in 1973 through alcohol abuse grants.

National Institute of Health, Scientific Communication and Public Education is a program to insure the fullest possible dissemination of information on alcohol, drug abuse, and mental health through full-scale programs and educational activities. This program has a different emphasis than the previously considered NIH alcohol and drug abuse programs. Where those programs emphasized the treatment aspect of drug abuse, this program is slanted toward the communication of information on drug abuse to the scientific community and the general public. However, we have been unable to determine a more accurate weighting scheme than the 50 percent estimate used for the other drug or alcohol abuse programs. We therefore estimate that $4,622,000 of this program's total expenditures in 1973 benefitted the severely disabled.

4. Armed Forces Programs

Veterans Administration Vocational Rehabilitation Service is a program of counseling, training, and loans for the purpose of restoring employability to the veteran with a service-connected disability, to the extent consistent with the degree of impairment. Using our standard vocational rehabilitation weighting scheme noted above, we estimated that 41 percent or $29,501,000 of these expenditures in 1973 benefitted the severely disabled.

Veterans Administration Alcohol and Drug Dependency Program provides medical, social, and vocational rehabilitation services to the alcohol or drug-dependent veteran. It is very difficult to make generalized statements regarding the share of drug or alcohol rehabilitation program recipients who are severely disabled. In the light of conflicting opinions, we have used 50 percent as our factor, based on the standard estimate that 50 percent of all "mental" disabilities are severe. We realize that this is a very uncertain estimation technique, especially given the physical aspect of addiction. Using a 50 percent weighting, we estimate that $23,288,000 was spent in 1973 for the severely disabled.

Specially Adapted Housing for Disabled Veterans is a program of payments by the VA to assist totally disabled veterans to acquire suitable housing, fixtures, and facilities necessitated by the nature of their disabilities. The emphasis is on allowing the paraplegic to develop as much self-sufficiency as possible. Given the orientation of this program to assisting "totally disabled veterans," we assume that 100% of total payments benefit the severely disabled. In 1973 this amounted to $12,891,000.

Specially Adapted Autos for Disabled Veterans is a program of direct payments by the VA to severely disabled veterans to assist in the purchase of suitably adapted automobiles, or to pay for the adaptation of a standard vehicle, consistent with the veteran's limitations. Again, we take 100 percent of these expenditures as aiding the severely disabled. We recognize, as in various vocational rehabilitation programs, that a person benefitting from this program may no longer be considered severely disabled after being helped. However, we must initially consider the programmatic constraints and take 100 percent as our weighting factor. We thus conclude that $6,809,000 benefitted the severely disabled in 1973.

Civilian Health and Medical Program of the Uniformed Services - Program for the Handicapped provides training and vocational rehabilitation for the handicapped and retarded dependents of active duty military personnel. For benefits to be authorized under this program, a separate program of the CHAMPUS administration, the dependent's diagnosis must represent "moderate or severe mental retardation or a serious physical handicapping condition." In addition, "minimal brain dysfunction and related disorders are considered to be serious physical handicapping conditions to engage in pursuits along with his peers."[32] Given these programmatic guidelines, we take 100 percent as our weighting factor. We therefore estimate that $30,410,000 was spent in 1973 for the benefit of the severely handicapped under this part of the CHAMPUS program.

United States Soldiers' and Airmen's Home is a largely self-supporting permanent residence for the assistance and care of elderly, invalid, or disabled soldiers of the Army or Air Force who served at least 20 years or suffered service-connected disability that renders wage-earning impossible. If we could ascertain the distribution of residents between the three categories, a more accurate estimate of the percentage of severely disabled residents could be made; however, data limitations prevent this. We have therefore taken 100 percent of these expenditures, or $12,226,000, as benefitting the severely disabled.

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[32] CHAMPUS Fact Sheet, FS32-1/30 (Denver, Colo.: CHAMPUS, 1971).

SUMMARY

~~Of~~ the programs we have identified as benefitting the disabled, nearly all also provide some benefits to the severely disabled. The exceptions are programs of assistance that are temporary or short-term in nature, such as formal sick leave plans or State temporary disability insurance. The majority of disability programs do provide help to the severely disabled in terms of income maintenance, vocational rehabilitation, medical care, and other services.

We shall now attempt to examine how both Vocational Rehabilitation and other Federal programs benefit the severely disabled. An examination of the program descriptions above indicates that, besides providing some vocational rehabilitation, programs assist the severely disabled with income transfers, various medical services and payments, and other types of service projects. By aggregating certain categories of payments we can better determine the relative assistance to the severely disabled.

Table 25-3 is a summary of federally supported assistance for the vocational rehabilitation of the severely disabled. The four programs (basic support, service project activities, DI recipients, and medical-vocational rehabilitation) administered by the Department of Health, Education, and Welfare account for $456 million, while the Veterans Administration program provides another $30 million. These five major vocational rehabilitation programs provide nearly half a billion dollars worth of services to the severely disabled, 80 percent of which is from Federal funds.

Thus, given our program-based attempt to identify the severely disabled, we can estimate that nearly half a billion dollars is currently spent for their vocational rehabilitation. Assuming that the SSA 1966 survey estimate (3.7 million people between ages 18 and 64 unable to work) has not drastically changed in the intervening 7 years, we can estimate that the average per capita annual expenditure on vocational rehabilitation in 1973 for the severely disabled under these 3 programs was a bit over $130.

Table 25-3

Program Expenditures for the Severely Disabled
Vocational Rehabilitation Programs
($ 000)

	Federal Funds	State & Local Matching	Total
DHEW	374,222	82,252	456,474
Veterans' Administration	29,501	-0-	29,501
Total	403,723	82,252	485,975

Vocational rehabilitation is only one of the services through which Federal programs assist the severely disabled. Table 25-4 presents a summary of all other program support to the severely disabled under "transfer payments," "medical payments," and "other direct service payments." A total of $24.4 billion was attributable to the severely disabled under these federal programs. Just over $3 billion of this money is from State-local matching funds.

For budgetary purposes it is perhaps more useful to view only Federal expenditures under these other support programs, rather than Federal expenditures plus state and local government matchings. Table 25-5 presents these data for analysis. Federal payments under the three categories totaled $21.2 billion. If we include Federal payments under vocational rehabilitation programs, the total becomes $21.6 billion. We therefore conclude that $21.6 billion of Federal funds benefitted the severely disabled in 1973, through both vocational rehabilitation

Table 25-4

Program Expenditures for the Severely Disabled:[1]
Other Federal Support Programs
($ 000)

	Transfer Payments	Medical Payments	Other Direct Service Payments	Total
DHEW	9,259,816	5,913,938	927,736	16,101,490
Veterans Adminis.	3,359,066	1,915,425	69,955	5,344,446
Misc. Federal Agencies	2,728,081	102,081	88,674	2,918,836
Total	15,346,963	7,931,444	1,086,365	24,364,772

1. Federal expenditures plus mandatory State and local government matchings.

Table 25-5

Federal Expenditures for the Severely Disabled:[2]
Other Federal Support Programs
($ 000)

	Transfer Payments	Medical Payments	Other Direct Service Payments	Total
DHEW	7,798,115	4,403,169	738,561	12,939,845
Veterans Adminis.	3,359,066	1,915,425	69,955	5,344,446
Misc. Federal Agencies	2,728,081	102,081	82,357	2,912,519
Total	13,885,262	6,420,675	890,873	21,196,810

2. Federal expenditures only.

and other programs. This amount represents 63 percent of all Federal expenditures for the disabled.[33]

Programs administered by DHEW provided 61 percent of these payments, VA programs provided another 25 percent, while the remaining 14 percent of payments were under the jurisdiction of other Federal agencies.

Given the survey results noted earlier, this result would appear to indicate that expenditures on the severely disabled are somewhat greater than their proportion of the total number of disabled might indicate. If one believed that the needs of the severely disabled were significantly greater than the non-severely disabled, then it would appear that on an aggregate basis the current program provides a relatively adequate level of support for the former group. Two aspects of this conclusion need further elaboration. First, we have noted the relative nature of the comparison. It may well be that the overall support for the disabled and severely disabled, given their needs and social preferences, is inadequate. Second, while noting the gross level of program expenditures related to the severely disabled, we are unable, without survey data, to provide the necessary information to judge how equitable the distribution of support is.

We can get some notion of the differential treatment accorded the severely disabled if we examine the percentage distribution of payments to and for the disabled under four different types of assistance: transfer, medical care, direct services (excluding vocational rehabilitation), and vocational rehabilitation.

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33. In other work we have estimated that $33.5 billion of federal expenditures benefit the disabled; however, this becomes $34.4 billion if allowances are made for Food Stamp assistance to the disabled. See An Evaluation of the Structure and Function of Disability Programs, Progress Report No. 2 (New Brunswick, N.J.: Disability and Health Economics Research, Bureau of Economic Research, Rutgers University, 1975).

	Transfer Payments	Medical Payments	Direct Services	Vocational Rehabilitation	Total
Severely Disabled	64%	30%	4%	2%	100%
Non-Severely Disabled	21%	73%	2%	4%	100%

It is evident that the majority of aid to the severely disabled is in the form of income support or income maintenance. There are probably two major causes for this pattern. One is that since this group of people have shown an inability to enjoy "substantial gainful employment," they suffer poverty levels of income. Second, given the severe nature of the disability in these cases, there is probably a belief that various service expenditures are unlikely to have a significant impact.

Nearly all of the remaining aid is for medical care, probably reflecting large medical bills and an inability to pay for these services. Note that the non-severely disabled have 73 percent of their payments under medical assistance, with most of the balance accruing as transfer payments.

The differences in the benefit packages provided the severely disabled compared to the non-severely disabled is even more striking if viewed from an alternative perspective. Below we calculate the share of payments received by each group under each type of assistance.

	Transfer Payments	Medical Payments	Direct Services	Vocational Rehabilitation
Severely Disabled	83%	40%	75%	44%
Non-Severely Disabled	17%	60%	25%	56%
All Disabled	100%	100%	100%	100%

we note that 83 percent of all Federal transfer payments to the disabled go to the severely disabled; given their inability to work, attend school or engage in similar "normal" activity, this does not seem unreasonable. The fact that only 40 percent of federal medical payments to the disabled go to the severely disabled is harder to explain. One might expect that their medical costs would be higher than the costs of the non-severely disabled. Perhaps the relative inability of medical services to correct permanent and severe impairments that lead to severe disability or the medically stable nature of impairments which lead to severe disability are significant factors in determining this apparent low level of medical support for the severely disabled. Federal direct services to the severely disabled account for 75 percent of all federal direct services to the disabled. This most probably reflects a higher priority to the more expensive needs of the severely disabled. The severely disabled also appear to be receiving a large share of the funds allocated to vocational rehabilitation. Again on this basis alone, it is most difficult to tell how effective or adequate these expenditures are. Perhaps a detailed analysis of those individuals in the R-300 file who meet RSA's severe disability criteria could be helpful.

In general, a better breakdown of the numbers of severely and non-severely disabled would be a great help in analyzing program data. But it certainly appears that less than 40 percent of the disabled are severely disabled, leading one to conclude that the severely disabled do get a relatively large part of the money allocated to aid the disabled population. As a word of caution, we must note that these distributional figures are obviously influenced by our decisions regarding which individual programs are included, and what percentage of total expenditures under a given program are allocable to the severely disabled. We feel that our universe of programs is fairly sound and complete.

We also feel that our weighting schemes are a solid attempt at handling the complex definitional question of what constitutes "severe disability." We are confident of our conclusion that the severely disabled as defined through program regulations, information, and eligibility criteria receive a large share of assistance through present Federal programs, and that the mix of aid they get varies from that of the nonseverely disabled.

Gaps in the provision of transfer, medical care, and services to the severely disabled are more difficult to assess under this kind of analysis. While we have been able to estimate the numbers of severely disabled who do benefit under various disability assistance programs, we are unable to reach any conclusion about those severely disabled who do not. We have little information on those persons who are not receiving services. The necessary complementary analysis requires a survey approach so that it would be possible to estimate the number of disabled meeting a predetermined definition of severity, their needs that are being met and those that are not met.

Conclusions

In this report we have estimated that at the Federal level approximately $21.6 billion was being spent in 1973 to assist the 10 million or so severely handicapped, or approximately $2,200 per severely disabled individual. Until the goals of these expenditures in terms of reduction in poverty, rehabilitation, medical care, and levels of provision of other services are carefully spelled out and a detailed program-oriented survey of the severely disabled is done, we will not know how efficiently, equitably, or adequately this money is being spent. For example, is the nearly $14 billion in Federal transfers being spent to reduce poverty or replace lost wages of the severely disabled, and to what extent is either outcome being achieved? Are the possible vocational goals of the disabled being overlooked, or have we realistically considered the costs and benefits of such programs and made an efficiency decision after remaining bound to an equity (somehow defined) constraint? Are the funds for the over 2 million disabled workers under DI being correctly allocated to transfers and vocational rehabilitation for DI recipients?

The answers to these questions are difficult, if not impossible, to produce. We feel that this chapter describes the current set of programs and describes what they do and for whom. Additional analysis is necessary; better data are essential. Specific goals are required for developing programs to deal with the consequences of and appropriate social responses to severe disability among our citizens.

APPENDIX

Most Severely Disabled - Expenditures

Data are for FY 1973 unless
otherwise indicated: (A)

TRANSFER PAYMENTS

Federal - HEW

Program	Agency	Expenditures - All			Expenditures - Severely Disabled		Number of Severely Disabled Beneficiaries
		Federal ($000)	State and Local ($000)	Total ($000)	Amount ($000)	Percent of "All"	
Social Security Admin. DI and Disabled Spouses Benefits	SSA,HEW	5,253,000	-0-	5,253,000	5,253,000	100%	3,341,000
Aid to Families with Dependent Children (AFDC)	SSA,HEW	3,328,550	4,068,226	7,396,776	1,109,516	15%	1,500,000
"Black Lung" Benefits for Coal Miners	SSA,HEW	1,045,162	-0-	1,045,162	1,045,162	100%	302,000
Supplemental Security Income (SSI) 1/	SSA,HEW	1,815,413	697,579	2,512,992	1,507,795	60%	1,654,052
Aid to the Permanently and Totally Disabled (APTD) 2/	SSA,HEW	766,000	681,469	1,447,469	1,447,469	100%	1,164,000
Old Age Assistance (OAA) 2/	SSA,HEW	1,051,000	730,136	1,781,136	302,793	17%	326,807
Aid to the Blind (AB) 2/	SSA,HEW	56,000	45,876	101,876	101,876	100%	78,000

TRANSFER PAYMENTS (CONT'D)

Federal - Non-HEW

		Expenditures - All			Expenditures - Severely Disabled		
Program	Agency	Federal ($000)	State and Local ($000)	Total ($000)	Amount ($000)	Percent of "All"	Number of Severely Disabled Beneficiaries
Veterans Administration Compensation for Service Connected Disability	Dept. of Vet. Benefits, V.A.	3,039,411	-0-	3,039,411	2,006,011	66%	484,660
Veterans Administration - Pension for Nonservice Connected Disability	Dept. of Vet. Benefits, V.A.	1,439,420	-0-	1,439,420	1,353,055	94%	976,131
Armed Forces Retirement	Retired Mil. Per. DoD	4,392,218	-0-	4,392,218	690,443	16%	157,576
Federal Civil Service Retirement (A)	Civil Service Comm.	3,696,427	-0-	3,696,427	739,285	20%	255,400
Federal Employees Comp. Act (FECA)	Employment Standards Adm., DoL	206,449	-0-	206,449	82,579	40%	(nest)
D.C. Employees' Workers' Compensation	Office of W.C., DoL	(nest)	-0-	(nest)	(nest)	40%	(nest)
Longshoremen's and Harbor Workers' Act	Office of W.C., DoL	(nest)	-0-	(nest)	(nest)	40%	(nest)

TRANSFER PAYMENTS (CONT'D)

Federal - Non-HEW (Cont'd)

		Expenditures - All			Expenditures - Severely Disabled		
Program	Agency	Federal ($000)	State and Local ($000)	Total ($000)	Amount ($000)	Percent of "All"	Number of Severely Disabled Beneficiaries
Railroad Retirement	Railroad Retirement Board	2,456,791	-0-	2,456,791	417,654	17%	95,200
Food Stamps	Food and Nutrition Serv. of Dept. of Agriculture	2,217,000	-0-	2,217,000	798,120	36%	4,473,000

TRANSFER PAYMENTS (CONT'D)

State and Local

Program	Agency	Expenditures - All Federal ($000)	 State and Local ($000)	 Total ($000)	Expenditures - Severely Disabled Amount ($000)	 Percent of "All"	Number of Severely Disabled Beneficiaries
Workers' Compensation	(napl)	-0-	2,426,000	2,426,000	970,400	40%	(nest)
General Assistance (GA)	(napl)	-0-	741,000	741,000	111,150	.15%	(nest)
State and Local Employees' Retirement (A)	(napl)	-0-	4,015,000	4,015,000	310,000	8%	92,000

TRANSFER PAYMENTS (CONT'D)

Private

Program	Agency	Expenditures - All Federal ($000)	State and Local ($000)	Total ($000)	Expenditures - Severely Disabled Amount ($000)	Percent of "All"	Number of Severely Disabled Beneficiaries
Whole Life Insurance Disability Payments	(napl)	-0-	-0-	316,600	316,600	100%	(nest)
Federal Life Insurance Disability Payments	(napl)	-0-	-0-	41,747	41,747	100%	(nest)
Private Health Insurance Disability Payments	(napl)	-0-	-0-	2,127,741	2,127,741	100%	(nest)
Accidental Death and Disability Payments	(napl)	-0-	-0-	270,725	270,725	100%	(nest)
Automobile Bodily Injury (A)	(napl)	-0-	-0-	4,064,991	406,499	10%	(nest)
Malpractice and Miscellaneous Bodily Injury (A)	(napl)	-0-	-0-	865,019	86,502	10%	(nest)

MEDICAL PAYMENTS

Federal - HEW

Program	Agency	Expenditures - All Federal ($000)	 State and Local ($000)	 Total ($000)	Expenditures - Severely Disabled Amount ($000)	 Percent of "All"	Number of Severely Disabled Beneficiaries
Medicare (HI & SMI)	SSA,HEW	9,039,000	-0-	9,039,000	2,259,750	25%	5,300,000
Medicaid (MA)	SRS,HEW	4,402,000	4,198,000	8,600,000	2,924,000	34%	5,507,580
Maternal and Child Health Services and Project Grants	Health Services Admin., HEW	206,100	206,100	412,200	37,098	9%	(nest)
Crippled Children's Services	Health Services Admin., HEW	64,900	64,900	129,800	129,800	100%	442,500
St. Elizabeth's Hospital	District of Columbia Adm., Wash., D.C.	37,721	-0-	37,721	37,721	100%	9,800
General Hospital and Medical Care	HEW	804,700	-0-	804,700	563,290	70%	(nest)
Medical Vocational Rehabilitation	SRS,HEW	157,700	39,400	197,100	80,811	41%	(nest)

MEDICAL PAYMENTS (CONT'D)

Federal - Non-HEW

Program	Agency	Expenditures - All Federal ($000)	State and Local ($000)	Total ($000)	Expenditures - Severely Disabled Amount ($000)	Percent of "All"	Number of Severely Disabled Beneficiaries
Veterans Administration Hospitals	Dept. of Medicine & Surgery, VA	2,553,900	-0-	2,553,900	1,915,425	75%	812,059
Civilian Health and Medical Program of the Uniformed Services (CHAMPUS)	OCHAMPUS, Denver, Colo.	402,256	-0-	402,256	64,360	16%	133,796

MEDICAL PAYMENTS (CONT'D)

State and Local

		Expenditures - All			Expenditures - Severely Disabled		
Program	Agency	Federal ($000)	State and Local ($000)	Total ($000)	Amount ($000)	Percent of "All"	Number of Severely Disabled Beneficiaries
Workers' Compensation	(napl)	-0-	1,400,000	1,400,000	420,000	30%	(nest)
General Assistance (GA)	(napl)	-0-	107,924	107,924	36,694	34%	(nest)
General Hospital and Medical Care	(napl)	-0-	4,329,200	4,329,200	3,030,440	70%	(nest)

MEDICAL PAYMENTS (CONT'D)

Private

Program	Agency	Expenditures - All Federal ($000)	 State and Local ($000)	 Total ($000)	Expenditures - Severely Disabled Amount ($000)	 Percent of "All"	Number of Severely Disabled Beneficiaries
Blue Cross and Independent Hospital Coverage	(napl)	-0-	-0-	7,699,000	1,231,840	16%	(nest)
Blue Shield and Independent Medical and Surgical Coverage	(napl)	-0-	-0-	3,884,000	621,440	16%	(nest)
Insurance Plans Hospital Coverage	(napl)	-0-	-0-	5,392,000	862,720	16%	(nest)
Insurance Plans Medical and Surgical Coverage	(napl)	-0-	-0-	3,810,000	609,600	16%	(nest)
Accidental Plans Medical and Surgical Coverage	(napl)	-0-	-0-	28,281	4,524	16%	(nest)

SERVICES

Federal - HEW

	Program	Agency	Expenditures - All Federal ($000)	State and Local ($000)	Total ($000)	Expenditures - Severely Disabled Amount ($000)	Percent of "All"	Number of Severely Disabled Beneficiaries
Social Services	Social Services to Public Assistance Recipients	SRS,HEW	1,607,455	535,818	2,143,273	514,386	24%	(nest)
	Developmental Disabilities Grants and Projects	SRS,HEW	28,258	5,086	33,344	22,007	66%	(nest)
Education	Education for the Handicapped Programs	OE,HEW	79,819	1,333	81,152	81,152	100%	(nest)
	Educationally Deprived Children	OE,HEW	1,809,000	-0-	1,809,000	90,450	5%	118,500
	Gallaudet College	Gallaudet College	13,429	-0-	13,429	13,429	100%	1,039

SERVICES (CONT'D)

Federal - HEW (Cont'd)

Alcohol and Drug Abuse

Program	Agency	Expenditures - All			Expenditures - Severely Disabled		Number of Severely Disabled Beneficiaries
		Federal ($000)	State and Local ($000)	Total ($000)	Amount ($000)	Percent of "All"	
National Institute of Health - Drug Abuse Community Serv. Programs	Alcohol, Drug Abuse & Mental Health Adm., HEW	108,275	-0-	108,275	54,137	50%	(nest)
Drug Abuse Formula Grants	Alcohol, Drug Abuse & Mental Health Adm., HEW	15,000	1,500	16,500	8,250	50%	(nest)
National Institute of Health - Alcohol Abuse Grants	Alcohol, Drug Abuse & Mental Health Adm., HEW	30,000	3,000	33,000	16,500	50%	(nest)
National Institute of Health - Scientific Communication & Public Education	Alcohol, Drug Abuse & Mental Health Adm., HEW	9,243	-0-	9,243	4,622	50%	(nest)

SERVICES (CONT'D)

Federal - Non-HEW

	Program	Agency	Expenditures - All Federal ($000)	State and Local ($000)	Total ($000)	Expenditures - Severely Disabled Amount ($000)	Percent of "All"	Number of Severely Disabled Beneficiaries
Education	American Printing House for the Blind	Amer. Prtg. House for the Blind, Louisville, Kentucky	1,697	-0-	1,697	1,697	100%	21,846
	Books for the Blind and Physically Handicapped	Library of Congress, Wash., D.C.	8,874	-0-	8,874	8,874	100%	383,000
	National Technical Institute for the Deaf	Nat. Tech. Inst. for the Deaf, Rochester, NY	7,223	-0-	7,223	7,223	100%	600
Armed Forces	Veterans Administration Vocational Rehabilitation Service	Dept. of Veterans Benefits, VA	71,956	-0-	71,956	29,501	41%	12,114
	Veterans Administration Alcohol and Drug Dependency	Dept. of Veterans Benefits, VA	46,576	-0-	46,576	23,288	50%	(nest)

SERVICES (CONT'D)

Federal - Non-HEW (Cont'd)

			Expenditures - All			Expenditures - Severely Disabled		
	Program	Agency	Federal ($000)	State and Local ($000)	Total ($000)	Amount ($000)	Percent of "All"	Number of Severely Disabled Beneficiaries
Armed Forces	Specially Adapted Housing for Disabled Veterans	Dept. of Veterans Benefits, VA	12,891	-0-	12,891	12,891	100%	665
	Specially Adapted Automobiles for Disabled Veterans	Dept. of Veterans Benefits, VA	6,809	-0-	6,809	6,809	100%	6,401
	Civilian Health and Medical Program of the Uniformed Services - Program for the Handicapped (CHAMPUS-PH)	OCHAMPUS, Denver, Colorado	30,410	-0-	30,410	30,410	100%	62,946
	U.S. Soldiers' and Airmen's Home	U.S. Soldiers' and Airmen's Home, Wash., D.C.	12,226	-0-	12,226	12,226	100%	(nest)
	GRAND TOTAL		50,514,846	23,599,968	102,614,918[1]	35,755,692		

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[1] Includes private expenditures.

Note: The totals in this section do not necessarily add up to those given in the text since, for this table, VR programs and several of the smaller programs were omitted.

FOOTNOTES

nest = not estimated

napl = not applicable

A = data are FY 1972

1. This program began January 1, 1974, and replaces the categorical programs of APTD, OAA and AB. It is included here for illustrative purposes only. The data are for the last six months of FY 1974, and do not represent any projection of a full year's expenditures; these numbers would not be included in any estimate of total expenditures for the severely disabled under existing programs in 1973.

2. This program ended January 1, 1974, and its recipients were transferred to the Supplemental Security Income program. It is included here since it was funded in 1973; this sum is therefore included in our totals.

Chapter 26

DISINCENTIVES IN INCOME TRANSFERS

A recurrent theme in our investigation of the severely handicapped is their consistently lower incomes and the fact that public income transfers constitute a major source of their income. Problems with these programs clearly are felt throughout the policies designed to rehabilitate this group. For the most part, the transfer programs tend to group their benefits to those who are eligible. For example, an eligible recipient of Supplemental Security Income might also be receiving some Disability Insurance, health coverage under Medicaid and/or Medicare, Food Stamps, Social Services and Vocational Rehabilitation. Most of the severely handicapped, however, do not benefit in this fashion. Those who do have a public income transfer, however, almost always have at least some health benefit under Medicare or Medicaid. Most of those in institutions receiving public institutional care are covered under Medicaid.

In this chapter, the structure of these programs with respect to their incentives to encourage individuals to work are briefly examined. We point out that there have been few empirical studies of the effects of such incentives, although many individuals reported them.

The essence of the incentive problem can be illustrated by a blind beneficiary of Social Security Disability Benefits. Counting his ability to work and earn a little bit, and the lack of a means test so that his wife's earnings were not considered, the combined value of his income and medical benefits was such that he would have to earn an income,after tax and expenses, of over $7,000 to just equal his present benefits. A rough estimate of his before tax and expenses earnings level would be about $10,000. Thus, in exchange for working full time a full year at about $5 per hour, he would be no better off than not working at all now.

An estimate of the gross earnings of a quadriplegic in need of attendant care would be $18,000 to cover his expenses compared to the value of his currently received public care. While these are individual costs of unique individuals they point out the nature of the problem with the current programs.

In both Social Security Disability Insurance (DI) and in Supplemental Security Income (SSI), the definition of disability is related to ability to perform substantial gainful activity. This is defined as earnings of from $130 to 200 per month, regardless of the extent of the impairment or the need for supporting medical and other services (the blind are exempt from this limitation). In each of these programs there is a mandatory requirement to refer an individual to VR whenever feasible; i.e., when the individual is expected to be able to earn enough income after rehabilitation to go off the rolls. Yet it is clear that there are significant incentives for many of these severely handicapped persons to appear as non-employable in face of a high unemployment rate and income which may be below what they have from the public program. Indeed, if a male head of household can demonstrate disability sufficient for SSI, his family can often be eligible for Assistance to Families with Dependent Children (AFDC), the cumulative effect of which may be income and benefits to the total family far in excess of what could be earned.

The award of income transfers often has positive effects on individuals with severe impairments who cannot work. The transfers allow for basic subsistence needs to be met and are likely to be valued as much for their predictability and ongoing nature as for their absolute amount. With an assured source of income, handicapped persons can devote energy to recovery and rehabilitation, and be somewhat less preoccupied with the search for a way to pay for food, rent, and clothing. In some instances, this need for income is significant when the person may not show symptoms of permanent and total disability and may not be eligible for the current transfer programs. For example, some disabled persons, such as those with multiple sclerosis, have intermittent remission and may not qualify as "permanently and totally" disabled.

The Disability Insurance program is modeled after the Old Age and Survivors Insurance (OASI) program. It is designed around the same basic retirement concept as the aged program. In the original Social Security Act with the high unemployment of the depression period, the OASI provisions were designed to take the elderly out of the labor market in a manner which would permit them some subsistence in a non-welfare, non-stigmatized income transfer program. To encourage those ends the requirement for full labor force withdrawal was imposed. Those currently receiving OASI can work and earn up to $2,520 before any reduction in benefits and up to $5,000 before all benefits are eliminated. Nonetheless, there is still the basic concept of retirement from wage earning. Wages are the only source of income which affect payment, as the benefit is paid regardless of other pensions or nonwage income.

The OASI program was accompanied with a welfare program designed to provide benefits to individuals who were not covered by the insurance principle until a mature insurance porgram was in place. At that time the economic recovery that was expected and the mature insurance program would cause the Federal intrusion into the State-run welfare programs to wither away.

When disability became an issue for programmatic social insurance support through legislation in 1954, the same basic retirement notions held. The idea was focused on the positive side; that is, the concept was that some workers who became permanently and totally disabled would never earn enough coverage to make use of the retirement program and could not even participate in the labor force. At the time, there was no federally supported program for the disabled. In 1954 the first step was to establish a "disability freeze" in which a worker's currently insured status and the basic benefit would not be reduced by including, in his average earnings computation for retirement, the zero earnings during the time of disability. In 1956 Disability Insurance paid cash benefits to disabled workers under age 65. Other provisions have grown over the years to include coverage for children of retired workers who have been disabled from childhood and have no expectation of being in the labor market. These are paid after 18. There is, as of 1972, a 5-month period between onset of disability and eligibility for payments. Since 1972 the disabled have been covered by Medicare if they have been on the rolls for more than two years.

This has created a number of anomalies in the program. For example, a disabled person who finds a job and goes off the rolls loses eligibility for DI and Medicare. If the individual comes back, the cash payment may resume, but he must wait another 2 years for the Medicare benefits. Judging from the reports we have received, this requirement has created significant reluctance to work on the part of many severely disabled.

In 1965 legislation was enacted to require referral to VR of persons who receive benefits under the DI program. At one point the referrals were actually made, but the nature of the VR rules was such that a good deal of redundant paper work was the result. Since persons had to have vocational potential, and many of these beneficiaries did not, it seemed that not too much was being accomplished. Eventually procedures were worked out so that criteria for actual referral were developed and most of the work is done on case record reviews. When a DI beneficiary is referred to VR and VR determines that the individual has vocational potential, an estimate is made of the potential earnings. If it appears that the earnings will be sufficient to remove the individual from the trust fund rolls, then the Social Security Administration will pay for 100 percent of the service costs to a State agency, up to a cumulative maximum of 1.50 percent of the Disability Trust Fund, or a cumulative amount of $70 million. When it appears that the individual's earnings will be less than enough to remove him from the DI rolls, the State agency treats the individual as a regular case. In some instances the SSA and the State agency share costs.

It is important to make an additional observation. The definition used by SSA relates to performance of substantial gainful activity (SGA). This is defined as earnings in excess of $200 per month, regardless of the nature of the physical condition of the individual. A deaf-blind-quadriplegic who earned more than $200 per month would not be considered permanently and totally disabled from the DI perspective.

Thus it is easy to see how the stringency of the rules for provision of VR services significantly narrows the opportunity for the pool of severely disabled to get rehabilitation. We have not mentioned the aged since there is no requirement for referral on their part and no substantial gainful employment definition. As we have pointed out, however, persons over 65 are among the most severely handicapped and constitute a very high proportion of the individuals so designated. In March 1974, there were 1.4 million SSI recipients, 2.0 million DI beneficiaries out of which about 600,000 received benefits from both programs. Thus about 2.8 million or 67 percent of the estimated number of severely handicapped, aged 18-64, are covered by one or another of these programs. A very significant breakthrough in services to this group could occur simply by extending the trust fund rules for services to this group.

Supplemental Security Income

Problems in the SSI program are similar. The program which SSI replaced, Aid to the Permanently and Totally Disabled, was a State-run program with Federal grants-in-aid and some general Federal rules. For the most part, this program permitted States to define the degree of disability which would qualify.

While this led to unevenness across States, it also permitted persons to be eligible based on the severity of their condition rather than on some arbitrary earnings figure as used in the DI program. When welfare reform under H.R. 1, of the 92nd Congress was designed, the decision was made to have the Federal program under the Social Security Administration. With natural reluctance to administer two different though similar types of rules, SSA recommended, and the Congress agreed, that the SSI program should be administered under the same types of rules as DI. Thus, the character of the SSI program moved to a labor force retirement program. The essential difference in the two programs now is in the prior earnings history of the disabled individual. Where the person was in covered employment and had high enough earnings, the individual is fully on DI. If the earnings were low, the individual may be on DI with supplement from SSI. If the individual had inadequate prior coverage for DI, then SSI alone is paid.

Unlike the case with the blind, with AFDC, and with the elderly on SSI, the provisions for allowing people to work and keep a portion of their earnings is severely truncated by the imposition of the earnings factor in the definition of disability.

Wise points out that the income cutoff has lasted 20 years. The blind who are exempt from the income-related part of the definition of disability can earn up to $4,524 per year before total cutoff, while the other disabled can earn only up to $2,400.[1]

Two personal accounts of difficulties encountered by disabled individuals illustrate some of the problems severely disabled persons are forced to deal with. One individual described by Wise reports receipt of a high level

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[1] Elden H. Wise, "The Right to Work Versus Social Security Disability Benefits," Rehabilitation Literature, March 1974.

of benefits, over $500 per month, which is necessary for the support of his family (he has six children). He has been an insurance man and wants to work at becoming an independent insurance agent. However, as his clientele builds up over a substantial period of time, he will earn enough to be cut off Social Security, probably long before he can be assured of making anything comparable to his present benefits. He would like to be assured of some financial security before taking the risk and making commitments to clients, etc., but under the present programs, there is no way for him to have that security.

Saxon reports that a client was seeking to go back to full-time work but could not afford to pay for the transportation which was necessary due to the nature of her disability.[2] She sought to be able to exempt her transportation costs from her income taxes but was repeatedly told that while one can deduct expenses for transportation to the doctor, one cannot do the same for transportation to work. Under these circumstances, the woman was almost dissuaded from going to work. She eventually received an allowance (a "restaurant and housekeeper" allowance) authorized by a Deputy Mayor who intervened in her case. She was thus able to afford to go back to work, but her struggle for such special recognition was arduous and is not a procedure available to most of the disabled.

Another issue related to disability and income maintenance is that some diseases do not follow patterns of steady deterioration but may involve periods of deteriorated health alternating with periods in which the individual can engage in some gainful activity.[3] The present income support programs do not have enough flexibility to provide financial security to such individuals for intermittent periods. This is another area where research could provide

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[2] Bridget Saxon, "A Public Charge Charges the Public," Harpers, November 1973.

[3] Joe R. Brown, "Recent Studies in Multiple Sclerosis: Inferences on Rehabilitation and Employability," Mayo Clinic Proceedings, October 1969.

insight into the necessary adaptations of income maintenance in order that such individuals would have access to income to meet their needs.

Another area of concern involves Worker's Compensation where the compensation laws differ from State to State. The maximum levels of support under Workmen's Compensation do not meet the objective stated in the legislation, of providing a substitute income for the worker with a job-related disability. Berkowitz and Burton compared the maximum benefits for permanent and total disability with the 1968 poverty line and found that the maximum 1968 benefits (including any allowances for dependents) did not meet the poverty standard of living for the four-person family ($3,555) in 38 of the 51 jurisdictions.[4] The authors noted that they were examining maximum benefits and, in actual fact, significant portions of those awarded benefits do not receive the maximum. The effect of overlap is minimal, because only 2 percent of workers receiving Social Security disability benefits were affected by the provisions that their benefits would be reduced if they were also receiving substantial Workers' Compensation.[5] The author points out that States may be neglecting to improve their Workers' Compensation coverage because they expect workers to be adequately covered by Social Security benefits. It is important to note, however, that some of the workers are not eligible for Social Security and that the failure to improve Workers' Compensation has a serious effect on these individuals and their families.

Workers' Compensation also involves the issue of payment for injury-related medical care and/or rehabilitation during the period during which the

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[4] Monroe Berkowitz, Rehabilitating the Disabled Worker: A Platform for Action in New Jersey (Trenton: the Comprehensive Statewide Planning Project for Vocational Rehabilitation, State of New Jersey, 1972); and John F. Burton, Jr., "The Maintenance of Income Objectives in Workmen's Compensation (National Workshop on Rehabilitation and Workmen's Compensation, 1974).

[5] Burton, The Maintenance of Income Objective.

litigation may take place when cases are contested. There is some evidence that substantial medical debts are accumulated during this period and that inadequate medical and rehabilitation services may be the result of the patients' fear that they may have to foot the bill in the end. Evidence shows that diagnostic work is obtained by most patients but that followup care is often not obtained until after settlement. Berkowitz suggests that the delay in rehabilitation which results may be detrimental to the future employability of the individual. Furthermore, once a settlement is reached, much of it goes to the repayment of past debts, and very little goes toward rehabilitation. Since many of the settlements are relatively low, they do not make it possible for the individual to set himself/herself up in business, although clients are sometimes instructed by their lawyers to request settlement on this basis.

Nagi and Riley studied applicants for Social Security, and examined the differences in physical condition, rehabilitation histories, and access to sources of income of those on Public Assistance compared with that of those not receiving Public Assistance.[6] It was found, both by legal definition and clinical examination, that the disabled on Public Assistance were no less disabled than those not on Public Assistance. Furthermore, their rehabilitation histories indicated that a higher proportion of those on Public Assistance were accepted for vocational rehabilitation services and became employed or ready for employment, and a smaller proportion of their cases were closed as unsuccessful. By examining availability of income other than Public Assistance, it was found that the group on Public Assistance did not have access to forms of income which were available to those who were not on Public Assistance. This finding supports the idea that Public Assistance is a last resort and that the

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6. Saad Z. Nagi and Lawrence E. Riley, "Coping with Economic Crisis: The Disabled on Public Assistance," Journal of Health and Social Behavior, December 1968.

reasons for being on Public Assistance involve need for support not available from any other source including earnings.

The recent reforms in SSI to create a work incentive may well work as an incentive for the blind, for whom the cutoff point is high per year, but are unlikely to work for other physically disabled people for whom the cutoff effectively remains at $2,400 due to the definition of disability used. That is, if one makes $2,400 ($200 per month) he or she is no longer considered disabled. In order to create better work incentives for the severely disabled, both SSI and DI should drop this provision and establish only a reasonable benefit reduction rate. Then persons could be selected on the basis of their severity and those who chose to try to work would not be penalized.

It is apparent that for those disabled people who have excessively high medical expenses, basic reform in Medicaid, or the establishment of publicly financed, comprehensive health insurance, or a comprehensive public health service is particularly needed in order to avoid penalizing them for becoming employed. This, of course, is especially important for the most severely handicapped, since their medical expenses are often very high. The 2-year wait for Medicare eligibility, especially for reapplications, should also be abandoned.

The disabled veteran's benefits program should be studied and considered as a model for transfer payments and health care for nonveterans. Its relatively high benefit levels, unrelated to earnings, combined with a health care system, provide a degree of financial and medical security uncommon in our society.

We as a Nation have not developed any clear income maintenance policy with regard to the disabled which might alleviate some of the problems of financial dependency and disability. One of the basic conflicts which is apparent in the literature is the issue of whether it is necessary for the disabled to work in order for them not to present too great a burden to the rest of society. The position which the disabled are seeking involves the right to chose whether to work or not. Any system which tries to force the disabled to measure their lives in terms of work, an area in which it may be more difficult for the disabled to function than in many others, may do more harm than good. At the same time, any system which expects the disabled not to work and does not require that the society make room for the full participation of the disabled who desire to work is also in effect depriving those of the disabled who do wish to work a basic source of fulfillment and a way in which they might contribute a great deal to the society.

Because of the nature of the continuing value placed on work, there are substantial punitive aspects to income maintenance programs. Any attempt to change the structure of such programs and to alter their negative efforts to the disabled should take into account the values of the society and the ways in which they contribute to the difficulties of the disabled individual in being financially dependent. While various suggestions have been offered regarding alternative forms of income maintenance for the disabled, there has been too little discussion and research into the need for developing a coherent policy. If such a policy were established, many of the contradictions in the present system would become apparent. Suggestions which are included in the literature include specific alterations of specific programs, such as a fund to cover medical and rehabilitative expenses of those injured workers who are involved in contested cases while seeking Worker's Compensation. Other kinds of suggestions include a guaranteed income, as well as national health insurance. Certain other programs can serve as examples of kinds of changes which could be made in other public income maintenance programs. For example, veterans' benefits for those with service-connected disabilities, involve partial levels of support for differing levels of severity of disability, and the veteran can go back to work without losing benefits. Experimental research on the effects of different income maintenance strategies on the disabled and severely disabled population has not been done. Hence more research is needed to help in the formulation of policy on income support strategy. Furthermore, the income maintenance strategy chosen should reflect a national examination of the roles which can open up for the disabled in terms of varying ways in which they can contribute to the society.

Chapter 27

PROGRAMMATIC OPTIONS FOR PROVIDING SERVICES TO THE SEVERELY DISABLED

In this section we will explore some of the options which follow from the previous material. It should be understood that from our perspective, as contractors, we cannot weigh the complex of factors that real policymakers do in allocating their values and aspirations, and so our "weighting" of various factors attempts to be neutral. Where we may have introduced some bias into the discussion is in our attempt to keep the discussion focused on key points; several logical combinations of options may not be discussed. If there are five factors with only two options on each, there are twenty-five possible combinations. We are dealing with a far more complex situation, so the theoretically possible combinations are very great. We believe, however, that we have presented the key factors in such a way that policymakers can make their own variations.

OPTIONS FOR ILR

We have made the case that for most of the severely handicapped there is now the ability to provide services not being provided widely or equitably to a large number of persons. Thus, the technology for service provisions is known, many of the services could be feasibly delivered, and most persons would benefit from such services. Expansion of VR and "pre-vocational" services is largely a function of the resources available and the nature of the labor market. These are decisions for the Congress and the Administration, primarily with respect to investments in human capital.

The most crucial decision area is in regard to development of an independent living program. The logical options for this are summarized below.

1. Have no ILR program.
2. Expand use of Extended Evaluation and add to success outcomes such as homemakers.

3. Add ILR program.
    - A. In non-VR agency
    - B. In separate, but VR-related, agency
    - C. In VR
        1. residual to VR
        2. separate from VR
        3. single program with VR
        4. precedent to VR

One has only to look at the disabled to find that they have unmet needs. Anyone who does so has a desire to meet those needs. Go to any nursing home, talk to any sensible person with a severe disability, and you are struck by an almost overwhelming desire to "do something" for them. The catch, though comes in looking across many groups or across many purposes and trying to set priorities, because there are not enough resources. The choice that has to be made is almost always cruel. The range of options is limited; to do nothing for A and use all the scarce resources for B (or vice versa); or to make some allocation of resources between the two. The allocation option removes the guilt of not doing anything at all and gives the hope that more resources will be made available if the program is at least in existence. But this option may flounder by spreading resources so thin that neigher A nor B can work effectively.

It is this last concern that drives a number of thoughtful persons in the field to argue that, with the kind of money that is being discussed (for example, the appropriation authorization in the 1972 and 1973 bills was $30 million for the first year and $80 million for the third), the VR program could be greatly helped. Appropriations for the basic program in the past 5 years have been relatively limited and inflation has brought about actual decline. We have discovered, too, that the cost of vocational rehabilitation for the severely handicapped is somewhat greater than for the less handicapped, although, given current program operations, not less successful.

If there is another $80 million or so available, it could be easily spent within the confines of the present program. Of course, the assumption that the money is there to go one way or another may be questioned. There could be such resistance that not going ahead with an ILR program may also mean no new money in VR as well. The Congress and the Administration can know this better than a contractor.

If the decision is no ILR program, what does it mean? In means that the population at risk is about where it is now; that is, the services will or will not be there depending upon whether people can find them, develop eligibility, do their own advocacy. People in nursing homes or people rejected for severity will remain as they are now. This does not mean they are unserved but that they are served in the system as it now exists.

Expand Extended Evaluation and Add Additional Non-Wage Occupational Outcomes

One way to get more to the severely handicapped without setting up a new program or without simply continuing status quo is to modify the existing program to expand the possibilities for service provision which may end short of a wage-occupation placement. There are State directors of VR who feel that they are achieving ILR through their use of extended evaluation and through homemaker rehabilitation. The expectations, however, in these cases are that these outcomes must be vocational in nature, and appropriate; they are treated as "least choice" outcomes. In parts of HEW, the homemaker outcome is viewed as a "cheat" when compared equally as a successful rehabilitation with someone placed on a wage-paying job. While such extreme debunking is "wrong," it points out the way in which expectations about vocational outcomes are framed. It is a sort of "if you say jobs, mean jobs" attitude that does not accept the benefit of rehabilitation to homemaking or self-care. As a consequence, some States hold the "homemaker" occupation to be primarily relevant only to women whose occupation was this prior to coming to VR. If the Congress and Administration view the self-care, homemaking outcome as in fact equally important in what it does for those clients as job placement does for others, then expansion of the conditions under which this outcome is appropriate would, in effect, expand the services and number of clients with severe handicaps served without vocational objectives. This could even be described as an outcome appropriate to persons who already have a job but need the additional assistance.

An additional outcome would be "deinstitutionalization" as a successful rehabilitation. The returns to governments of reducing nursing home stays for people who could, with rehabilitation, move back to the community may be as great as returns from rehabilitation of public assistance recipients. The logic of calling such self-care another form of "homemaking" follows from the notion of homemaking as an occupation itself and would fit within the existing confines of the way the general program operates. This would not, in general, be another full-blown ILR program, as one of the following options will show, because it is still based on ability to benefit from services to meet the desired outcome. One would expect incentives of counselors to remain focused on the vocational job objectives. One would also expect that not all handicapped persons would feel an entitlement to the program except when the rather clear eligibility criteria are met.

Similarly, the Extended Evaluation concept (EE) could be expanded to include restoration to self-care. Many States do not use EE now because of its ostensible restrictiveness as a tool for decisionmaking. The objective of EE at this time is to evaluate over a period of time clients of questionable vocational outcome. If the person is unequivocally in or out of the program, EE is not used. Some directors, however, apparently use this umbrella to provide ILR services. That is, they will suspend judgment on feasibility longer than will other directors, handle the individual longer, and thus provide an array of services to benefit the individual who is finally determined to be infeasible. One procedure that could get more people so served would be a requirement that the agency not reject a person for severity until he has undergone a period of EE. Thus, for the severely handicapped services could be provided and a period of assessment used to assure that, at end, if a client is infeasible for VR, it is not for one of the myriad inferior reasons such as rationing, worker error, or the like. In the interim, the client will have received an array of services intended to enhance functioning with a vocational objective.

Establish an Independent Living Program

The decision could be to develop an independent living rehabilitation program with characteristics ranging from modest to major. A small program whose focus and objective are to receive persons without vocational potential who appear to be able to benefit from services would be a reasonable small start. It would also be reasonable to think through a major reform of existing disability programs around given ends and to make independent living a part of such programs. We have pointed out how these programs vary with respect to definition of disability, eligibility, and benefit delivered; we have also pointed out how these are fragmented and tend to be "lumpy" with respect to the distribution of benefits. We have pointed out how these programs often work against an individual's achieving his maximum potential for fear of loss of benefits. While most of these programs raise the question of employability, they do so with respect to eligibility and labor market retirement as a basis for benefits. Therefore, these may be seen as programs for independent living insofar as they penalize full vocational rehabilitation.

To pull together in one coherent system the long-term care, income maintenance, employment, and vocational and social services to be provided, regardless of which outcome was achieved, would be the outer limit of program revision.

Since the bulk of the following discussion will assume a much smaller enterprise, we will here discuss briefly one of several approaches to the grand scheme.

If one were to determine that the objective of a disability system for the severely disabled was to provide medical and restorative services to help them improve their health and personal functioning, to provide rehabilitation and social services to help them improve their self-care and vocational functioning, income to support them through the process and to make up for certain costs of living, and, where appropriate, to keep them competitive on a wage basis with other workers, then one can conceive a single system to which anyone wishing assistance due to disability could come. Some local assessment team working from regulations which described objective criteria could establish an assessment which would be based on the factors used anywhere in the country. Once an assessment of disability was made and the individual deemed eligible, the team would then work with the individual and family to determine the range of "need," such as for nursing care, homemaker services, vocational rehabilitation, transportation, income, and the like. An evaluation of individual and family resources would be responsible for determination of resources in the catchment area and could make the tradeoff decisions with the individual with respect to home care, community care or institutional care, work versus welfare, and so forth. They could be responsible for determining that the adequate availability of facilities, services, and the like were present and could make the determination of the community level of response. If it were to be modeled on the system in Poland or Yugoslavia, they could also be responsible for handling the affirmative action program with employers or, indeed, could work out industry-agreed "quota" placement. Such a system could, in effect, be the intake screen for all benefit programs related to disability.

Far fetched? Somewhat. But it is probably impractical for various "political," rather than technical, reasons. It would be a political problem of great magnitude, one suspects, to try to get the SSI and DI programs changed so that they function to support persons because of the costs of their disabilities, not because their disabilities cause them to withdraw from the labor market. It will be difficult to get the various social service, rehabilitation and medical professions to work that closely together. It will be difficult to get program administrators to agree to give up the crucial rationing function of intake. As a system it would be a multi-billion dollar operation with hundreds of thousands of employees working in often nonroutinized operations. One reason Social Security, for all its expenditures, is manageable in spite of its size is the relative routinization of its work. But to take such a system and tie it to one in which individual assessments are made on a range of discretionary criteria suggests a quality control problem of massive proportions.

Yet it could be done. Much would need to be worked out with respect to the purposes of the program, the assessment technology, the criteria for who gets what and who pays, and when. These are the problems of any significant program development. But all of them are tractable. It would provide a basis for a place where any disabled person with other than a trivial problem could go and get whatever was needed in a coherent and comprehensive program. It could handle some of the problems of long-term care and the kind of disincentives in the current welfare programs. It would take the $22 billion or so currently in the Federal budget for the disabled as a base and redesign the funds for more efficient and effective use. We are not sanguine this will happen.

What is more likely is that some program of more modest dimensions, another program to fit into the patchwork, will be developed with less grandiose objectives directed at what can be done from a service perspective to make people without vocational objectives as well off as services can make them. There are two essential options on the form and four options on the placement of such a program.

The form options are two. It can be a nongovernment agency or it can be a government agency. If it is a government agency, it can be in an established or a new agency outside of rehabilitation, it can be related to rehabilitation but not part of the VR agency, a model much like that in the old work-evaluation work-adjustment services section (Section 15 of the Act prior to 1973), or it can be within the VR agency. If it is within the VR agency, it can have four relationships to the VR program itself: residual, pre-VR, independent referral to and from, or co-mingled. We will discuss each in turn.

Nonpublic Agency for ILR

When discussing this option for a nonpublic agency we must carefully define our terms because we are talking about a program being run by private, nonprofit organizations but with Federal grants and supervision. Quibblers may argue that this would make them public programs, so we make the distinction in that this voluntary sector would indeed be accountable for the funds and results and have to adhere to standards but would not be fully tax supported.

The idea of such arrangements with the voluntary sector may seem novel at first, but in fact such arrangements have existed for quite some time. Sheltered workshops, rehabilitation facilities, voluntary organizations such as the Easter Seal Society, Cerebral Palsy, and Epilepsy Foundations, have been providing services for the most severely handicapped for years, often with grants, purchase of service contracts, or other arrangements with public programs. This sector probably has the most dedication and experience in providing services to the most severely handicapped who have been neglected by most other public programs. It was such organizations which worked for programs for the retarded, for muscular dystrophy, and the like. It is they who have been the mainstay of service provision for persons with cerebral palsy and mental illness. If there is criticism it is that they have been too much staffed by volunteers without the necessary training, passion and advocacy aside, who may have occasionally done less good than they could have. But over the years they have developed a degree of professional competence for working with the public agency castoffs that suggests they must be doing something right.

Another serious possibility to be considered is setting up consumer-run self-help organizations to fill the vital gap in the disability service delivery system. Our findings seem to indicate that one of the major reasons why VR reflects clients for severity is that they lack motivation. One of the factors we find in persons with severe disability is lack of appreciation of their own worth. Whether it is the long period of recovery from depression due to the crippling effects of a serious accident, or the young person for the first time coming out from under the overprotective environment of the home, not to mention the "attic" cases one still runs across, the severely disabled person needs role models, examples, energizing of himself to be willing to meet the difficult job of not being dependent. Public agencies are staffed with professionals. In many cases they have little time and large responsibilities. Most often they meet not with people but with clients, not with peers but with the disabled.

Where does one go if one is quadriplegic in an electric wheelchair to find a job, housing, transportation, friends, and love? Not to a public agency.

But there is a reservoir of strength in a group, where some, perhaps, may have "made it," Banded together they often get concessions from public programs or from reluctant political figures. They can persuade a mayor to assure that at least all new curbs will have curb cuts, or a governor to forcefully address requirements for accessibility in buildings constructed with public funds.

They can swap tales about attendants, find people to repair appliances and other devices.

We speak here of no ghetto of the disabled but of a mechanism of self-help. This type of organization can be seen as a resource to public agencies. Counselors seek them out for help with an individual; they, in turn, pressure the agencies to do more than they might for given individuals. A number of such programs are already in various stages of development. Perhaps the best example is the Center for Independent Living in Berkeley, California.

CIL grew out of the Physically Disabled Student Program at the University of California, Berkeley, in 1972. It is staffed almost entirely by people with severe disabilities. As a self-help group they have an aggressive belief that the blind and disabled have a right to be fully integrated into the community. One of their primary methods is the development of peer group support, peer counseling, and peer role modeling. As activists, in addition to being advocates, they press freely on the reluctances and limitations of legislative law-making bodies and on tradition-bound agencies whose service focus or array is adequate to meet their needs. They set up and provide services themselves, since for many of the severely handicapped the services required are not in the domain of any given agency; instruction in home remodeling, for example, or the assurance of equipment repair, or an inventory of experienced attendants.

Then, too, there are areas which many public agencies will not easily touch, such as sex counseling for the severely disabled. It is their disabilities, their lives, their passion which will insure continued pressure on social agencies to make their needs felt and met. It is unlikely that any public agency could sustain such a role.

While not all such programs need be organized and operated as CIL is, public policy-makers should investigate the potential of such a model for filling in this needed function in the rehabilitation system.

Public Agency Models

Other Public Agency

There is, as one person with great dedication to VR said, no reason to assume that rehabilitation has to be seen as the system that does everything for the disabled. When one gets to people who are too severely disabled for VR, then they are in need of social services, retardation services, mental health services, but not rehabilitation. From this perspective, the concern is with "diluting" rehabilitation with what is seen as the vagueness of the social service programs, or the excessive and inefficient expenditure of money for little measurable gain. There is fear that without the specificity of the vocational outcome, criticisms such as the charge of nonaccountability levied against social services would slip over into rehabilitation. Decisions to spend public funds on an individual who may need homemaker or shopping services (known as chore services) is seen by many in VR as an invitation to disaster. Let social services do it, they say. While we did not do an evaluation of what social service programs do with respect to the severely disabled, we were able to determine that they estimate about $500 million of federal funds is being spent doing it in FY 1975 out of Title XX, or its precedent Title VI. However, as is pointed out, little is known at the Federal level about what is actually done or accomplished through this route.

If services for meeting the needs of persons in institutions for getting into the community are unmet or if independent living services are unmet, why not see what it is the social services do and why these needs are unmet? Since the amount of funds is nearly as great as the basic VR program, and the ends tend not to be vocational in orientation, so goes this line of reasoning, the Congress should require social services to provide this activity.

For others, the focus, depending upon their primary interest, would make the same observation about the developmentally disabled or mental health programs. There are service delivery systems to take care of such persons. If the Congress and the Administration are concerned that they are not doing well enough, they should probably be focusing their attention and funds on those systems, not introducing possible conflict, overlap, duplication, and competition with VR. To argue that those programs are not doing their job is to beg the question of why one turns to VR to do it.

It is argued, for example, that there is no capacity in VR to serve children. There are important programs to serve handicapped children that could serve as the basis for such a program better than VR. The same holds true for the elderly. For the severely disabled, such as certain of the mentally ill and the developmentally disabled, there is the fear that the production goal of rehabilitation would cut off services to certain persons which under these other systems would be provided. In one visit, one program director showed proudly the progress that had been made over 3 years with a particularly disabled youth. The youth could now dress. A VR director commenting on essentially the same example felt that it was well and good if they could get the funds for such work, but he clearly thought they were "wasted" when he pointed out that he had to close intake for lack of funds for services to persons he could vocationally rehabilitate. It was his preference to leave such services to the other programs and the question of resources to the political process.

Since our study was unable to find evaluations of the operations of social service programs, we cannot speak knowledgeably about their relative strengths or weaknesses. We can speak to the difficulty we had in finding examples of good cooperation between VR and social services on any kind of systematic and ongoing basis. This leads us to speculate that if the program for independent living were to be designed on the assumption that VR and social services will work together, it is likely to fail. Probably the authority should be lodged fully in one program or another. The expectation that, even within programs for the disabled, good case management, referral, and other arrangements for the benefit of a given client can cross program boundaries appears to be without good probability for realization in all but the most exceptional cases.

There is, of course, no reason to think of these as totally either/or conditions. One could imagine the Congress and the Administration passing legislation to improve the ability of programs in mental health, social services, and developmental disabilities to do certain things and to assign additional ILR program responsibilities to VR. But as we said at the outset, if we get into too many variations on the themes, the themes will be hard to follow.

VR-Related, but Other Agency

Section 15 of the 1968 Vocational Rehabilitation Act, authorized an organizational entity as a service arm to VR and other manpower programs for performing work-evaluation work-adjustment assessment (WEWA) and services. The idea was that this autonomous service would better assist other programs if it were not solely concerned with vocational rehabilitation. The WEWA technology was to be used for the disadvantaged as well as the disabled and was not to be the province of any one program. Hence, to expand service to the nonhandicapped disadvantaged without changing VR requirements, this device was established.

While Section 15 became law, it was never funded except in a few projects. Thus there is no example to determine how such a set of arrangements as we propose may work in practice. Nonetheless, the option of an ILR program separate from, but closely related to, VR would solve some of the concerns of some VR officials. Many of these persons want ILR, if it is to be, as a separate program from VR. Their reasons are several. They fear the cost of ILR services, if comingled with VR, would be so expensive as to sap the funds from VR. The second reason is the fear that independent living outcomes may be so much easier to achieve that the counselors will not make the extra effort to push on into vocational rehabilitation. Certainly, if an independent agency were established with responsibility for ILR, the boundaries would be clear enough with respect to funds and the outcome orientation with two separate counselor staffs. Presumably, any vocational rehabilitation would be in the VR program and anything short of that would be in ILR. Counselors would simply have to achieve their own goal without regard to which is easier.

ILR in VR Agency

Of course, the ILR could be set up within the agency that administers VR with expectation that the organizational -relationships within the agency could be worked out. If one were to look at the options, they would be most succinctly described if one thought about decisions about clients and client flow.

Residual to VR. This approach would have the agency screen clients for vocational potential. Clients would be selected as now. Only those clients failing or rejected due to severity would then get ILR services as necessary. Thus, the pool for FY 1972 would have been the 68,000 cases closed in status 08, 28 or 30 by virtue of severity. This option would have the effect of assuring that at least some benefit is bestowed on those for whom a vocational outcome is not possible.

Separate from VR. This approach within the VR agency would be to set up totally distinct units, each having its own manpower and budget, and to establish internal agency referal procedures. This option may be so rigid as to constitute an internal agency option much like the independent agency related to VR described above.

Melange Program. In this approach, there would be no distinction between the programs. Any handicapped persons arriving at intake would be provided the services from which they could benefit, for as long as they could benefit, regardless of outcome. Thus, there could be few "unsuccessful" outcomes, since most people would be rehabilitated to a vocation or to independent living.

Precedent Program to VR. In this approach, the ILR program would, in effect, be the evaluation arm and service provider as in Extended Evaluation. All handicapped persons wishing services would apply and be seen by the ILR program, which would determine that their ILR needs were met, and only then refer them to VR. Thus the VR program should experience fewer nonrehabilitated because most of the people VR would see would have had most of their needs met, except for vocational needs.

There is one other area of option which could influence some of the options given above, which were based on services to the individual. In this model, services may be provided to the family, but only when related to the progress of the individual toward the goal. In family rehabilitation, the family is the client and the rehabilitation unit. The idea is that the family is what helps or hurts the handicapped individual, or indeed the nonhandicapped individual.

The idea of rehabilitating an entire family is probably best described in the program of the Arizona Job College (AJC). This organization accepted for rehabilitation intact families of very poor, rural minorities in a small town outside of Phoenix. The idea behind it was that it doesn't pay to put a lot of training into a man to get him a job if his family has never lived in a house with indoor plumbing or they cannot make nutritious meals. The program brought the entire family to the site of the AJC, where they moved into trailers with full modern furnishings. They were taught how to deal with flush toilets, garbage disposals, and other modern appliances. While the breadwinner was undergoing vocational training, the spouse was learning how to take care of a home, how to buy and cook nutritious meals, how to repair appliances, and even to acquire a secondary market skill. The children were in Head Start or special classes. Parent-child training programs were instituted as well as other counseling on problems such as drinking or wife-beating. Health care was provided, as was legal counseling, both because these were poor people with more than their usual scrapes with legality and also because these are the persons most easily ripped off by the shady side of the market place.

This is expensive rehabilitation, but it seems to have more promise for these very difficult cases than the more fragmented way in which it is done in most places. And since no one has ever totaled up what those fragmented costs may be, there is no way to say for sure this method, with its visible budget, is or is not more expensive. It does show promise for being effective.

For the severely handicapped such an approach may also be more effective. Adjustment to severe disability is a family problem. Adjusting to a disabled person's striving to become independent is a family problem. In some of the Mexican-American subcultures the disabled are viewed with such shame that getting the family to support the rehabilitation process is very difficult, and often the program fails. What is needed in such instances is not just family services but family rehabilitation. As a model it has been tried and found promising but with many questions unasked. However, it is clear that this is a different model for rehabilitation than underpins the options which went before.

Then there are those who would promote a network of comprehensive medical rehabilitation centers, much like the spinal cord injury centers or similar units for other conditions. The logic of this approach is compelling in a variety of ways. The medical management and medical rehabilitation aspects of services to the severely handicapped are significant, ongoing, and often unfunded by health insurance or public health programs. Giving the individual intensive care with respect to his condition and all of its ramifications, including self-care and vocational rehabilitation, has been shown efficient and effective in such centers. It is expensive care, no doubt, but for the most part, once the research and training aspects are capitalized, seems to be quite cost-effective. Extension of these medical-professional models into areas other than spinal injury and stroke, however, raises serious questions of consumer discretion. There are many who feel that these models impose upon the otherwise competent individual a crushing expectation of dependency on the professional's judgment, often without the involvement of the individual.

It seems to us that such centers are needed in more places, and with that they should be broadened in scope from those now functioning. We feel, however, that they then become resources to the various State agencies rather than the primary service core. Some programs in rehabilitation centers, such as Texas Rehabilitation Research Institute, have demonstrated some good ability to take clients beyond the medical dimensions and into the community, but the experience is limited and expensive compared to the need. State agency programs which utilize the strengths of CMRCs more fully for this population, but which reserve to themselves the counseling, coordination, and case-management role, suggest to us a more viable approach.

Coverage for ILR

If a program of independent living rehabilitation took the form in the vetoed bills -- that is, a separate program -- the question of who should be eligible must be handled. From some of ths preceding options, the eligibility criteria appear obvious. For a residual VR concept of an ILR program, the eligibles could be those selected initially as potential VR clients who fell short. (In such cases it would be important to be on guard for instances where the counselor accepted clients initially for services, knowing full well the person may have no VR potential, but was in need of the services.)

Other models are not so clear. A definition of severity must be imposed if the program is to remain within fiscal constraints and focused on the most severely disabled. The options for screening the eligibles on the basis of severity and disability are roughly as follows:

All of the handicapped could be screened, but only those with proven lack of VR potential would be referred. The criteria for infeasibility could range from the current program, which is highly dependent on age as a proxy, or it could use standardized instruments nationwide, such as a Barthel score. Persons above a certain point would be accepted for ILR if there were agreement there was no vocational objective. Variations on this theme would include development of a severity scale and further assessment instruments for determining motivation and other barriers along with severity.

Another method would be one suggested in the previous bills, a cost-duration model. That model posits that severity can be captured as cases with long duration and higher than usual or average costs. There are a number of problems with the cost-duration model, but it does serve the function of being objective in definition.

There are those who would propose that the ILR program be limited at the outset to the physically handicapped in the 18-64 age group. The theory is two-fold. The mentally ill and mentally retarded have service delivery systems, as do children and the aged. It is primarily the physically disabled without VR potential that are largely unserved. The second point is that VR knows the most about the physically handicapped and is most likely to be successful in a new program. The argument here is that if there is to be growth, the other groups could come in later when the program was running and expansion would not be such a difficulty.

It must be decided whether eligibility extends to persons served in institutional programs, especially the aged. The criteria of age becomes largely meaningless when looking at ILR. We have pointed out that age is partly useful as a VR screen because of the nature of the labor market, humanitarian impulses aside. There is no reason to use age at all in ILR when the outcome could well be enhanced self-care. The screenout criteria may be more important in such cases. At some point an elderly person with progressive chronic brain syndrome can only be watched, not rehabilitated. Neither the custodial dimension nor the medical management should be within the province of the ILR program unless it is to be no more than another name for long-term care.

In large measure, the decision of who will be served is a function of the policymaker's willingness to make investments. At this time, there is little firm evidence that retooling part of the VR system to serve the severely disabled without VR potential will be very good for anyone but the working-age group of physically handicapped. There are some isolated projects which suggest that rehabilitation of the aged and of children could be feasible, but on a small scale initially. There is some, but again limited, evidence that in a team situation VR can work with institutionalized mentally ill. However, when the restoration aspect begins to take on major proportions, especially when that has little to do with routine medical management as is the case of paraplegics and quadriplegics, there is substantial ambiguity as to whether rehabilitation should be involved, even with an independent living objective. For example, heroin addicts undergoing methadone treatment may be candidates for ILR, since many are poor candidates for VR, judging from current experience. But what might an ILR role be? The same issue would hold for a chronic schizophrenic who could be assisted to leave the mental hospital after 20 years if someone were to supervise, to assist with adjustment, to assure medication is taken, but such management is largely the province of long-term care with little concern for rehabilitation, even independent living rehabilitation. Given the great promise, though, some suggestions are made for demonstrations into the issues.

Services to the homebound are also an area of need, but one which should be fully investigated before a major program is undertaken. Technological breakthroughs such as the electric wheelchair have radically changed the issue of who is homebound, but such significant events are rare and the costs are high. Not only will the research be necessary but also the marketing of products at prices the severely disabled can afford. Thus, we feel that there are many persons who are homebound who, like the CIL group, would be not so limited if they had the motivation, the resources for the wheelchairs, the accessible homes and jobs and transportation. But then, many persons are homebound less by tradition and expectation than by their location and age. In rural areas with limited service and mobility and employment opportunities, and in many households, it is expected that the severely disabled will be at home. We must not forget, too, many are so impaired that unassisted mobility and self-care will be beyond them, as is the case with some cerebral palsied persons.

This is not to say that communications, learning, even productive activity cannot occur. They must occur, however, within the home for the most part. Many homebound programs, where they exist, still look like medieval cottage industries relying on weaving, doll-making, and the like. There is promise, however, for better. In California, experiments are being made in having severely homebound persons handle peak-load ticketing requests for airlines, since they can have phones and the necessary terminals right at home. Since this also saves the airline the cost of office space, it seems of advantage to them. Cable TV which would send and receive two-way could become a major training device as well as a way to bring the homebound into jobs where their responsibilities included observation. Again, these are areas which further investigation seems called for.

Modifying Other Programs

There are a number of suggestions which should be very attractive in achieving Congressional desires to expand services to the severely disabled. When such desire, however, resides in one Committee and the program to be modified resides in another, one feels little hope for success. There are no particularly good mechanisms, it would appear, for one Committee to really relate to another with respect to its concerns, especially when there may be differences in opinion as well as jurisdiction.

Thus, in a hopeful vein rather than an assertive one, we suggest several possible candidates that could with quick result open the opportunities for improved services.

For example, a larger proportion of the severely disabled aged 18-64 might receive Social Security Disability Insurance or SSI. This sizeable number could have vastly expanded assistance if the regulations governing payment for rehabilitation services with 100 percent Federal money were not so narrow as at present. For instance, if the mandatory referral to VR were under conditions that the individual was to receive those services from which clear benefit could be received toward a vocational or self-care improvement, far more services could be provided to far more persons.

If Medicaid and Medicare rules were such that a screening by rehabilitation experts was required shortly before or after a placement in a nursing home or other facility, with an eye to a program of rehabilitation for getting the individual into a community setting or his own home, then one would expect some changes in the allocation of government costs of people in those facilities, and another source of services to the severely disabled.

Along the line of modifying other programs, it might be suggested that part of the authority, and the funds, for serving the blind and disabled should be moved from Title XX to rehabilitation if one is convinced that rehabilitation will be more effective than social services.

OPERATIONAL DEFINITIONS OF INDIVIDUALS WHO ARE SEVERELY HANDICAPPED

A. Introduction

In a previous section of this report, we defined a number of key terms which are critical to an understanding of the major policy issues raised by this study. As defined in this study, the residual limitation resulting from a congenital defect, disease, or injury is an impairment. An individual with an impairment has a disability if he is unable to perform some key life functions over a period of time (e.g., ability to care for oneself). When the disability is such that the environment imposes impediments to the individual's goals -- to travel to work, for example -- the individual has a handicap. These definitional conventions provide a useful framework for understanding the results of numerous surveys, analyses, and literature reviews. They are not particularly helpful, however, in giving providers of rehabilitation services guidance in establishing priorities in serving individual clients.

A frequent criticism leveled at State vocational rehabilitation counselors is that they accept into the rehabilitation process those people who appear easiest to rehabilitate and reject the more difficult ones. A second criticism is that their eligibility decisions are based on arbitrary factors rather than objective characteristics.

In this section, we focus on how the Vocational Rehabilitation program could operationally define individuals who are severely handicapped. A valid operational method of defining severity is essential in order to measure the progress of State VR agencies in carrying out the Congressional mandate of placing priority consideration on serving the severely handicapped and to identify those who might fit under a new program for independent living. We explore four alternative methods that may be used to operationally define severity, including that which is currently published by the Rehabilitation

Services Administration. These four methods are by no means exhaustive, nor are they mutually exclusive. They do suggest, however, some of the possible ways to operationally define severity. The perceived advantages and disadvantages of each of these methods are discussed in the conclusion of this section.

Alternative Methods of Operationally Defining Severity

1. Current RSA Guidelines[1]

The current guidelines for establishing the severity of disability revolve around disability type, although other characteristics of individuals may be considered. There are four elements in the present system. The first is disability type. Individuals who have particular disability types such as blindness in both eyes, orthopedic impairments involving three or more limbs, or multiple sclerosis, as well as a number of other disabilities are presumed to be severely handicapped. Other disabilities may also lead to an individual being regarded as severely disabled if certain other conditions which render the disability more severe are present. Examples of this latter group include blindness in one eye with the other eye defective and epilepsy, if not seizure-free for two years.

Current guidelines on psychotic and psychoneurotic disorders state that a person is severely mentally handicapped if that person is now requiring institutional care in a mental hospital or psychiatric ward of a general hospital; or has a history of being institutionalized for treatment for three months or more, or on multiple occasions; or meets the descriptions for moderate or severe.

Finally, individual cases with documented evidence of loss and limitations meeting the criteria of certain Functional Limitations Factors are also considered to be severely handicapped. In this grouping are those conditions

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[1] For a complete listing of the RSA guidelines, see Rehabilitation Services Manual, Statistical Reporting System. (DHEW, 1974).

whether a single disability or a combination of disabilities, which when presented in terms of clinical description and functional limitations, the State agency can use to determine that a substantial loss of functional capacity and restriction of activity exists. These functional limitations include: (1) inability to make use of public bus or train; or (2) inability to perform sustained work activity for six hours or more; or (3) disfigurement or deformity so pronounced as to cause social rejection; or (4) speech unintelligible to nonfamily members; or (5) inability to climb one flight of stairs or walk 100 yards on the level without pause; or (6) the loss of manual dexterity or coordination sufficient that a client is unable to button buttons, wind a watch, or write intelligibly.

In addition to meeting one of the criteria specified above, the client must require multiple vocational rehabilitation services over an extended period of time in order to be classified as severely handicapped.

The present method used by VR to define severity has both advantages and disadvantages. One of the major advantages is that it is well known and widely accepted by those in the rehabilitation field. As mentioned previously, in our nationwide survey of providers of rehabilitation services, the vast majority of respondents (80 percent) felt that the current RSA definition provides an adequate definition of severely handicapped individuals for vocational rehabilitation purposes.

Another advantage of the present system is the flexibility and discretion which it affords the counselor in assessing the employment potential of a prospective client. Counselors generally feel that this discretion is necessary to accurately assess each case on an individual basis.

The flexibility of the system can be illustrated by the severe disfigurement criteria spelled out previously. In some instances, employers may not hire an individual because of his physical appearance, although the individual may have minimal physical limitations. For example, the client with severe facial disfigurement may have a high physical functioning rating but never be able to obtain a job on his own because of employer prejudice. The present system allows the counselor to consider this person as severely handicapped.

The system also permits consideration of motivational factors and an individual's self-image. For example, an individual who would score high on a scale measuring functional ability may be so distraught by the nature of his disability that he cannot face family or friends, let alone a prospective employer. His emotional state, then, more than his physical condition may create the severity of the disability.

Persons with multiple sclerosis, muscular dystrophy, or sickle cell anemia may show little physical dependence but may still need selective and individualized counseling and placement because of the progressive nature of their disabilities. These individuals need the correct rehabilitation service and job placement from the beginning of their contact with VR.

A major disadvantage of the current system is the fact that it does not explicitly take into account environmental factors such as age, income, or education. For example, consider the case of the individual who is blind in both eyes, who had practiced law for a prestigious law firm and earned a substantial salary over a number of years. According to the current system, if this individual became unemployed, he would be classified as severely handicapped, regardless of any of the other factors or the level of his financial assets.

There is another problem with using diagnostic labels to determine severity of handicap. It has come to our attention during this study that many persons who are blind, retarded, using wheelchairs or otherwise severely disabled in the present system object to the stereotyping which can result from being labelled "severely disabled." This type of stereotyping is part of the same set of attitudinal barriers they have to face from employers and others with whom they have to associate.

The ambiguities of the current system also present some problems. In the most recent Program and Financial Plan submitted to DHEW, various State VR agencies claimed that from 15 to 60 percent of their clients were severely handicapped. The wide range in this statistic suggests that either State agencies are operating very differently in carrying out the Congressional mandate to serve the severely handicapped or that the current operational definition used by State agencies is so vague as to allow for wide reporting discrepancies.

Finally, as we have demonstrated in the chapter on definitions, there is only a minimal relationship between diagnostic labels and severity as measured by actual functional limitation. (See Table 27-1).

2. Extended RSA Guidelines

One method for meeting some of the objections to the Current R-300 guidelines would be to extend those guidelines so that only subgroups of each diagnostic type would be considered to be severely handicapped.

As one example, the current RSA guidelines qualify all individuals afflicted by epilepsy as severely handicapped if they have not been seizure-free for 2 years. Extended guidelines might classify various types of individuals according to both the type(s) of seizures they experience and the frequency of their occurrence, as illustrated by the guidelines used by the State of Massachusetts.[2]

Epileptic seizures can be divided into four major types which may occur separately or in combination. These major types and the frequency of their occurence are described as follows:

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[2] Massachusetts Rehabilitation Commission, Professional Manual of Policies and Procedures (Boston: The Commission, 1972).

Table 27-1

Disability Type by Severity

R-300 Disability Type 1/	Total Barthel Scores[2]											
	Totally Dependent (0-20)		Severely Dependent (21-61)		Moderately Dependent (62-90)		Slightly Dependent (91-99)		Independent (100)		Total	
	N	%	N	%	N	%	N	%	N	%	N	%
Visual			1	5	2	10	2	10	15	75	20	100
Hearing					1	11			8	89	9	100
3 + limbs	17	19	22	25	24	27	10	11	16	18	89	100
Side			6	15	13	33	4	10	16	41	39	100
Upper limb(s)			1	3	7	23	7	23	15	50	30	100
Lower limb(s)	3	3	15	14	34	32	20	19	34	32	106	100
Trunk, back, spine	4	2	9	5	67	37	31	17	71	39	182	100
Amputations	2	8	3	12	8	33	3	12	8	33	24	100
Mental					2	17			10	83	12	100
Neoplasms					4	50			4	50	8	100
Allergies			1	2	7	17	4	10	29	71	41	100
Blood diseases					1	17	1	17	4	67	6	100
Epilepsy	1	2			7	16	4	9	31	72	43	100
Cardiac			6	4	48	30	17	11	90	56	161	100
Respiratory			2	7	7	24	6	21	14	48	29	100
Digestive					10	48	2	10	9	43	21	100
Genitourinary					4	29	2	14	8	57	14	100
Speech					1	20			4	80	5	100
Other	1	2	2	5	17	40	9	21	13	31	42	100
TOTAL	28	3	68	8	264	30	122	14	399	45	881	100

1. The R-300 file contains data on all persons who contact the Rehabilitation Services Administration. These diagnostic categories are taken from the 1969 definitions in effect when these individuals were closed from VR. The categories were altered somewhat in 1973.

2. The total Barthel score is a measure of an individual's ability to care for himself and move around.

a. Grand Mal (the great illness) is the most common and most disturbing of the seizure types. It is a true convulsion. The following are typical of grand mal seizures; (1) there may be a premonition (aura) which may consist of a feeling of dizziness, visual problems, the detection by the epileptic of a strange smell or strange sound, nausea, or other symptoms, which the epileptic comes to recognize as the warning of a coming attack; (2) sudden loss of consciousness; (3) a tightening of the muscles with the body rigidly extended (the tonic spasm) which usually lasts from 1 to 3 minutes; (4) jerking movements of the head, arms, and legs (the clonic spasm) which usually lasts from 2 to 3 minutes; (5) the recovery period; and (6) a period of sleep which may last from 5 to 30 minutes or even several hours. Grand mal attacks may occur from once a year to several times a day.

b. Petit Mal (the small illness) is the next most common form of seizure. This seizure consists of a momentary loss of consciousness without warning of change in posture or muscle tone. There is usually no confusion following a petit mal attack. Frequency of attacks may vary from two or three a week to several hundred a day.

c. Jacksonian (named for the English neurologist who first described one) is localized, beginning in one extremity or side of the face and progressing through the arm and/or leg on the same side. Quite often there is no loss of consciousness.

d. Psychomotor (psychic) is the most formidable type of seizure. During such an attack, the epileptic may do things that are purposeful but are not appropriate to the occasion, actions of which he will have no memory afterwards. The length of the attack may vary from a few minutes to a more extended period of time. During an attack, the epileptic may act as if he were intoxicated; he may be irritable and out of sorts; he may become quite violent and have to be restrained. Frequency of attacks may be highly variable. It is not uncommon for them to be associated with other types of seizures, usually grand mal.

Extended guidelines regarding epilepsy might specify for example that individuals experiencing seizure types (a) and (d) be regarded as severely handicapped. However, the basic objection to using diagnostic lables as proxies for severity of handicap would still not be eliminated. It is evident that the degree to which any individual is severely handicapped by a specific disability depends on a number of factors in relation to both the individual and his environment. Furthermore, as a survey of individuals rejected from VR illustrated, there is only a minimal relationship between disability type and functional limitation.

3. Functional Limitations - Employability Scale

The scale proposed below was developed after considering the results of the survey of persons rejected from VR, and the provider survey, which showed that VR counselors consider age and employment history important factors in determining severity. The measures included in this scale emerged from those two surveys as the variables which, in practice, seem most closely related to employment potential.

a. Severely Physically Handicapped

While one could list many, many possible criteria for making priority determinations among the physically handicapped, it is possible to narrow the list to some of the most important and objective measures of severity. Six key measures have been identified from the VR and Provider Survey results:

--Ability to function independently (as determined by the Barthel Index).

--Other functional limitations

--Employment history

--Educational level

--Communication ability

--Age

Ability to Carry Out Physical Functions Independently (Barthel Index). The ability of an individual to physically function independently of others is of major importance in evaluating his severity of handicap and employment potential. The ability to function independently can easily be measured by the Barthel Index, as we did in our surveys of persons rejected by the Vocational Rehabilitation program and of individuals in Comprehensive Medical Rehabilitation Centers. The Barthel Index contains nine "self-care" items which are considered basic to an individual's ability to care for himself and six additional "mobility items" which pertain to the ability to move around without assistance.

The Barthel Index has five categories which measure the extent of dependency in self care and mobility:

Score	
0-20	Totally Dependent
21-61	Severely Dependent
62-90	Moderately Dependent
91-99	Slightly Dependent
100	Independent

These scores were derived from the Barthel scale, which assigns weights to each item on the Barthel Index in the manner illustrated below. The total Barthel score is considered to be a more accurate indicator of physical dependence than either of its two subscores, "self-care" and "mobility."

BARTHEL INDEX SCORING

ADL FUNCTIONS	Can do be self	Can do with human assistance (someone else is usually present when client does this)	Cannot do at all
Drinking	4	0	0
Eating	6	0	0
Dressing upper body	5	3	0
Dressing lower body	7	4	0
Putting on brace or artificial limb	0	2	Not applicable
Grooming	5	0	0
Washing or bathing	6	0	0
Bladder continence	10	5 (accidents)	0 (incontinent
Bowel continence	10	5 (accidents)	0 (incontinent

SELF CARE SCORE (MAXIMUM 53)

ADL FUNCTIONS	Can do by self	Can do with human assistance (someone else is usually present when client does this)	Cannot do at all
Getting in or out chair	15	7	0
Getting on or off toilet	6	3	0
Getting in or out of tub or shower	1	0	0
Walking 50 yards on level	15	10	0
Walking up or down one flight of stairs	10	5	0
IF NOT WALKING:			
Propelling or pushing wheelchair	5	0	0

MOBILITY SCORE: (Maximum 47)

TOTAL BARTHEL SCORE: (Maximum 100)

A very low score on the Barthel Index (i.e., 0-20) is a necessary and sufficient condition to establish that an individual is most severely handicapped. Such severely handicapped would, in general, not be suited to the traditional VR program unless a given agency had a special program for the severely handicapped. An independent living program which included the services of a rehabilitation facility and/or a special program for job training and placement for the severely handicapped (e.g., the program at George Washington University)3 would probably better suit the needs of these individuals.

Under the Functional Limitation-"Employability" Scale described here, individuals with Barthel scores between 21-61 would be classified as severe for VR purposes and receive priority consideration for services. For individuals with Barthel scores above 61, other criteria must be utilized in making final decisions as to severity. Any <u>one</u> of the criteria presented in the following paragraphs (other functional limitations, poor employment history, low educational level, communication impairment, or greater age), in conjuction with Barthel scores of 62-90, would be sufficient to classify an individual as severely handicapped for VR purposes. Any <u>two</u> of the criteria in conjuction with a Barthel score above 90 also would be sufficient to qualify an individual as severely handicapped.

Individuals with Barthel scores above 61 but who do not possess any of these other characteristics would <u>not</u> qualify as severely handicapped. They would be eligible for VR services, but would not be given priority consideration.

<u>Other Functional Limitations</u>: While the Barthel Index provides a convenient summary scale for measuring independence in self care and mobility, certain

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3. Specialized engineering and placement services for the severely handicapped are provided under this program.

functional limitation items provide useful supplementary information about an individual's ability to function in order areas of daily living. In the VR and CMRC surveys, three items, (1) lifting or carrying weights of 10 pounds, (2) stooping, bending, or kneeling, and (3) reaching with both arms, appeared to be especially discriminating. These items reflect abilities which, in most instances, appear crucial in evaluating an individual's work potential. Under the model described here, an individual would be asked if he could do each item with no difficulty, some difficulty, or not at all. If an individual could not (1) lift or carry weights of about 10 pounds, (2) stoop, bend or kneel, or (3) reach with both arms, and had a Barthel score of 62-90, he would then be classified as severely handicapped by VR.

Communication Ability: The survey of persons rejected by VR revealed the importance of an individual's ability to communicate with friends, relatives, or fellow workers. It is unlikely that an individual with extremely low communication skills could secure a job without assistance. The following communication variables could be noted at intake and should an individual be impaired in any of them, and had a Barthel score of 62-90, he would be categorized as severely handicapped. Communication variables include:

Speech (intelligibility) is significantly impaired (i.e., simple conversation is unintelligible to non-family members.

Hearing is significantly impaired (i.e., deafness or hearing loss exceeds 70 decibels in better ear with corrections).

Vision is significantly impaired (i.e., blindiness in both eyes, or blindness in one eye with the other eye defective, or unable to obtain driver's license for visual reasons).

Employment History: Another criterion which can be used in conjunction with the Barthel Index to determine the extent of one's handicap is employment history. Those disabled individuals who have been unemployed for four or more years prior to contacting VR are very unlikely to be successful in the competitive labor market. Thus, those individuals without recent competitive employment and a Barthel score of 62-90 would be categorized as severely handicapped. Those with scores above 90, while eligible for VR services, would not be classified as severely handicapped, and would not receive priority consideration.

Educational Level: Educational level is another important variable affecting an individual's pereived employment potential. Individuals with extremely low levels are generally less likely to be successfully rehabilitated, since their job possibilities are limited. Those individuals with higher education generally have the potential to be placed in a mich wider range of jobs. For example, the individual who has a sixth grade education, who has worked in a steel factory for 30 years, and who becomes quadraplegic is not likely to be placed back in his old job. Furthermore, the options available to him are quite limited. In contrast to this, the college-educated professional who has the same injury has a much greater chance of returning to his old job or using his educational skills in some other kind of professional job. Thus, for VR purposes, individuals who have completed less than 9 grades of school and who have a Barthel score of 62-90 would be classified as severe. Those with scores above 90 with less than a ninth grade education would be eligible for VR services but would not be categoriezed as severe.

Age: Age constitutes another important and easily measurable criterion of eligibility. It is the common experience of VR counselors that the older client is more difficult to place in employment.[4] Potential employers seem to believe

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[4] On the Provider Survey, age was listed by counselors as the second most important factor in assessing severity of handicap. The VR survey substantiates this in that the average age of persons rejected by VR was considerably higher than those accepted for VR services, and even though older persons so rejected were less physically dependent than the younger persons rejected for severity.

that the older individual is more difficult to train and, once trained, less lilely to remain on the job long enough to repay their investment in training. In the employer's eyes, the older individual is viewed as one who will retire soon, whose health may fail, and who may have more difficulty adapting to and coping with his environment than younger persons.

In view of this situation, any individual over 50 years of age with a Barthel score between 62-90 would be considered under the assessment scheme outlined here as severely handicapped for VR purposes.

b. Severely Mentally Handicapped

In order to reduce ambiguities and outright errors in judgment regarding an individual's state of mental health, it would be desirable to have some objective, standardized criteria for determining whether an individual is psychotic, neurotic, etc., and to further delineate those who are most severely psychologically handicapped from those with lesser handicaps. In the absence of such criteria one must rely on counselor's or psychiatrist's judgments.

At the present time, the most widely used and extensively research personality test is the Minnesota Multiphasic Personality Inventory (MMPI). While this or other tests might prove to be useful in differentiating severe from moderate psychiatric handicaps, research with a substantial number of potential VR clients with psychiatric handicaps would be required to determine its efficacy as well as the most appropriate form and scoring system to be used. The issues which should be addressed in such research include the following:

1. Whether the test can relaibly distinguish indivudals who are severely handicapped from others with respect to vocational potential.

2. Whether the degree of accuracy attained through use of test procedures exceeds the accuracy of simpler methods more familiar to VR personnel, such as counselor's or psychiatrist's ratings of the clients mental state, and past mental

and work history.

3. Which items and/or subscales are necessary to produce the breifest test version with the maximum information necessary for the task at hand? Items which are generally not included on personality tests such as past work history and education may be included. Empirical research to cetermine the proper weights to assign items is necessary if items vary in importance for prediction of severity:

4. Whether simple scoring and interpretation systems can be constructed, thereby minimizing administrative difficulties in using such a test; and

5. Whether the use of test procedures is cost-effective, that is, would testing procedures produce more efficient, more accurate, and less costly scoring, and increased success in placement, or would they deplete resources better used for training, placing, or otherwise rehabilitating these persons?

Regardless of how well the above issues are resolved, it should always be recognized that no test is infallible, and that individual exceptions can be made upon the counselor's judgement.

The method currently used to categorize severely handicapped is sufficiently ambiguous to be subject to widely varying interpretations. Previous research indicates that the consensus between psychiatrists on even gross distinctions, such as neurotic, psychotic and character disorder, is far from perfect, and that the level of agreement decreases considerably when any finer distinctions (such as severely, moderately, and mildly neurotic) are to be made. However, the current method of classification must stand for the meent pending further research which is standardized on the VR population and which is <u>designed</u> to measure that which is being asked--to differentiate the severely mentally handicapped, a vocational perspective, and those who are less severely handicapped.

With respect to identifying persons with severe physical handicaps, the Functional Limitations Employability Scale has several important advantages over those discussed previously. Because all of the elements in this scale (e.g., age, educational level) are operationally defined and relatively easy to measure, the same conclusions regarding an individual cleint can be reached regardless of who administers the scale. In addition, the compoents of this scale, by all indications, capture the severity of handicap accurately, as it relates to actual employment potential. Reliability and validity of this method, then, are its two key attributes.

Another important advantage of the Functional Limitations-"Employability" Scale is the ease with which it can be administered. Rehabilitation counselors and administrators are not likley to have much trouble in using a scale of this nature.

The major problem with this method of assessing severity is its relative lack of flexibility. For example, individuals suffering from early stages of degenerative diseases, such as multiple sclerosis and muscular dystrophy, might score high on the Barthel scale and not be rated as severely handicapped (thereby giving them lower priority). Most rehabilitation providers, however, would want to give these individuals priority consideration. It should be recognized that it would be relatively easy to make accommodations of this type and still use this basic model.

4. Multidimensional Evaluation Scale[5]

A major problem in assessing client employability by using any of the first three methods is that a number of variables which may affect a disabled person's degree of handicap and employability, such as motivation for work, family support, and adjustment to disability, are not included. These variables, which are subjective in nature and therefore pose measurement difficulties, are included in the Multidimensional Evaluation Scale (see Figure 1). Items from the R-300 are used but the bulk of the form is committed to counselor ratings of client functioning in various areas: education, physical functioning, adjustment to disability, and social competency.

All scales have five-point ratings, with the extremes defined. The definitions are viewed by the authors as levels of functioning in relation to employment and are designed to eliminate, as much as possible, the problems encountered in loosely defined rating scales.

This multidimensional evaluation technique could be used to determine the severity of handicap by establishing some overall scoring system for severity; for example, a score of 96 and above might qualify an individual as being severely handicapped and thereby eligible for priority consideration by VR.

The major problem with such a scoring system would be the difficulty of accurately weighting the various items on the scale relative to each other. For example, is the client's "health status" as important or more important than his perceived "decision making ability" in assessing severity? If the former

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[5] The scale and the discussion which follows is adapted from materials contained in a report from the Study Group on Rehabilitation of the Severely Disabled, presented at the Eleventh Institute on Rehabilitation Services held during May 20-23, 1973, and sponsored by the Research and Training Center, West Virginia University. Technical information regarding the development and use of this technique, is available from Lowell Lehart, Technical Project Director, Department of Institutions, Social and Rehabilitative Services, P. O. Box 25352, Oklahoma City, Oklahoma 73125.

is more important, how much more important is it? These questions are best answered through empirical research on this instrument.

Another major problem with a method such as this is its apparent lack of reliability across counselors and caseloads. Nevertheless, the multi-dimensional evaluation scale is considered here and presented below because it does provide a more thorough picture of the multi-dimensional aspects of client "employability," and because it is relatively easy to administer.

Figure 27-1

MULTIDIMENSIONAL EVALUATION SCALE

I. OVERALL VR PROGNOSIS

A. Anticipated Change in Client's Level of Functioning During Services

________ 1. Alleviate
________ 2. Improve Greatly
________ 3. Improve Somewhat
________ 4. Remain the Same
________ 5. Deteriorate

B. Employment Potential

________ 1. Presently employed in competitive labor market and will continue on same job or higher job
________ 2. Employable at former job or another job without training
________ 3. Vocational training required; client has training potential
________ 4. Limited vocational training potential
________ 5. No vocational training potential

C. Employment History; To An Employer, the Client's Past Work History Would:

________ 1. Make a very favorable impression
________ 2. Make a favorable impression
________ 3. Seems adequate
________ 4. Seems inadequate, but acceptable with reservations
________ 5. Extremely bad employment history

D. Availability of Facilities and Client's Attitude Toward Temporary Relocation (Minimum of three weeks)

________ 1. All necessary facilities are available or client looks forward to temporary relocation
________ 2. Client accepts temporary relocation and adjustment problems will be relatively few or will not be severe or client resists using available facilities
________ 3. Client accepts temporary relocation but may have difficulty adjusting to his new surrounding
________ 4. Client is reluctant to relocate even temporarily and may encounter severe adjustment problems
________ 5. Client strongly opposed to temporary relocation; adjustment problems would definitely endanger chances for success

E. Availability of Transportation

________ 1. Client has easy access to an automobile or inexpensive public transportation
________ 2. Client must be driven by family, friends, or use taxi, which are avail[illegible]le
________ 3. Client must be driven by family, friends, or use taxi, but these resources are not readily available
________ 4. Many special considerations must be made by the counselor to provide transportation
________ 5. Client is homebound or must remain in a hospital or institution

II. EDUCATION

A. ________ 13 years and ~~above~~
B. ________ 10 to 12 years
C. ________ 7 to 9 years
D. ________ 0 to 6 years
E. ________ Special Education

III. ECONOMIC/VOCATIONAL STATUS

A. Vocational Level

________ 1. Professional, Technical and Managerial
________ 2. Licensed or certified trades and crafts, or other highly skilled work
________ 3. Semi-skilled and clerical
________ 4. Unskilled
________ 5. Disability status precludes employment

B. Weekly Earnings

________ 1. $100.01 per week and above
________ 2. $70.01 per week to $100.00
________ 3. $50.01 per week to $70.00
________ 4. $10.01 per week to $50.00
________ 5. $10.00 per week and below

C. Work Status

________ 1. Wage or salaried worker (competitive labor market) or self-employed (except BEP)
________ 2. Wage or salaried worker (sheltered workshop), state agency managed business enterprise (BEP)
________ 3. Homemaker, unpaid family worker, not working student
________ 4. Trainee or worker (non-competitive labor market)
________ 5. Not working other

D. Primary Source of Support

________ 1. Own Earnings
________ 2. Dividends, Interest, Rent, and Savings
________ 3. Family and friends, or non-disability insurance (Retirement, Survivors, Annuity, etc.)
________ 4. Disability and Sickness Insurance (SSDI, Workmen's Compensation, Civil Service, etc.)
________ 5. Public Assistance, Private Relief, or Resident of Public Institution

E. Dependency of Client on Others for Financial Support

________ 1. Completely independent
________ 2. Approximately 25% of income comes from sources other than earnings
________ 3. Approximately 50% of income comes from sources other than earnings
________ 4. Approximately 75% of income comes from sources other than earnings
________ 5. Totally dependent on sources other than earnings

IV. PHYSICAL FUNCTIONING

A. General Health Status Other Than Disability

________ 1. Feels good most of the time; has feelings of vitality
________ 2. Generally feels good, but reports minor problems that seem reasonable
________ 3. Multiple complaints, which seem mostly reasonable
________ 4. Multiple complaints that seem mostly unjustified by physical condition
________ 5. Multiple complaints that seem totally unjustified by his physical condition

B. Mobility

________ 1. Totally independent

________ 2. Ambulatory, but somewhat restricted or with minimal use of devices

________ 3. Ambulatory with major devices, as unassisted wheelchair

________ 4. Ambulatory only with assistance of another person, as assisted wheelchair

________ 5. Bedridden

C. Physical Independent for Tasks Other than Mobility

________ 1. Totally independent

________ 2. Minimal assistance required

________ 3. Dependent for one major or several minor tasks

________ 4. Dependent for several major tasks

________ 5. Constant need for attendant services

D. Work Tolerance

________ 1. Minimal restrictions to type of work client can do

________ 2. Occupations limited to light physical activity but able to work full-time

________ 3. Sedentary work, low stress, or close supervision required; but able to work full-time

________ 4. Unable to work full-time because of mental or physical condition

________ 5. Current disability status precludes employment

E. Prominence of Vocationally Handicapping Condition (Including Mental and Emotional)

Handicap is:

________ 1. Hidden and cannot be directly observed

________ 2. Hidden and would only be observed episodically

________ 3. Noticeable only after a period of interviewing, or only slightly noticeable

________ 4. Marked and obvious, noticeable at once and continually manifest

________ 5. Marked, obvious, and continually manifest and will be repugnant to most employers

F. Compensatory Skills

________ 1. Has developed in other skill areas or with the use of devices, almost total compensation for disability

________ 2. Has significant development in other skill areas, or with the use of devices, abilities which help compensate for disability

________ 3. No real development in other skill areas and minimal use of devices

________ 4. Some deterioration in other skill areas

________ 5. Substantial deterioration in other skill areas

V. ADJUSTMENT TO DISABILITY

A. Identification with Worker Role

________ 1. Client feels personal need to be independent, and do his share

________ 2. Identity to worker role developing or deteriorated somewhat since disability but wants to work

________ 3. Weak identity to worker role, little idea of day-to-day work demands

________ 4. Client has adjusted to being dependent; talks of working but is unconvincing

________ 5. Client strongly identifies with handicap and clings to dependent role

B. Compatibility of Employment Expectations with Client's Personality and Physical Condition

________ 1. Client seems ideally suited for the work he desires

________ 2. Client's employment expectations are reasonable, although not ideal

________ 3. Client has no ideas concerning possible vocational goals, or his ideas are more "day dreams" than employment expectations

________ 4. Client's employment expectations are very unrealistic and impractical

________ 5. Client's employment expectations are so totally unrealistic and impractical, counselor must work with other professional persons, agencies, or institutions before client can proceed in the rehabilitation process

C. Client's Confidence in Himself as a Worker

________ 1. Highly favorable, client's self-confidence inspires confidence from others

________ 2. Client believes he can and will be a good employee in spite of his handicap

________ 3. Client feels he will become a fairly good employee but exhibits little initiative

________ 4. Client excessively timid or shows unimpressive over-confidence

________ 5. Client can never see himself as being able to hold a job

VI. SOCIAL COMPETENCY

A. Language Facility

________ 1. Reads and writes well; has no trouble understanding and communicating common vernacular and could learn to use technical language

________ 2. Reads, speaks, and writes adequately; has no particular problem filling out employment applications, or holding job interview

________ 3. Reads, speaks, and writes adequately for job applications and interview, but speaks slowly and may have some difficulty with other than simple written instructions

________ 4. Reads, speaks, and/or writes poorly, and will have difficulty interpreting even simple written instructions

________ 5. Almost complete lack of language, functionally illiterate, extremely small vocabulary

B. Decision-Making Ability

________ 1. Takes strong active role in decision-making

________ 2. Slow to make decisions but makes his own decisions

________ 3. Wants others to make decisions but will take some part in decision-making process

________ 4. Others make decisions for him and manage his personal affairs

________ 5. Will neither help make decisions not take action on help from others; counselor must work with other professional agencies, persons, or institutions before client can proceed in the rehabilitation process

C. Role in Family

________ 1. Assumes appropriate role

________ 2. Assumes appropriate role but some counselor reservation

________ 3. Participates in familial affairs but evidence of underlying ambivalence toward family

________ 4. Refuses to assume appropriate role

________ 5. Conscious effort to disrupt family

D. **Family Support**

________ 1. Good; family shows great deal of understanding of client; very supportive and helpful

________ 2. Moderate; although not ideal, support is adequate

________ 3. Fair; support given but is inappropriate; evidence of underlying ambivalence on the part of the family

________ 4. Poor; support given but there is definite indifference on the part of the family toward client or his rehabilitation

________ 5. Very poor; family definitely non-supportive, strong opposition

C. Conclusion

The development of an operational definition which accurately measures or identifies severely handicapped individuals is of critical importance if the severely handicapped are to be effectively served either by the Vocational Rehabilitation Program, a new Independent Living Program, or some other kind of rehabilitation effort.

While a number of criteria could be used in making an assessment of these alternatives, three seem to stand out. The most important are the validity and reliability of the method for determining severity of handicap. Does the scale measure what it purports to, and would similar outcomes be obtained by any counselor using this method? Also of importance is the ease with which the method can be implemented by program providers.

In terms of validity and reliability, the multi-dimensional evaluation approach appears to be the weakest of the four described. The variables which the scale attempts to measure are often subjective and therefore subject to widely different interpretations by the tester.

The current RSA regulations and RSA extended approach also have reliability and validity problems. As noted before, estimates of severely handicapped ranged from 15 to 60 percent for different State agencies, which suggests that the reliability of the current method is low. The extended approach might fare somewhat better if specific criteria for severity are more thoroughly spelled out. The primary validity problem in using either RSA method is that there is only a minimal relationship between disability type and actual functional limitations.

The Functional Limitations - "Employability" Scale, on the other hand, since it is being composed of easily measured and standardized components, is the most reliable of the four methods discussed. It also appears that this method has the highest validity of the four methods considered here. For example, the Barthel Index scores presented were highly related to other functional limitations in the VR Survey, and all of the other items have an operationally proven relationship with employability as attested to by vocational rehabilitation providers.

The easiest of the four alternatives to administer is the current RSA approach, since it is relatively easy to determine disability type and no additional training of counselors or administrators would be necessary. It would be relatively easy to implement the RSA extended method, although the finer distinctions within disability types would probably increase the difficulty of administration somewhat. The Functional Limitation - Employability Scale and the Multidimensional Evaluation Scale are both fairly simple to administer, but since they are new approaches and are slightly more complex to interpret, they would pose somewhat greater administrative problems in making the change-over and involve more counselor time than the use of the current methods. If these new methods succeeded in reducing some of the time normally spent on client evaluation, however, these additional "costs" might be off-set.

Finally, it should be recognized that any system of assessing severity will be examined by a wide range of disability groups, all of whom have vested interests in receiving priority for services within the VR system. Representative of various groups should be consulted regarding major changes which may affect decisions about which of their members will receive a share of the services which VR has to offer.

Chapter 28

FINANCIAL OPTIONS FOR PROVIDING SERVICES TO THE SEVERELY DISABLED

Many possibilities exist for the design and financing of rehabilitation programs; we will attempt to explore some of the major aspects and options. Again, many of these options can be combined and possible combinations are innumerable; it is not within the scope of this paper to list all possibilities. The concepts discussed here are solely for the purpose of guiding the policy-maker, and no final recommendations are made. Only a few changes might be suggested for VR as it stands. For Independent Living, Rehabilitation (ILR), however, new options are possible. Since much of what may be provided in ILR is in the nature of personal support--i.e., housing modifications, cars, relocation assistance--mechanisms for cost participation by potential users are more important.

Financing is discussed along three dimensions: (1) Federal participation, (2) funding through other programs, and (3) client cost-sharing. At different points, we treat different programs serving the disabled in order to illustrate various financial options.

OPTIONS CONCERNING FEDERAL PARTICIPATION

Options along this dimension include: Full Federal financing, special revenue sharing and joint funding between Federal, State and local levels of government.

Full Federal Funding

Programs fully funded by the Federal Government are generally designed and administered by the Federal Government. These programs tend to insure equity across States by applying uniform eligibility standards and benefit provisions on a nationwide basis, thus assuring that residents of poorer States receive adequate benefits and services. A system of uniform standards and provisions across States, established at the Federal level, also removes from the States the burden of setting up and running programs unique to the State. However, an independent living program designed and administered at the Federal level may neglect to account for between-State variations in financial and service needs. For example, a flat "maintenance" or subsistence payment that is equal for all States may be inappropriate for areas with exceedingly high costs of living and for those with very low costs (although this could be solved by adopting standards which vary among States). A program which serves an urban population may not appropriately serve the needs of a rural population. In addition, a new federally funded program implies the shifting of even more State and local burdens to the Federal Government. If it is desired to move Vocational Rehabilitation in the direction of the most severely handicapped with concomitant reduction in efficiency, then full Federal financing might well be considered.

Programs fully funded by the Federal Government are financed through appropriations from general revenues or by special taxes. OASDI (Old-Age, Survivors, and Disability Insurance, or "Social Security") and Railroad Retirement benefits, which provide cash payments to workers and their survivors and dependents in the event of the worker's old age, disability, or death, are financed by a payroll tax, half of which is paid by the covered employee and half by his employer. (In the case of OASDI, a tax is paid by self-employed persons on their earnings.) Medicare's hospital insurance, financed in the same way as OASDI serves individuals aged 65 and over who are eligible for Social Security or Railroad Retirement benefits, persons entitled to Social Security Disability Insurance, and persons with chronic kidney disease. It is non-income-tested and provides hospital insurance in the form of payments to providers of inpatient hospital services and post-hospital care such as skilled nursing facilities and home health services.

Medicare's Supplementary Medical Insurance, on the other hand, is financed half by general revenues and half by premiums paid by participants in the program. The program serves persons aged 65 and over or disabled beneficiaries in the program at least 2 years or with chronic kidney disease who elect to enroll and is non-income-tested. Benefits are paid to either the provider or the beneficiary for medical services and care, home health services, outpatient hospital services and physical therapy, ambulance, and certain medical devices, supplies and equipment.

The Supplementary Security Income (SSI) program for the aged, blind, and disabled, which replaced former Federal grant-in-aid programs to these groups, is an open-ended program federally administered program financed from general revenues which makes direct payments to those who, after income and assets are taken into account, fall below a certain standard of need under nationally uniform eligibility standards and benefit levels. Prior to the implementation of SSI, programs for the aged, blind and disabled were State-administered, or State-supervised and locally administered; States determined benefit levels; and funding was Federal-State or Federal-State-local. This allowed for wide variations among States in benefit levels, treatment of income, and eligibility criteria.[1]

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[1] This discussion refers only to the Federal SSI portion and not to State supplementation of SSI. The implementation of SSI raised cash benefit levels in many areas; yet benefit levels were lower than they previously had been for individuals in 28 States and for couples in 30 States. State supplements for new recipients are optional with the States; all but 13 States provide supplementation. For single individuals with no countable income and no special needs, living independently, State supplements to the Federal SSI payment of $146 range from none to $123 for the aged and $146 for the blind and disabled in Massachusetts. Thus state supplementation of Federal benefits reintroduced variations in benefit levels.

Veterans' programs such as compensation to veterans with service-connected disabilities and pensions to veterans with non-service-connected disabilities are financed through open-ended Federal appropriations.

A major argument in favor of full Federal funding is that if States have a great degree of control, wide variations between State programs (and therefore inequities) may result, in both population served and services provided. An example is the Medicaid program, a Federal-State program funded from general revenues to help pay for health care costs of those receiving public assistance and for "medically needy" persons. Provision of services to the "medically needy" population--persons who do not qualify for the program out of "categorical need" (by virtue of being covered by other programs) but who are in need of services due to low income and who are aged, blind, disabled, or members of families with dependent children--is optional with the States. Medicaid also requires the provision of certain services (without specifying any particular amount, duration, or scope of care), but a wide range of services remains optional with the States. Thus, in addition to variations in persons eligible for Medicaid, States also diverge widely in the amounts and types of services offered.

As part of a survey conducted by the Council of State Administrators of Vocational Rehabilitation (CSAVR), State agency directors were asked about their preferences for financing an independent living program. Responses ranged from 60 percent Federal cost-sharing to 100 percent Federal funding. It is significant to note that almost half of the directors did not favor full Federal funding. These directors preferred Federal-State matching, on the grounds that this would allow the flexibility for States to develop practical programs to meet clients' needs at the local level and keep the States responsive to individual State needs. Federal matching would also give States an incentive for effort and participation.

Some of those who preferred 100 percent Federal funding envisioned difficulties in raising the State share for an independent living program, feeling that it would be viewed by State legislators and others as another welfare program. It was also felt that if matching were required, costs would be prohibitive for States; and that 100 percent Federal funding eliminates the hassle of getting matching funds.

Special Revenue Sharing

Under a special revenue sharing plan a program would have a given Federal allotment, funds being dispersed to State and/or local governments by means of an allocation formula determined by population, target population, State income and/or other State characteristics. Use of a formula which takes into account different State and local needs allows the dispersal of the most resources to those States which are in greatest need of assistance in achieving national goals. It also preserves the role of the Federal Government as a redistributor of income.

Special revenue sharing funds would be dispersed specifying national policy objectives but allowing State and/or local choice of program means, thus allowing broad State and local discretion and flexibility in the design of the program and the administration of federally raised funds with minimum interference from the Federal Government. Thus, while maintaining a national goal in a specified area, States and localities would be allowed maximum flexibility in determining how best to serve a population in order to achieve federally specified goals.

To distinguish special revenue sharing from "block grants" or grants-in-aid, there is usually no specific requirement that a State contribute a given amount for the program aim. Matching requirements tend to deflect State and local expenditures into areas where Federal funds are most available and to lead to the neglect of nonaided program needs which are also important. In a program established without matching requirements there would be no "local manipulation, and Federal complicity, around the provision of the local match. Moreover, the fact that specially shared revenue would all be Federal funds underlies the national stake in [the program] and the appropriateness of establishing national goals."[2]

Under a special revenue sharing plan the administrative complexity which is often a part of grants-in-aid--narrow and inflexible rules and regulations, applications for grants, reporting, and other procedural requirements--would be minimized. In the Nixon administration's six initial special revenue sharing proposals of 1971-72,[3] planning was required but was not a condition for receipt of funds, and release of funds was not conditioned on prior Federal approval. There was a requirement for reports to the Federal administrator who in turn had to make an annual report to the President and Congress. Thus much administrative rigidity would be eliminated and States would be freer to tailor the use of funds to their specific needs.

On the other hand it can be argued that when localities are allowed such broad discretion in the use of funds as would occur with special revenue sharing, it cannot be certain that all would be able to achieve national goals in rehabilitation without specific direction or that, without monitoring of funds, misuse would not occur. Critics of general revenue sharing claim that revenue sharing "is not being focused on the neediest States and cities, that some localities are using it to discriminate against minority groups, and

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[2] Melvin A. Mogulof, "Special Revenue Sharing in Support of the Public Social Services," Working Paper 963-16, The Urban Institute, Washington, 1973, p. 19.

[3] The six proposals were in the areas of transportation, manpower, education, urban community development, rural community development, and law enforcement.

that citizens have little voice in how shared revenue should be spent."[4]

Federal/State/Local Funding

Programs which are federally authorized but jointly funded by State (and sometimes local) governments generally allow greater variation among States in terms of program design and administration and reduce the financial burden on the Federal Government. Arrangements under which States contribute to program financing may involve (1) an allocation formula to determine the Federal contribution to individual States based on such State characteristics as total population, target population, and income, etc.[5] and/or (2) a matching ratio that fixes the number of Federal dollars for each dollar contributed by a State towards a particular program, possibly variable by State and possibly subject to a maximum determined by an allocation formula.

Possible allocation formulae for determining amounts of Federal contributions to States include: (1) a fixed percentage of Federal outlays across all States; (2) a percentage which varies by State according to such factors as per capita income or other measures of wealth; and (3) a percentage which decreases with income and rises with the level of State "effort."

A program to promote the independence of the disabled could use combinations of various allocation formulae and matching rates. There are numerous precedents for using multiple allocation rates and matching formulae in the same program. For example, under the former programs for the aged, blind, and

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[4] Joel Havemann, "Ford to Recommend Few Changes in Revenue Sharing," National Journal Reports, January 1975, p. 85.

[5] Population or estimates of target population may be used as factors to measure potential demand or need. Income measures may be used as factors on the assumption that making Federal funds more available to "poorer" States than "richer" States (i.e., taking into account States' ability to pay) will stimulate program growth in "poorer" States and will thereby prevent inequities. The use of income factors also maintains the position of the Federal Government as a redistributor of income.

disabled,[6] States were reimbursed by the Federal Government for $31 of the first $37 of the average monthly grant per recipient. For amounts in the average grants exceeding $37 and up to $75, the Federal Government paid between 50 to 65 percent based on a formula which took into account State per capita income. States which had a Medicaid plan had the option of using the "Federal medical assistance percentage" to determine the Federal share of assistance payments, which varied from 50 to 83 percent and which imposed no maximum on the Federal share of amounts based on the average grant. The Federal Government paid 75 percent of expenditures for defined services and 50 percent of other administrative costs. State participation in the programs was mandatory; local participation was optional. Federal funds were appropriated from general revenues.

In the CSAVR survey of VR directors referred to earlier, some directors felt that the current matching ratio in effect for VR (80 percent Federal funding) should also be used in an ILR program in order to insure equity among program recipients in any jointly administered VR-ILR program. It may be desirable for the ILR portion of a joint program to be funded at a lower level than the VR portion, so that counselors will not be motivated toward achieving independent living goals alone when a vocational goal may also be possible with extra effort. On the other hand, if it were difficult to raise the State share for an ILR program (for instance, if legislators and others prefer to dispense money to a program that will show an economic return by leading to productivity on the part of the individual), it might be easier to raise funds if the Federal match were 90 percent.

The VR program has used several combinations of allocation formulae and matching rates. Initially the allocation formula to determine the maximum

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[6] Old Age Assistance (OAA), Aid to the Blind (AB), and Aid to the Permanently and Totally Disabled (APTD), now replaced by the Supplemental Security Income program.

allotment for each State was based on State population alone, and the matching rate, which determined the amount of Federal reimbursement for State expenditures, was 50 percent. The minimum allotment for each State was $5,000. At present, separate authorizations are made for different types of grant programs. Grants for innovation and expansion of VR programs and services to handicapped individuals are allotments to States of amounts bearing the same ratio to the total sum appropriated as the States' populations bear to the U.S. population. The minimum allotment is $50,000 and Federal matching is 90 percent, as an incentive. Grants for research, training, special projects, and demonstrations are not subject to allocation formulae, and matching ratios are often unspecified and left to administrative determination.

Grants for basic vocational rehabilitation services are currently allocated by means of the "Hill-Burton" formula, so that a State's allotment for basic services is directly proportional to its population and inversely proportional to the square of a per capita income factor. The minimum allotment to which a State is entitled is (1) one-quarter of 1 percent of the total appropriation, (2) $2,000,000, or (3) the total payment to the State in fiscal year 1973, whichever is the greatest. The Federal Government will match the State's share at 80 percent.[7]

The Federal allotment to which a State is entitled for Vocational Rehabilitation may generally be expressed by the following equation.[8]

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[7] The VR agencies are reimbursed at 100 percent of the costs of rehabilitating disabled blind recipients of SSI, and 1 1/2 percent of Disability Insurance (DI) trust fund monies are available to finance rehabilitation costs of DI recipients at 100 percent under specific and stringent rules.

[8] The following formulations and explanations are from JWK International Corp., Vocational Rehabilitation State Allocation Study (Annandale, Va.: The Corporation, 1974), pp. III-8 and III-9.

$$A_i = \frac{P_i a_i^2}{\text{sum of } P_i a_i^2 \text{ for all States}} \times T \qquad \text{III-1}$$

where: A_i = allotment ($) for current fiscal year for State i;

P_i = population of State i;

T = total amount of federal funds authorized to be appropriated for basic vocational rehabilitation services in current fiscal year;

a_i = "allotment percentage" for State i.

The "allotment percentage," a_i, in the above formula is defined as follows.

$$a_i = 100 - 50 \frac{PCI_i}{PCI_{US}} \qquad \text{III-2}$$

where: PCI_i = per capita income of State i;

PCI_{US} = per capita income of United States.

Use of the term "allotment percentage" for a_i is somewhat misleading, since in the Hill-Burton formula it is actually the square of this term that determines the relative variation of the allotment from a population-only based allotment.

Three exceptions exists to formula III-2. First, if the use of the formula yields an allotment percentage of less than 33 1/3 percent for a State, the allotment percentage for that State is set equal to 33 1/3 percent. Second, if the formula yields an allotment percentage that is greater than 75 percent, the percentage is equal to 75 percent. And third, the allotment percentages for the District of Columbia, Guam, the Virgin Islands, American Samoa, and the Trust Territory of the Pacific Islands are all set equal to 75 percent. It is noted that, for the current distribution of State per capita incomes, the 33 1/3 and 75 percent limits are never actually exercised for any State.

In recent years there has been mounting debate concerning the equity of the allocation formula. The present formula, introduced in the Vocational Rehabilitation Amendments of 1954, was intended to encourage the development of VR service programs in the poorer States. Thus the formula which was developed put strong emphasis on States' ability to pay as represented by per capita income. Critics argue that "circumstances have changed since then. While the purpose of the early legislation appears to have been accomplished, the more populous States, which generally have the higher per capita income, now have outstanding problems in meeting the greater needs associated with 'urban overburden'."[9] The existing formula, introduced in 1954, is believed to be inequitable in distributing funds in today's environment. It is argued that the square on the allotment percentage has the effect of placing a burden on the higher-income, urbanized States and of failing to recognize the severe needs for Federal funds in these areas. The State Allocation Study by JWK International Corporation found that "the current [Hill-Burton] allocation formula introduces substantial inequities in allocating funds to States," equity being defined as the extent to which the allocation matches the incidence of the VR target population.[10] According to one study, if an allotment percentage in one State is one-half that of another State (population held constant), the first State would be entitled to only one-quarter as much Federal money as the second. If the per capita income of one State is half that of another (population held constant) and if the per capita income of the richer State is 25 percent less than the U.S. per capita income, then the allotment of the poorer State is 33 percent larger than that of the richer one. However, if the per capita income of the richer State is 25 percent larger than that of the U.S., then the allotment to the poorer State is 100 percent greater than that of the richer one. Thus squaring the per capita incomes over States with higher per capita income.

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[9] Statement of Ewald B. Nyquist, submitted to the Subcommittee on the Handicapped, Senate Committee on Labor and Public Welfare, 1/10/73.

[10] JWK International Corp., op. cit., Allocation Study, p. II-1.

The JWK study, considers the following as concepts which could be represented in an allocation formula: the potential demand for VR services, the ability of a State to pay, State effort, the costs of providing VR services, and State willingness to pay for VR services. They found no satisfactory way of representing the last three factors. Two formulas emerged from the study which were felt to be more equitable than the current formula. One allocates funds proportional to the [illegible]mated target population (a proxy measure of potential demand). The second (presented with reservations) modifies the first by including an unsquared per capita income factor as a proxy for ability to pay.

Some of the benefits of States' sharing in the costs of programs include: (1) the financial and administrative burden on the Federal Government is decreased; and (2) design of the program and administration of funds are more flexible and the program can be more geared to the special needs of individual States--i.e., there is greater State and local determination of the character and structure of the program and the means by which program goals are achieved.

An argument against Federal/State financing is based on the Federal match. When program A provides for Federal reimbursement at 75 percent and program B provides for Federal reimbursement at 50 percent, biases in favor of using program A whenever possible are bound to occur. Thus different matching formulas may lead to different utilization of programs arising from the percent of the Federal match and not based on the merits and/or appropriateness of the programs themselves. In addition, the match can affect equity of treatment of different categories of individuals within individual programs. For example, the current VR program has a fixed matching rate of 80 percent for services provided clients. If it is true that counselors are more likely to favor those with less severe disabilities and are less likely to help the more "difficult" severely disabled, a federal percentage of 90 percent for this category and 80 percent for the less severely disabled might provide greater incentive for counselors to help the most severely disabled. Were this to occur, it would be necessary to insure that clients covered under the 80 percent match were not negatively affected. It should be recalled that for a given Federal budget constraint, the higher the match, the less the multiplier effect of the State match and the less the total available. At 75 percent the Federal is 3 to 1 State; at 80 percent it is 4 to 1; at 90 percent it is 9 to 1. For $9 Federal at 75 percent the State matches $3 for a total of $12. At 90 percent the State matches $1 for a total of $10.

A final consideration in the financing of an ILR program is whether financing should be open- or closed-ended. Open-ended funding allows for program growth and expansion: with closed-ended (fixed) funding, once States have utilized their full Federal allotment by matching all the Federal money available to them, they can go no further with their programs without using 100 percent State funds. On the other hand, with closed-end appropriations comes greater Federal budgetary control over appropriations. Examples of programs serving the disabled which have open-ended funding are Medicaid, SSI, Medicare, OASDI and Railroad Retirement. Some closed-ended programs are Vocational Rehabilitation, Crippled Children's Service, Title XX Social Services, Aid to Education, and programs of the agency under the Older Americans Act.

OPTIONS CONCERNING FUNDING THROUGH OTHER PROGRAMS

It should also be realized that programs can be funded from more than one source. There are many examples of joint funding: Medicaid pays the costs of premiums, deductibles and co-insurance of the eligible poor's participation in the Medicare program in some States; VR services for certain DI recipients are by DI Trust Fund monies; and VR agencies are reimbursed at 100 percent of the costs of rehabilitation for certain blind and disabled recipients of SSI. In addition, VR agencies are required to make maximum use of similar benefits provided by other programs.

It is conceivable that fees and services in a program for independent living could be financed in part through other programs which provide similar benefits. As mentioned above, the DI Trust Fund and SSI currently pay 100 percent of the costs of vocational rehabilitation for recipients who qualify under work-related rules. The possibility could be examined of relaxing these rules so that the DI Trust Fund and SSI could cover the costs of independent living services to disabled populations.

Other programs can also be used to defray the costs of services in an independent living program. One such program, which also serves disabled individuals, is Social Services (Title XX), the goals of which include the achievement or maintenance of self-sufficiency and economic self-support, and the prevention or reduction of inappropriate institutional care through the provision of home-based care, community-based care, or other types of less intensive care. Under Title XX, services provided will be at the discretion of the States under broad Federal guidelines, so that not all States will provide the same services or serve the same populations. Some of the services in an independent living program which could be provided under Title XX might include services related to home management and maintenance, transportation services, training and related services, meal services, and health support services.

The Medicaid program also has a goal of providing rehabilitation and other services to help individuals retain or attain the capacity for independence or self-care. Medicaid optional services vary across States; for persons in an independent living program, those eligible for Medicaid could receive such services as hospital and physical care, x-ray and laboratory services, home health care services, drugs, prosthetic devices, physical therapy, and other rehabilitative services. Medicaid is a very complex program in which eligibility and service delivery vary from State to State. For instance, Tennessee allows only 20 days per year of inpatient hospital days, while New York and California impose no limitations. Some States cover the medically indigent while others cover only the categorically eligible. The end result in the VR program can be seen in the fact that Tennessee, for example, spends 43 percent of its total VR budget on medical restoration services, while New York spends only 1 percent.

Another major source of medical care is the Medicare program, which covers the aged, those with end-stage renal disease, and other eligible disabled individuals. As such, it is a source of funding for VR clients. Medicare does not cover in full many costs of services, although Medicaid can in some States for those eligible for that as well. Other sources of medical care, for those eligible for the programs, include Crippled Children's Service, private insurance, CHAMPUS, the Veterans Administration, State and local programs, community mental health programs, alcoholic and drug treatment programs, the Developmental Disabilities program, and workers' compensation.

Resources of still other programs should be utilized in an independent living program. If higher education were included in the program, it could be mandated, as in the VR act, that no services or training be provided in institutions of higher learning without first trying to obtain grant assistance from other sources to pay for all or part of such training. Programs which could be used to provide such assistance include basic education opportunity grants, guaranteed loans for persons with low income, and scholarships. The GI Bill can also be used for educational expenses for those eligible. Financing of training services might be provided through programs such as the Work-Incentive Program, the Comprehensive Employment and Training Act, vocational education or training programs, and other manpower and training programs.

VR can provide maintenance payments for individuals undergoing a rehabilitation program. In a program for independent living, individuals would also be in need of such subsidies. For those who are most severe, entitlement to Disability Insurance or public assistance programs such as SSI, AFDC, and General Assistance should be fairly automatic.

This section is not intended to be an exhaustive review of other programs serving the disabled, but as an illustration of how the resources of other programs can be used in a program of independent living. In utilizing other program benefits, care must be taken to insure continuity of service, organization of supply, and program coordination. In the event that an ILR program had a fixed appropriation, as does VR, then it makes sense that full investigation should be made of alternative sources of funding from more open-ended programs which provide similar benefits.

OPTIONS CONCERNING CLIENT COST SHARING*

In discussing the financing of a program of independent living, some consideration should be given to the possibility of client cost sharing since some services provided under a program of this type might include those normally provided by the individual -- meal preparation, homemaking, recreational activities, etc.

Client cost sharing could include payments associated with inclusion in the program and payments associated with use of the program's care benefits.[11]

Payments Associated with Inclusion in Program

The options within this dimension include (1) no payment, (2) insurance payments, (3) capitation fees, and (4) income-scaled capitation fees. Use

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*Much of this section is adapted from William Pollak, "Federal Long-Term Care Strategy: Options and Analysis," Working Paper 970-04-01, The Urban Institute, Washington, 1974, pp. 7-18.

[11] Inclusion in program means that ine is eligible for benefits in the event that one suffers an illness or impairment covered by the program. It does not mean that one uses the program.

of any of the latter three options creates alternatives consisting of the rates at which payments can be set or the schedules which can be employed to determine payment rates. It is apparent, however, that additional options can be created by combining aspects of the options presented here and that still others exist which are unrelated to those presented here.

1. No payment

Persons may be included in the program without paying any fee. If this is done, the program's deficit on other accounts will have to be financed either from general revenues or from a special tax unassociated with inclusion in the program.[12] Medicaid and Social Services currently impose no inclusion fee and the Federal shares are financed from general revenues whereas Medicare's hospital insurance also generally imposes no inclusion fee but is financed by a special earmarked tax. Financing of the program through general revenues will be more progressive than financing it with insurance-type or capitation inclusion fees, both of which will tend to be regressive in nature. No statements about incidence can be made concerning special taxes or income-scaled capitation fees since their incidence will depend on the particular schedule used to establish tax payments or fees.

2. Insurance payment

An individual's payments for insurance approximate the expected value of his program benefits. Consequently, because the expected value of program benefits vary among individuals, insurance payments will also vary among individuals. Under what might be called a pure insurance payment, an effort is made to identify accurately the expected value of payments to an individual (i.e., his risks). This enables the seller to impose a low premium so as to attract the buyer while assuring that he will not lose money on a large group of similar-risk insurance buyers. The most severely disabled (or highest risk) persons

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[12] If coverage of program is universal, then an inclusion fee will be indistinguishable from a special tax.

who are likely to face higher medical expenses than those less severely disabled (or lower risk) will consequently pay higher premiums than less severely disabled persons. Second, a program funded by an insurance type payment is not considered redistributive.[13] In each instance the premium payment approximates the value of the insurance policy -- that is, the expected value of insurance benefits. No category of individuals pays an excess over expected program benefits in order to subsidize the program benefits of another category of individuals -- and in this sense an insurance type program is not redistributive.

Third, a large share of all persons who will require services from an independent living program over the next several years already suffer from an illness or impairment rather than being at risk of a disabling condition. A program literally financed by insurance-type payments would benefit these people little since their payment would have to cover costs which are known with certainty. An insurance-type program would therefore be practicable and helpful to the already impaired only if it was diverged from in order to finance the care of this large category of persons.

3. Capitation Fee

If the program is financed by a capitation fee each eligible individual pays the same flat fee for inclusion in the program. If the capitation fee option is selected, further discussions must be made concerning the dollar values at which the fee can be set. An independent living program which is financed by capitation fees may resemble an insurance program on the benefit side. It is not, however, an insurance program as defined above because it is not financed by fees corresponding to risks but rather is financed by fees.

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[13] Taken by itself, without accounting for program benefits, the incidence of the insurance type fee is likely to be regressive as noted below.

which are equal for all potential beneficiaries.

An independent living program which is financed by capitation fees is redistributive. It redistributes from those who are identifiable at the outset as low-risk participants to those identifiable as high-risk participants. Because it redistributes, an independent living program financed by capitation (or other non-insurance type) fees would have to compel eligible individuals to join. If not compelled, many of those who are donors in the redistribution would reject the program. They could purchase its insurance component in the private market without subsidizing the coverage of higher risk (and poor, if the fees are scaled to income) individuals as they do in a capitation fee financed program. But since the desertion of donors would destroy a redistributive program the inclusion of donors must be compelled.[14] Medicare medical insurance is financed half by capitation-type premiums and is not compulsory, but half is financed out of general revenues; the premium ($6.70 per month) is probably less expensive than what is obtainable in the private market.

If the objective of an independent living program were to serve all those needing care, a program financed by insurance type fees would fail in part because many persons would be unable to pay the premium required for coverage unless the program were tied, for example, to Social Security. A program financed by capitation fees diverges from insurance fees by favoring those in high risk categories. It does not, however, assist persons whose low income would prevent the payment of a capitation fee just as it would prevent the payment of an insurance premium. An alternative is that fees for the poor be paid by other programs, as

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[14] If financed out of general revenues compulsion arises in the compelling of tax payments.

the Medicare premium for the eligible poor is paid by Medicaid. It also could be avoided by financing the program with an adjusted capitation fee.

4. Adjusted Capitation Fee

An adjusted capitation fee is a fee paid by each individual which, though independent of the individual's risk category, rises with income. If this financing option is selected, alternatives within it include (a) the minimum level of income at which a payment must be paid, (b) the rate at which payments rise with income once income level (a) is reached, and (c) the maximum inclusion fee which is levied by the program. If fees are scaled to income in order to avoid undesired distributional effects, that should be done with attention paid to possible conflicts with work-incentive objectives of income maintenance programs.

Payments Associated with the Use of Program Benefits

In the Vocational Rehabilitation program from its inception until 1943, there was no Federal requirement for an economic need test, although in practice States attempted to draw in client contributions. Under the 1943 amendments, States were required to use economic need tests to determine client contributions or financial supplementation. In 1954, the Federal requirement for economic need tests was amended, and in 1965 it was eliminated. Economic need tests are now optional with the States, except that Federal regulations specify that States may not apply a need test as a condition for furnishing (1) evaluation of rehabilitation potential; (2) counseling, guidance, and referral services; and (3) placement. When the 1965 amendments were under consideration, the House Education and Labor Committee stated in its report (House Report 432) that "the Committee wishes to emphasize its feeling that rehabilitation services should be made available on the basis of the person's handicap and not on the basis of economic need." In a report later requested by the Committee it was shown that there had been progress toward the Committee objective in that most States liberalized the conditions governing their need tests. Eleven States eliminated economic need tests from their general VR plans, and eleven States did so in their plans for the blind. These changes seemed to indicate that Federal standards prior to the amendments had been restrictive.

State agencies today may choose to require need tests for all services except those federally exempt; to require no tests at all; or to selectively apply a test to all services not exempt from Federal regulations. As of October 1971, 42 general VR agencies required some economic need tests, and 33 of them used the selective approach in applying the need test.

While this is the manner in which VR operates, there are other approaches which merit consideration. Under discussion in this section will be program usage requiring (1) no payment, (2) deductibles, and (3) co-insurance and co-payments.

1. No Payment

Persons may receive services from programs without paying any fee, as currently occurs in the Medicaid and Social Services programs, VA hospital, nursing home and medical care programs, and, in some States, the VR program. If this is done, fees must be financed from general revenues or from a special tax. This type of arrangement may be selected if most of the persons in a program have low incomes and are unable to pay for services. If only a small percentage of those served can afford to pay, the administrative and accounting costs involved in charging fees may be larger than the amount that could be collected by the imposition of deductibles and/or fees for service.

2. Deductibles

The virtue of a program which is insurance on both the payment and benefit sides is that for a fixed price it assures financial compensation for disproportionately burdensome large and unexpected expenses. A "deductible" provision eliminates coverage of expenditures below the deductible threshold. Options along the "deductible" dimension are the different dollar levels at which the deductible can be set. Deductibles can reduce the cost of program without impairing coverage of large expenses by placing on individuals the costs of a certain low level of service utilization. Medicare's hospital insurance currently imposes a deductible of $92 per benefit period for hospital stays; Medicare's medical insurance imposes a deductible of $60 per calendar year.

Much of the negative character of deductibles in an independent living program could be eliminated by establishing, instead of a single fixed deductible amount, a schedule of deductibles ranging from a zero or very low level for the poor to some maximum level for those with incomes above a selected level. Recognition of this possibility increases options along the deductible dimension and requires that a deductible schedule rather than simply a level be specified. This will complicate the administration of the program.

3. Co-Insurance and Co-Payments

Under a co-insurance provision the program will pay only a percentage of expenditures with the remainder (the "co-insurance" or "cost-share") becoming the responsibility of the client. Under a co-payment provision cleints pay a flat fee (e.g., $1) for each service unit, such as a physician or homemaker visit or prescription. Options on a simple co-insurance dimension include the many values at which the co-insurance percentage can be set. Medicare's hospital insurance employs the co-payment method; the 61st through 90th day of hospitalization per benefit period are subject to a co-payment of $23 per day. Subsequent care in a skilled nursing facility is subject to a co-payment of $11.50 per day for the 21st through 100th day. Medicare's medical insurance utilizes a co-insurance payment: individuals are responsible for 20 percent of the reasonable charges for covered medical expenses.

The co-insurance share, however, need not be fixed. It can vary directly with income in order to avoid undesired equity or distributional impacts or to effect a redistribution of costs and can rise or fall (smoothly or in one or several steps) with the level of expenses incurred by the client. For example, co-insurance of 20 percent could be required on expenses up to $4,000 during one year but could be cut off on expenditures exceeding that amount. Co-insurance also might be set at different levels for different categories of care or services if incentives (or disincentives) to encourage (or discourage) utilization of particular categories of care or services are sought. Thus co-insurance of 20 percent and 10 percent might be imposed respectively on two alternative types of service in order to encourage greater utilization of one or less utilization of the other than would occur with uniform co-insurance levels. These possibilities obviously enrich the alternatives available along the co-insurance dimension. Similar variations can also be based on flat co-payments. Thus co-payments can be varied with income, limited to a per annum maximum, and varied among categories of care.

A co-payment or co-insurance provision reduces the budget cost of a program and reduces it more as the co-payment percentage of co-payment level is increased. As with deductibles, the inclusion of unscaled co-insurance or co-payments can introduce a dissonant note if the objective of the program is to avoid placing undue hardship on persons needing an independent living program. Scaling of levels to income obviously can reduce or eliminate the dissonance -- again at the cost of introducing administrative complexity and the possibility of conflicts with work incentive objectives of income maintenance programs. Co-payment or co-insurance costs may also be absorbed by other programs for those with low income; for example, Medicaid now pays the co-insurance and co-payment amounts of the Medicare program for the eligible poor. Co-insurance and co-payments, however, keep the use of program services from being free to participants and thereby discourage excessive use of services. "If resources are truly scarce, as they are in a number of service areas, this is clearly a desirable objective so long as co-payment are not set so high as to significantly discourage utilization by the target population."[15] This of course is a primary function of fees generally and of co-insurance and co-payments in medical and some other insurance programs.[16] There are substitutes for many elements of an independent living program--the number and appropriateness of substitutes vary of course with the defined scope of the program. The availability of substitutes is relevant to the analysis of co-insurance and co-payments. It suggests that their rationing impact is likely to be effective with services needed in an independent living program, since the fee will induce the use of informal care substitutes rather than the neglect of care.[17]

These points do not conclusively justify the use of either co-insurance or co-payments in a program of independent living. For instance, there are "a number of problems inherent in this approach, such as the possibility that service usage will be denied to the poor, equity considerations (e.g., that persons in like circumstances, however defined, should be treated equally) and the like. These disadvantages should be weighed against the very real benefits of the approach before a final decision as to net desirability is rendered."[18]

It should be realized that the preceding discussion does not provide a rationale for a particular co-insurance or co-payment level or schedule and fails to consider the difficulties of administering co-payment provision. It is apparent, however, that some mechanism will be required to ration program-financed independent living program services -- particularly those which are close substitutes for regularly

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[15] Terence F. Kelly, "Fee Schedules and Social Services," Working Paper 963-9, The Urban Institute, Washington, 1972, p. 1.

[16] Co-insurance does not serve this rationing function in insurance programs where insurance payments are independent of insuree behavior--e.g., in the case of fire insurance.

[17] There obviously are many instances in an independent living program as well as in acute care when informal substitutes for formal care do not exist. For example an impaired elderly individual with no family will not substitute family provided assi tance for a formal meal program because there is a financial incentive to do so.

[18] Kelly, "Fee Schedules," p.1.

marketed goods and services, and services which families of impaired individuals (when present) can provide. A variety of mechanisms can serve this function. Indeed a major component of counselors' efforts often is the identification and management of appropriate sharing of care efforts between formal programs (physical therapy, visiting nurses or home health aides, homemakers, and so on) and the families of clients. Co-insurance and co-payments represent a mechanism which can work along, or more likely, can influence care decisions in concert with other mechanisms including the intervention of counselors.

Finally, it should be mentioned that some upper limit on co-insurance or co-payments will probably have to be set "to ensure the availability of services to those whose needs are substantial but whose means are limited. One alternative is to charge fees up to a maximum level of cost, thereby reinforcing consumer choice in discretionary areas while not excluding services to those whose needs are less a function of discretion than of catastrophe."[19]

SUMMARY

This paper has attempted to assess some of the financial options involved in providing services to the severely disabled through a program for independent living. We have looked at options in the degree of Federal financial participation in the program, in the utilization of the resources of other programs, and in the possibilities for client cost sharing. No conclusions have been drawn; it is hoped that the discussion here can be helpful in informing policymakers of the general characteristics of the options under consideration.

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[19] Ibid., p. 4.

Chapter 29

SUMMARY OF MAJOR FINDINGS

Definitions

1. For this report, we have termed the residual limitation resulting from a congenital defect, disease, or injury an impairment. A person with an impairment, then, may or may not have a disability, an inability to perform some key life functions. When the disability interacts with the environment to impose impediments to the individual's goals for travel or work, for example, the individual has a handicap; that is, there are severely handicapping environments as well as impairments.

2. Severity refers to the degree of impairment, disability, or handicap. At the worst degree of severe, these three terms are virtually synonymous. Furthermore, when an impairment is mild or moderate, a disability or handicap may or may not exist.

3. An impairment can only be alleviated or remediated through devices or medical care. A disability can be remediated through training, or devices or medical care. A handicapping condition, on the other hand, can be remediated through changes in the environment, or training of the individual, or both.

4. Different persons react differently to a given impairment. Thus, similar impairments may result in different disabling or handicapping conditions. Some persons are more disabled or handicapped by a given level of impairment than others for reasons other than the impairment itself, such as motivation, age, education, family, and environmental or attitudinal barriers.

5. Disabled persons face different handicapping conditions in different areas of life. For example, some severely disabled have a relative minor

handicap with respect to transportation, whereas others are severely limited by transportation.

6. Diagnostic labels are sometimes used as proxies for disabilities or handicaps. One often hears that if a person has a condition--blindness, paraplegia, retardation--that person has a "disability" or "handicap." However, any given diagnostic label implies a range of severity. Such labels often further stereotype the abilities of individuals which are incorrect.

Estimates of Severely Disabled Population

1. Most data files do not contain information on handicapping conditions at all; a few focus on disability. The primary data sources useful for population estimates measure inability to work attributed to some health condition or disability. However, there is no current ongoing system for data collection on the characteristics or number of the handicapped for VR purposes.

2. A comparison of the major sources of data on the disabled population results in different estimates even when controlling for year of survey, definition of disability, severity, etc. Our estimates are based on the most methodologically sound parts of different approaches. We estimated that in 1975 there are approximately the following number of most severely handicapped persons in the United States, when severe disability is considered to be analogous to severe handicap:

Noninstitutional population	8,280,000
Under age 18	180,000
18-64	4,200,000
65 and over	3,900,000
Institutional population	1,787,000
Total U.S. population with most severe handicaps	10,067,000

3. In general, the severely disabled noninstitutional population are older, more female, slightly more nonwhite, less well educated, and slightly more southern, and they have more than one impairment compared to the less severely disabled.

4. The largest States have the largest absolute number of severely disabled. The most frequent disability types are musculoskeletal and cardiovasular impairments, followed by mental and nervous system disorders.

VR and the Severely Disabled

1. Persons who are defined as disabled because of their inability to work tend to be older than persons of moderate work disability and to have a variety of characteristics which suggest that the labor market does not accept them because of a combination of impairment and other factors, rather than because of the extent of their impairment. The analysis of the VR program with respect to who is accepted and rejected, and who is successfully or unsuccessfully closed reflects these same factors. Because of its vocational orientation, the VR program seems to be making conservative choices regarding acceptances. For example, about 12 percent of people in our sample who had been rejected by VR because of severity were working or had worked within 1 year of being interviewed. A much larger percentage had worked within 3 years.

2. Age plays a crucial role in the impact of a disabling condition. The older person is more likely to consider himself to have severe work disability, is less likely to be admitted to the rehabilitation program, is more likely to be identified by the rehabilitation program as severely handicapped, and if admitted, is less likely to complete the program successfully.

Special emphasis on the severely handicapped in need of rehabilitation services implies focusing on older clients. Since older clients are more difficult to place, total resources would have to be increased and resources allocated from younger to older clients. Such a reallocation of resources would probably lower the number of rehabilitations per dollar expended.

3. The referral source plays a key role in the rehabilitation system. Those referred from welfare agencies are more likely to be rejected for services. If they are accepted, however, they are more likely to complete the program. Those referred from public and private health agencies and service organizations are also more likely to be rejected for services, and if accepted, they are less likely to successfully complete the program. Those referred from hospitals are more likely to be accepted for services but less likely to successfully complete the program. Severity of handicap is the most common reason for rejection for persons referred from all these sources.

4. Education generally makes it easier to overcome a disabling condition. The better educated are less likely to suffer severe work disability, more likely to receive services if they apply, and more likely to be successfully rehabilitated if they are accepted.

5. The probability of acceptance into the program is the same for whites and nonwhites. Nonwhites are more likely to consider themselves as having severe work disabilities and are less likely to be successfully rehabilitated after they are accepted.

6. A rehabilitant is likely to be younger, white, better educated, male, not a public assistance recipient, married and living with spouse, having dependents, living in a State with high rehabilitation expenditures per disabled individual, having competitive labor market experience, and

having only one disabling condition. The disabling condition is more likely to be speech or hearing, orthopedic, amputation, mental retardation, neoplasm, digestive disorder, or genitourinary impairment.

7. In high unemployment states, the probability of acceptance into the program is higher for females, nonwhites and older people. The probability of successful rehabilitation for all applicants if lower in high unemployment States.

8. The probability of severely handicapped being denied services is lower in those States with higher vocational rehabilitation expenditures per disabled person in the State. The implication of this finding is that two people with the same set of characteristics who apply for services would have different likelihood of admittance to the program depending upon the financial allotment to the State program.

Survey Findings

Survey of Individuals Rejected by VR

1. Our interview sample of 889 physically handicapped individuals closed from VR for severity was largely white, male, and urban, and had an average family income of almost $7,000. The most striking demographic characteristic is that half of the sample was over 50 years of age, with only 31 percent under 45 years of age.

2. Approximately half of the sample had some type of orthopedic impairment; the only other frequently occurring diagnostic type was cardiac and circulatory conditions, comprising 18 percent of the sample.

3. According to the Barthel Index, 45 percent of the surveyed population were found to be completely independent in self-care and mobility, 14 percent were slightly dependent, 30 percent were moderately dependent, and only 11 percent were severely or totally dependent. On the basis of the Barthel

Index, then, there is strikingly little evidence of overwhelming physical dependency in this sample. The same conclusion can be reached on the basis of other functional limitation items--most people closed for severity can perform almost all activities of daily living.

4. Cross-tabulations between diagnostic condition and severity revealed that there is only a minimal relationship between diagnostic labels and severity. This finding has important implications for the current RSA guidelines for determining severity.

5. The most severely disabled age group was the young, aged 16-30. Furthermore, as age increased, the percentage of respondents who were totally or severely disabled decreased. A sizeable portion of young people are actually closed for severity, while older persons appear to be closed for other reasons, such as the difficulty of job placement. This suggests that the severity closure reason is being used as a proxy for case difficulty.

6. Almost half (46 percent) of the individuals of prime working age who were functionally independent or only slightly dependent and closed by VR because of severity were either working at the time, had recent work experience, or wanted to work.

7. Further analysis of young, physically independent persons with recent work experience who were rejected due to severity showed that there was no single reason for their rejection--anticipated labor market discrimination, psychological problems, disagreement over VR's program, and scheduling problems. These factors as well as conservative judgments in placement on the part of the VR counselor, may have contributed more to closures for reasons of severity than the actual physical impairments of these individuals.

8. Sixty-eight percent of the persons surveyed had some type of equipment, such as wheelchairs, canes, or dentures. Two-thirds of the respondents

indicated that they did not currently need any further equipment. However, persons indicating some need for equipment listed on average of 1.3 types of equipment needed.

9. Social Security was the agency other than VR that was most frequently contacted by the severely handicapped, 88 percent having contacted this agency, followed by the Food Stamp program (34 percent), and Aid to Families with Dependent Children (26 percent). The benefit most frequently received from all agencies combined was cash income.

10. While one-half of the population received counseling from VR, only 29 percent received any services in addition to counseling.

11. Almost two-fifths of the population stated that they did not need any additional services; the remaining group, however, indicated an average need of three services per person. The most frequently cited service needs were vocational training (21 percent), transportation (18 percent), physical therapy (10 percent), vocational placement (25 percent), vocational counseling (14 percent), and educational costs (12 percent).

12. The youngest age group seems to have had the greatest need for services of some sort, which is consistent with their lower Barthel scores. Thus, the more dependent, the greater the need for services. Younger persons also had a heavier need for vocationally related services.

13. Types of service needs clearly differed for individuals with different degrees of dependency. Medical services are needed for the most dependent, and vocational services for those less dependent.

14. Based on the findings of this survey, it would appear that many of this group of disabled are in need of services, and that many want to work and appear capable of working but are sitting at home, often quite isolated socially. Others who are less physically able are often even more neglected,

in part due to conditions which could be changed with more careful planning for the needs of the disabled. The service and equipment needs identified are within the known ability of VR to deliver.

CMRC Survey Comparisons

1. A little over 300 patients of 10 Comprehensive Medical Rehabilitation Centers (CMRCs) were also interviewed. The CMRC and VR samples differed considerably in age distribution, the CMRC sample, having about three times as many individuals under 30 years of age as well as almost three times as many individuals over 60 years of age. Despite those important differences in the age ranges of the two groups, slightly over half of both populations are older than 50.

2. Both populations are largely male, married, white, and living with their families. The CMRC population, however, had a higher percentage of females, more individuals who were widowed or single and fewer persons who were living with their families.

3. The education level of the two populations differed markedly, with the CMRC population being considerably better educated than the persons rejected from VR. More than twice as many CMRC patients had attended college or graduate school.

4. The CMRC population was much more physically dependent, as measured by the Barthel Index. For example, 45 percent of the VR population as compared to 18 percent of the CMRC group were completely independent in self-care and mobility. Almost one-third of the CMRC group was found to be severely or totally dependent.

5. The physical needs of the CMRC sample exceeded those of the VR sample. The major physical needs included rehabilitation therapy, attendant care, and equipment.

6. The CMRC population had a higher percentage of individuals in white collar jobs and slightly more than twice as many employed as the VR population. The major reason cited by the majority of both populations for not working was physical condition, although the VR population cited this far more frequently. Finally, both groups needed similar kinds of services in order to facilitate their return to work, although the CMRC population had a higher need for medical and home care services than the VR population.

Problem Areas for the Disabled

Architectural Barriers

1. Local governments have made very limited efforts to eliminate barriers in public housing and facilities. Furthermore, a great majority of the Nation's cities have not initiated any programs designed to eliminate these barriers.

2. Public Law 90-480 appears to be weakly enforced, partly because of the language in that law which allows loopholes. Better enforcement of existing standards for a barrier-free environment and a local program which contained information on how modifications could be made are two key policy options that could be pursued.

3. According to the VR survey results, 16 percent of the sample had difficulty living in or getting in or out of their homes because of architectural barriers. The major reason the barriers were not removed related to the costs of the changes.

Geographical Mobility

1. Relatively little is known about the specific mobility patterns of the severely handicapped, although it can be inferred from various surveys that their residential mobility is considerably less than that of the general population.

2. In the VR survey, 7.8 percent moved to another area because of the availability of family assistance.

3. Generally, not enough information is available to make further conclusions about the geographical mobility of the severely disabled. Pilot projects on mobility as well as extended research into actual mobility patterns should allow for formulation of more meaningful policy options.

Transportation

1. According to the VR survey, transportation services were second only to vocational placement in perceived need. Most of the transportation needs of the sample were taken care of by friends and relatives.

2. Almost one-third of the sample of persons rejected from VR go outside once a week or less.

3. Different disability groups will need different types of transportation alternatives. For example, the needs of the blind individual are quite different from the transportation needs of a quadriplegic. Furthermore, these solutions for alternative groups will be different in terms of cost.

4. Finding solutions to transportation problems of the severely handicapped is a complex undertaking, since different types of severely handicapped require different types of transportation solutions. It is important, then, that a wide range of solutions be explored and evaluated so that the most effective national program options are developed. Among the options are paratransit, retrofitting existing programs, tax subsidies for excess transportation costs to the handicapped, and reform of existing public systems.

Employment

1. Besides the limitations placed on the severely handicapped by their impairment and their socioeconomic characteristics, a number of other factors affect their level of participation in the labor market. Some of the most

important factors are inadequate aggregate demand, capital disincentives, employer discrimination, and lack of full employment in the economy.

2. In the survey of individuals closed from VR, it was found that prior to their disability the sample worked in a wide range of professions, were industrious, and many were earning an average income. Of further interest is the fact that 12 percent of the sample had worked within a year of the date they were interviewed, including 6 percent who were employed at the time of the interview.

3. Seventy-one percent of the individuals who were currently employed had perfect Barthel scores, indicating that they were totally independent in the activities of daily livng. Closures from the program, then, seem to be based on judgments about employability rather than severity.

4. These survey results indicate that special methods may have to be developed to enhance the employment situation of the young, physically independent persons rejected. For the older population, some type of increased placement program on positions with reduced duration and intensity of work may be most appropriate. The policy options for enhancing the employment prospects of the severely handicapped cover a wide range. The alternatives include affirmative action, public sector employment, public service work programs, sheltered workshops, wage subsidies, employment quotas, and projects with industry.

Social Interaction

1. Our survey documents the fact that many severely handicapped are socially isolated and have poor self-concept.

2. The majority of their social contacts are limited to family members, with very few engaging to any significant extent in outside activities.

3. Large numbers of severely handicapped are prevented from participating in social activities by attitudinal barriers, architectural barriers, and transportation barriers.

Mentally Ill

1. The mentally ill have a high probability of being accepted into VR if they get to applicant status. They are also one of the groups which, on acceptance, has a high probability of ending up not successfully rehabilitated.

2. While the number of rehabilitated persons who are mentally ill have increased in absolute numbers, such rehabilitants have declined from 6.6% of all clients rehabilitated in 1969 to 5.5% in 1972.

3. Independent living for the mentally disabled currently is in the domain of the mental health system. If future programs for ILR include the mentally ill, separate responsibilities of the different programs and agencies must be identified. We were unable to clarify such differentiations.

Mental Retardation

1. Independent living for this group is currently the responsibility of experts in the field of services to the mentally retarded. If the mentally retarded are to be included in ILR programs, separate responsibilities of the different programs must be defined. We were unable to find any logical differentiation of roles in such a program.

2. Retardation is the primary disability in almost one-eighth of all rehabilitations. However, the severely handicapped retarded are still a minority of the retarded accepted, despite some evidence that the retarded as a group are more vocationally capable than is reflected in the current VR program.

3. The VR program could help retarded persons who are seeking jobs cope with serious problems of: 1) lack of training; 2) job discrimination;

3) difficulty in locating jobs suitable to abilities, and 4) inability to complete job application forms and procedures.

4. Policy options which address the above problems include (1) assuring availability of services; (2) developing sheltered employment in the competitive labor market rather than in special workshops; (3) having longer time periods for case carrying and services; and (4) placing greater emphasis on extended evaluation.

Blind and Visually Impaired

1. VR services are available to blind or severely visually impaired persons in every State. Notwithstanding the vastly expanded employment opportunities for the blind, agencies serving the blind must constantly devote a major protion of their efforts to job placements.

2. Foremost among the multiply handicapped who require extra and special services for their education and rehabilitation are those person who are both deaf and blind. The 1967 VR amendments authorized the establishment of a National Center for Deaf-Blind Youth and Adults which develops specialized intensive services needed to rehabilitate handicapped individuals and conducts research on the deaf-blind. It is not the state of knowledge which creates unmet needs, for this group, but the limitations in resources.

3. Little seems to be done to help the aging blind, who constitute a majority of all blind, reach a status of self-care. To attain this status they need a variety of rehabilitation services, which include home teaching, mobility services, and supportive services.

The Deaf

1. One-third of all deaf people have other disabilities besides deafness. Prevalence of deafness is more than three times as high in persons aged 65 and over then in all age groups combined.

2. The tested educational achievement of deaf persons lags far behind that of nondeaf persons, although the average deaf adult lags only one grade behind nondeaf persons. Similarly, deaf persons tend to be employed in positions significantly below their intelligence, skills, and education. The average income of the employed deaf is far below the national average. Nonwhite deaf males have five times the unemployment rates of white deaf males.

Provision of Rehabilitation Services

Survey of Providers

1. A clear majority of respondents to the Provider Survey considered it appropriate for the VR program both to focus the major portion of its attention on serving the most severely handicapped and to serve as the vehicle for providing rehabilitation services for independent living. Furthermore, two-thirds of the respondents believed themselves capable of serving the more severely handicapped, although they felt they needed more funds and staff to accomplish this objectives.

2. To facilitate the serving of severely handicapped through VR, a number of policies were favored such as: (1) an intensive training program for counselors; (2) a reduction of caseload size; and (3) development of a weighted case closure system.

Rehabilitation Facilities and Workshops

1. Rehabilitation facilities play a key role in service provision and evaluation of severely handicapped individuals. Furthermore, workshops are often the major source of skill training and, too often, the only source of jobs.

2. Providers, individuals, and organizations all agree that an increased number of rehabilitation facilities and added support to facilities

are essential to the provision of service to all of the severely handicapped who could be rehabilitated.

3. The development of a subsidy program to both workshops and to individuals in a workshop setting should be considered. The RSA-funded workshop study should provide greater insight into this area.

Technology

1. The basic problem addressed by technology is whether a loss of function suffered by an impaired organism can be replaced by artificial means. The Rehabilitation Engineering program of RSA contains great promise for significant breakthroughs and should be expanded.

2. In P.L.93-112, provision is made for funding the development and/or modification of devices which are not commercially feasible for production, to meet the needs of various disability groups. However, money has not been appropriated for this purpose.

3. A serious effort should be made both to extend the areas in which rehabilitation research is now being conducted and to manufacture and to disseminate devices for the disabled. Consumer involvement should be included.

4. It is also important to consider the training requirements inherent in dissemination both for professionals and the disabled users.

Benefit/Cost Analysis

1. Many types of analyses can be used to establish the value of certain program expenditures. Such analyses often focus on the "benefits" and "costs" of the given program, although they vary greatly in utility, assumptions, and conclusions. Vocational Rehabilitation is one of the few social programs for which benefit/cost analyses have been made. However, we wish to express reservations about the confidence that can be placed in these findings. While the technical aspects of the work have been very acceptable, the basic data have

simply not been available, and this has necessitated innumerable assumptions. If one wishes to accept these assumptions, the analysis conducted as part of this study shows that the benefit/cost ratio of serving the severe handicapped accepted by VR is less than that of the nonseverely handicapped accepted by VR, but is still high (9.1).

2. The limitations of the benefit/cost caluclations have not generally been recognized by advocates and critics of the Vocational Rehabilitation program. If Congress and the Department of Health, Education, and Welfare want to use benefit/cost analyses as important inputs to setting appropriations priorities, then addition data necessary to develop accurate benefit/cost estimates must be collected. Alternatively, if Congress desires to set priorities on the basis of other considerations besides economic efficiency (i.e., if Congress desires to place highest priority on the severely handicapped because of their greater need for services), then more comprehensive data are not as vital.

Other Programs

1. In the course of work on other programs for the severely handicapped, we found that no comprehensive review of the Federal programs and policies affecting the disabled existed before the recently completed effort by the Office for Handicapped Individuals.

2. While few data exist, it is clear that programs are fractionated, sometimes in competition with one another, and often inconsistent within themselves. The major problems are that programs: are inequitable, contain gaps in services, suffer from inadequate control, and are operated with insufficient knowledge and resources.

3. Our rough estimate is that $21.5 billion was spent to assist the 10 to 11 million severely disabled, or about $2,000 per severely disabled

individual in FY 1973, the last year for which complete expenditure data were available. VR expended just under $0.4 billion, or about 2 percent of the total budget for this group.

4. Coordination of such programs will be difficult because of their differing purposes and program structures.

Many programs contain severe disincentives to the vocational rehabilitation of the severely handicapped because the programs are predicated on assumptions of labor force retirement. Since these income maintenance programs bestow needed cash on the severely handicapped, ususally have concomitant medical benefits, and open eligibility to other programs as well, the cumulative benefits often require very high wage options before persons have incentives to show they are capable of labor force participation. We do not suggest persons are malignering, but that motivation is often necessary to overcome a handicap and without it, persons will not strive. Legislative changes would be required to allow these programs to be based on severity alone and not on labor force withdrawal, so that the severely handicapped could work without significant penalties in lost benefits. Such changes would permit greater coordination of these programs with VR.

Options

Programmatic Options

1. A strong case can be made that we have the technical expertise to provide services not currently being provided widely or equitably to a large number of the severely handicapped. Thus, the technology for service provision is known, many of the services could be feasibly delivered, and most recipients would benefit from the receipt of such services. Expansion of VR is largely a function of the resources available and the nature of the labor market. These are decisions for the Congress and the Administration, primarily with respect to investments in human capital.

The most crucial decision area is in regard to development of an independent living program. The logical options for this are summarized below.

1. Have no ILR program
2. Expand use of Extended Evaluation.
3. Add ILR program.
    - A. In non-VR agency
    - B. In separate, but VR-related, agency
    - C. In VR
        1. Residual to VR
        2. Separate from VR
        3. Single program with VR

If the decision is no ILR program, what does it mean? It means that the population at risk is about where it is now; that is, the services will or will not be there depending upon whether individuals can find them, develop eligibility, and do their own advocacy. People in nursing homes or people rejected for severity will remain as they are now. This does not mean that all severely handicapped will be unserved, but that they will be served by the system that currently exists.

One way to better serve the severely handicapped without setting up a new program or without simply retaining the status quo is to modify the existing program so that service provision which may end short of a vocational placement is expanded. There are State directors of VR who feel that they are achieving ILR through their use of Extended Evaluation and through homemaker rehabilitation. The expectations, however, in these cases are that these must be vocational in nature, and these outcomes are treated as "least choice." If the Congress and Administration feel that the self-care, homemaking outcome is equally as important as job placement, then expansion of the conditions under which this outcome is appropriate would, in effect, expand the services and number of clients with severe handicaps served without vocational objectives. This outcome could even be described as an outcome appropriate to persons who are employed but need the additional assistance.

One of the options specified is for a non-public agency to run the ILR program with Federal grants and supervision. The idea of the voluntary sector providing publicly funded services may seem novel, but such arrangements have existed for many years. Sheltered workshops, rehabilitation facilities, and voluntary organizations such as Easter Seals, cerebral palsy, and epilepsy organizations have been providing services for the most severely handicapped for years, often with grants, purchase of service contracts, or other arrangements with public programs.

Another possibility is consumer-run self-help organizations to fill the present gaps in the disability service delivery system. For example, the Center for Independent Living in Berkeley, California is staffed almost entirely by people with severe disabilities. They set up and provide services themselves, since for many of the severely handicapped the services required are not in the domain of any given agency--instruction in home remodeling, assurance of equipment repair, or an inventory of experienced attendants, for example.

Of course, the ILR could be set up within the VR agency, with the expectation that the organizational relationships within the agency could be worked out. The options are most succinctly described by looking at the decisions which must be made regarding client selection and flow.

One approach would have the agency screen clients for vocational potential. Clients would be selected as at present. Only those clients failing or rejected due to severity would then get ILR services as necessary.

Another approach within the VR agency would be to set up totally distinct units, each having its own manpower and budget, and to establish internal agency referral procedures. This option may be so rigid as to constitute an internal agency option much like the independent agency related to VR described above.

A third approach would be to have no distinctions between the programs. Any handicapped persons arriving at intake will be provided the services from which they can benefit, for as long as they can benefit, regardless of outcome. Thus, there could be few "unsuccessful" outcomes, since most people would be rehabilitated to a vocation or to independent living.

Lastly, the ILR program could, in effect, be the evaluation arm and service provider, as in extended evaluation. All handicapped persons wishing services would be first seen by the ILR program, which refers them to the VR program only after their ILR needs have been met. This should reduce the number of persons not rehabilitated in the VR program, because most of the people in VR will have had most of their needs met, except vocational.

Operational Definitions of Severity

1. The current RSA definition of the severely handicapped has a number of advantages and disadvantages. The major advantages are that it is

well known by people in the field, and it provides flexibility for the counselor who may consider such factors as the client's transportation difficulties. On the other hand, it continues the practice of "labeling," furthering the stereotyping of people who are severely handicapped. More importantly, there is only a minimal relationship between diagnostic labels and severity.

2. The extended RSA guideline alternatives have the same advantages as the current RSA definition but with somewhat finer disability discriminations.

3. A method which focuses on measuring functional limitations appears to have the greatest number of advantages since it is reliable, valid, and relatively easy to administer.

4. A method that would consider all aspects of a person's handicap would have a major advantage, in that it would take into account such factors as motivation, family support, attitude, etc. On the other hand, it would be difficult to develop a valid, reliable measure of this sort which predicts vocational performance.

5. In light of the wide discrepancy among States in the rate at which they report serving severely handicapped people, some objective instrument for establishing severity appears highly desirable.

Financial Options

1. Many possibilities exist for the design and financing of rehabilitation programs. Many of these options can be combined and possible combinations are innumerable. Financing was discussed along three dimensions: (1) Federal participation; (2) funding through programs; and (3) client cost sharing. Options along the first dimension include: full Federal financing, special revenue sharing, and joing funding between Federal, State, and local levels of government.

2. A major argument in favor of full Federal funding is that if states have a great degree of control, wide variations between State programs (and therefore inequities) may result, in both population served and services provided.

3. Under a special revenue sharing plan a VR program would have a given Federal allotment, funds being dispersed to States and/or local governments by means of an allocation formula determined by population, target population, State income and/or other State characteristics. Use of a formula which takes into account different State and local needs allows the dispersal of the most resources to those States which are in greatest need of assistance in achieving national goals. It also preserves the role of the Federal Government as a redistributor of income. On the other hand, it can be argued that when localties are allowed such broad discretion in the use of funds as would occur with special revenue sharing, there is no certainty that all would be able to achieve national goals in rehabilitation without specific direction or that, without monitoring of funds, misuse would not occur.

4. Programs which are federally authorized but jointly funded by State (and sometimes local) governments generally allow greater variation among States in terms of program design and administration and reduce the financial burden on the Federal Government. Arrangements under which States contribute to program financing may involve (1) an allocation formula to determine the Federal contribution to individual States based on such State characteristics as total population, target population, and income, etc., and/or (2) a matching ratio that fixes the number of Federal dollars for each dollar contributed by a State towards a particular program, possibly variable by State and possibly subject to a maximum determined by an allocation formula.

5. It should also be realized that programs can be funded from more than one source. There are many examples of joint funding: Medicaid pays the costs of premiums, deductibles, and co-insurance of the poor who are eligible to participate in the Medicare program in some States; VR services for certain Disability Insurance recipients are paid by DI Trust Fund monies; and VR agencies are reimbursed at 100 percent of the costs of rehabilitation for certain blind and disabled recipients of Supplemental Security Income. In addition, VR agencies are required to make maximum use of similar benefits provided by other programs. Procedures should be developed by which the rehabilitation agency could pay vendors for needed services through a revolving fund. VR would then be reimbursed from the programs which finances the services such as Medicaid.

Chapter 30

RESEARCH AND DEMONSTRATIONS

Research and demonstration was introduced into the VR program through the 1954 amendments to the Vocational Rehabilitation Act. This Act provided funds to support research and demonstration projects which promise some unique contribution to the present state of knowlege of rehabilitation theory or practice. The purposes of the program include: development of new information on methods and devices for use by persons involved in the rehabilitation process; increasing the effectiveness of existing programs; increasing community involvement and support; and providing data analyses and ideas to administrators which will aid them in developing programs for the disabled.

Since 1954, over 2,000 R&D projects have been conducted, involving between $400 and $500 million. Projects have been conducted on numerous types of disabling conditions, as well as on groups of persons having special conditions which relate to their disability (e.g., the homebound and the aged). Studies of the socially and culturally handicapped, administrative and program analyses, and many other R&D projects have been undertaken. A complete description of the research and demonstration funded under the Rehabilitation Act can be found in the annotated listing of R&D projects published periodically by the Rehabilitation Services Administration, in the Research Directory of the Rehabilitation Research and Training Centers, and in other RSA publications.

Through this R&D program, much has been accomplished. An international program in rehabilitation research was developed, making it possible to bring in foreign experience to enrich American experience. The R&D program led to the establishment of the Rehabilitation Research and Training Centers, Spinal Cord Injury Centers, and the National Center for Deaf-Blind Youth and Adults. It also succeeded in developing the technology and methods for the mobility training of the blind. A substantial number of the projects referred to in this report were funded by RSA.

The best of the R&D efforts are in the clinical and the rehabilitation engineering areas, where major breakthroughs have occurred. Those efforts should continue to be funded and expanded. In other areas, however, the picture is not so favorable, particularly in the areas of benefit-cost analysis, in understanding the interaction of the individual and his environment, and in developing policy analyses of the effect of other programs on VR and on the handicapped. When studies of these areas have been mounted, they have been sparse and limited.

An evaluation of rehabilitation research by Berkowitz[1] concluded that the reports were generally "wanting in the quality of their methodology," and that, while they were somewhat useful in development of policy positions, they were deficient as regards research. Methodological problems included lack of experimental design, lack of internal validity, absence of followup or outcome measurement, unrepresentative or poorly designed sampling procedures, and low-powered statistical analyses. Utility for making policy suffered from limited ability to generalize, lack of new information, and the need for further research to determine whether the data justified such conclusions.

One of the implications for research in the area of the severely handicapped is that while some of the research may have been clinically useful or useful on a limited scale, in order to obtain national or statewide estimates

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[1] Monroe Berkowitz, et al., An Evaluation of Rehabilitation Research, (New Brunswick: Rutgers University, 1974).

useful for policy planning, further analysis must be performed. In addition, the target population of the severely handicapped suffers from problems of definition -- much research on the handicapped does not adequately differentiate between the severely handicapped and the handicapped as a whole. When such definitions exist, they vary from study to study, some being based on ability to work, others on diagnostic labels, and still others on agency classifications from certain functional limitations, or a combination of factors. Thus, it is difficult to compare the results of studies.

The surveys which we conducted of persons rejected from VR and of persons who were formerly inpatients at the CMRCs highlighted the fact that the severely disabled are not a homogenous group. Their goals and abilities, their service needs and their rehabilitation plans vary. Research on the severely disabled should specify the characteristics of the persons under study as well as the rehabilitation goals or outcomes, such as homemaker status, full employment, or sheltered employment. Failure to specify sample characteristics and rehabilitation goals can produce information which is not useful for planning purposes or simply misleading. For example, in assessing the factors affecting successful rehabilitation, persons rehabilitated to homemaker status would probably not be affected by their educational level or the current employment situation, whereas persons rehabilitated to full employment might very well be affected by these factors.

This section poses some of R&D issues which are relevant to the determination of the needs, methods, and costs of rehabilitating the severely handicapped. Certain subgroups of this population which have specific problems are treated separately.

BASIC AREAS FOR RESEARCH

At intervals throughout this report are noted needs for further investigation of certain basic questions about the most severely handicapped, beginning with a definition of who these individuals are.

Definition of the Severely Handicapped

Definition of the population to be served -- that is, determining who is severely handicapped, who should be eligible for independent living services, and who might benefit from vocational services -- is essential for coherent policy planning. Development of accurate and economically feasible national and statewide estimates of the number and characteristics of the severely handicapped as well as the handicapped as a whole, requires cooperation among agencies concerned with handicapped people and agencies which conduct nationwide surveys for other, but related, purposes. To this end, it is recommended that RSA, in conjunction with other parts of HEW and with the Census, utilize ongoing national surveys and expand them to sufficient size to estimate incidence, prevalence, and statewide differences. Through cooperative efforts with the Social Security Administration, RSA could obtain followup data on earnings, job retention, mobility, etc., of individuals within and outside of the VR system, so that benefit-cost estimates could be predicted from hard data. Preplanned followup studies of VR clients over a significant period of time, such as 10 years, could provide valuable information about factors which affect successful outcomes and the likely course of individuals with different types of handicaps.

It has been indicated in various sections of this report that the prevalence of severe handicaps depends on a combination of social, economic, and labor market factors as well as on the nature of the individual's impairment; that is, as much on the severely handicapped environment as on the individual. Current RSA methods of determining severity, however, are based primarily on diagnostic category, which is only a very rough indicator of dependency. Research is needed to develop methods for determination of severity which are consistent, valid, and economical. Suggestions as to possible methods appear in this report.

Under the present system, it is not clear how many of the persons rejected for reasons of severity could have benefited from vocational services. It is known, however, that about 12 percent of those surveyed had found employment following the time of VR rejection, and others appeared to be potentially employable by a number of criteria. Demonstration projects which seek to ascertain the extent of progress which can be expected from persons, using various cutoff points with regard to severity and accounting for the exogenous reasons affecting nonemployment (such as the poor labor market and employer discrimination), or for failure to attain independence of living, if an ILR program is instituted, (such as environmental barriers), would lead to more fruitful methods of determining severity and placement criteria for appropriate programs.

Costs of Rehabilitation Services for the Severely Handicapped

One of the critical problems in serving the severely handicapped is the cost of such services. Little is known about the cost of rehabilitating the severely disabled, whether this rehabilitation is vocationally oriented or aimed at those who could benefit from ILR services. This type of analysis is crucial, since implementation of even the best of programs, no matter how effective, is unlikely to occur on a large scale if the cost is very high. In the survey of providers of rehabilitation services, over four-fifths felt that VR was potentially capable of serving more severely handicapped persons than it was presently serving. The two most common requirements for serving the severely handicapped cited were additional funding and additional staff. Certain isolated examples wherein a custodial type of institution was reoriented to a rehabilitation institution provide clues for some of the least costly methods of improving the lives of some severely handicapped persons. Other cost studies might explore cooperative methods of rehabilitation, wherein different agencies work together or share the funding requirements for certain types of rehabilitation.

Comparative cost studies for different approaches to similar populations might point the way toward determining which type of agencies are best suited to most economically handle the rehabilitation of particular types of individuals. For example, the majority of the population surveyed from the CMRCs were quite physically impaired, and a significant number were beyond retirement age upon admission to the facility. Most of these persons required medical and other services to achieve independent living, vocational services being inappropriate due to age or physical condition. Thus older, more physically dependent persons might be better served by CMRCs than by VR agencies. However, most persons cannot afford this type of care if they must rely on their own resources. Only 3 percent paid the major share for the CMRC stay themselves, the rest relying upon insurance and public sources (Medicare, Medicaid and welfare) to take up the bulk of payment. While the services may be valuable and appropriate for their needs, they are also very expensive, and neither the individual nor VR can be expected to carry the major burden of cost. In this regard, some examination of the role of social services and Medicaid may be fruitful.

The severely handicapped are a diverse group. Some are more physically handicapped than others, some have problems in addition to a physical impairment which increase their handicap such as lack of education, advanced age, etc., and some are mentally handicapped. The living conditions of these people and the availability of financial, physical and social/psychological assistance or support also affects the extent to which these persons are limited by their disability. For some, deinstitutionalization would be the first and perhaps only likely outcome of rehabilitation services, while others may be capable of full employment. The comparative costs of services oriented toward different outcomes, such as deinstitutionalization, ability to live independently, placement in an employment situation, or further education, should be examined for the different sorts of persons qualifying as severely handicapped, so that the likelihood of a successful outcome and the costs of services leading to these outcomes can be determined.

The costs of failure to rehabilitate persons to their full potential may be just as important as the costs of successful rehabilitation. The severely handicapped generally have less earning power, which may result in increased financial, social, psychological and perhaps physical dependency. If needs for assistance from others ramain high, other family members may be required to forego employment, work extra jobs, or limit their education. Enforced dependency may be quite demoralizing to the individual and his family, and may result in disruption of the family and other social interactions. Society suffers from the burden of supporting the individual and perhaps the family of the individual who is unable to work. However, research in these areas is somewhat inadequate in scope. A thorough study of the costs of failure to rehabilitate -- costs to the society, the individuals, and their families -- is needed in order to weigh the costs of rehabilitation against the financial, psychological, and social costs of failure to do so.

R&D IN PROBLEM AREAS

Certain areas which present particular difficulties to the most severely handicapped call for careful R&D efforts.

Employment

The severely handicapped are restricted in their labor market participation by many factors, including physical limitations, socioeconomic characteristics, inadequate aggregate demand, capital disincentives and employer attitudes.

However, the available literature dealing with those issues with respect to the severely handicapped is sparce. It is not possible to accurately determine the number who are capable of entering different kinds of work situations, the most productive use of their capabilities, or the magnitude of the benefits to the handicapped individual, their families, and society which would result from their working. In order to plan for vocational rehabilitation of the severely handicapped, a number of studies on these areas are desirable.

Analysis of the requirements of the severely handicapped for employment would provide some estimate of the numbers of such persons who could possibly enter the labor market, and of the special conditions which must be met before this could take place. Persons interviewed in the VR survey cited light work as the most frequent job requirement, followed by reduced work schedules, flexible work schedules, transportation, and special training and education. Slightly more than one-quarter of the sample cited accessible buildings as necessary. It is possible that some of these persons could work with less than optimal conditions, or that some of the survey choices were too vague or broad in scope and should be more operationally defined. For example, individuals citing a need for flexible work schedules could mean anything from a need for an occasional day off when in pain to a need for completely flexible hours on a daily basis. The relationship between these job requirements and performance in different sorts of jobs is not well known, nor is the relationship between other characteristics of the individual, such as age, specific physical limitations, education, etc., to job performance.

In conjunction with research estimating the number of individuals who could currently enter the labor market, if certain employment conditions were met, demonstration projects which seek to explore the full employment potential of the severely handicapped are needed, such as that being directed by United Cerebral Palsy of Kansas under an RSA grant. Under current practices, an individual might be denied placement or placed in sheltered workshops or employment requiring lower skill levels when he is potentially capable of more independence and of using more complex skills. Exploration of the time, expense, methods, and benefits involved in bringing such persons up to a higher skill level would provide some clues to programmatic changes which might greatly enhance the lives of the severely handicapped and their families, as well as reducing the number of persons unnecessarily institutionalized, dependent on public sources of income, or limited to sheltered employment possibilities.

Many jobs seem unsuited for persons having certain functional limitations. However, various projects have demonstrated how moficications in the work place can make it possible for disabled people to perform jobs which are otherwise impossible or impractical for them or dangerous to their health, In the course of this study, we found little current research which examined the extent to which work environment, equipment, and job structures constitute barriers to employment of the disabled. This type of study is necessary to determine the extent and types of modifications which could increase the employment potential of the severely handicapped.

Analysis of both the usual requirements for particular jobs and the modifications which could be performed to accommodate jobs to the severely handicapped might provide the basis for negotiations with employers regarding hiring of more handicapped. Many employers are not aware of the actual percentage of the job which requires, for example, heavy labor. If this percentage is low, as it often is, many jobs could be restructured to accommodate persons no longer able to perform heavy work, or equipment could be modified to permit operation by the handicapped.

In addition to job analysis, R&D projects are needed which seek to provide job development strategies, so that counselors and others responsible for job placement and training are knowledgeable about employment needs, job trends, and the acquisition of job-related skills. In the survey of providers of rehabilitation services, 86 percent felt the lack of job development and placement specialists for the severely handicapped was a major impediment to serving this population.

There have been few empirical studies of the disincentives to working or living independently. It is known, however, that most persons who have a public income transfer also have at least some health benefit under Medicaid or Medicare, Public income transfers often qualify other members of the family for AFDC, which may mean that the total income and benefits to the family significantly exceed possible earnings. In addition, agencies such as DI and SSI impose earnings factors in their definition of disability, which in turn affect the likelihood of VR acceptance. Research on the effects of different income maintenance strategies on the severely handicapped and handicapped populations is needed.

Discriminatory policies against hiring the handicapped, unduly high firing rates when nondisabled persons are available, and problems with insurance coverage which discourage hiring the handicapped except at the employer's risk, are all problems which are suggested, but not documented as to extent, in this report. Investigation of employment practices, employer disincentives to hiring the handicapped, and the extent of the problem today is needed to determine the reasons for and extent of differential treatment of the handicapped. The relationship of employer attitudes to practices and policies is virtually unknown, as is the extent of discrimination among subgroups of the severely handicapped. Labor union policies with regard to the disabled are critical to examine, since 1) union policies may act as barriers to hiring the handicapped, and 2) unions have powerful leverage for forcing employers to change policies which tend to restrict job opportunities for the disabled.

Many respondents reported that employers refused to hire them because their insurance would not cover them or would increase in cost if they were hired. In one instance, employment was denied because the handicapped person was ineligible for the (municipal) pension plan. Others reported employer discrimination because of fear of lawsuits if the disabled person became injured. A thorough examination of the incidence and impact of public and private insurance policies and practices which discourage employment or which fail to provide the protection for which they are intended is necessary for the development of fair, uniform practices.

Examination of policies of unions, employers and insurance companies which encourage fair treatment of the handicapped may suggest ways to combat differential treatment of the handicapped. For example, workers suffering upper limb amputations on the job were retained after a job analysis performance by the union involved discovered that, contrary to popular belief, over 80 percent of the work required on the job did not require the use of both arms.

Job structures, i.e., the requirements for entry, the physical requirements on the job, such as standing rather than sitting, rigid career ladders, etc., may constitute unnecessary barriers to the severely handicapped. There is a need for systematic research into job structures and their relationship to the capabilities of disabled people.

The extent to which psychological or motivational factors affect ability to find or retain employment and job mobility is not well known. A few studies, primarily based on British populations, indicate that attitudes toward self or work are more important determinants of return to work than are medical recovery or functional limitation. Other studies indicate that family attitudes and agency practices can increase dependency and discourage job mobility. Investigation of the relationship of attitudes of the severely handicapped, their families, and of rehabilitation or educational agencies to employment patterns of the severely handicapped is needed.

Health Care

A significant number of the severely disabled need some sort of medical care, restorative and other services, or coverage for medical services. These needs were found to vary by age and level of physical dependency. Currently, there are many types of service models operating, which may deliver anything from emergency life-saving procedures to visiting nurse services to plastic surgery. Obviously, these services have different priorities, are oriented towards different purposes, and have different costs. Coverage is often provided for those services which are necessary to maintain life, but less frequently for services which may improve the person's quality of life. Too little is known about the distribution of health care service needs among the severely handicapped to attempt anything more than short-term remedies. In order to develop long-term strategies for the improvement of medical and health care to the severely handicapped, further information is needed on the geographical distribution of present and potential unmet needs for self-care, primary, secondary, and tertiary care, the surplus capacity of existing medical and health service delivery systems, and on the cost and effectiveness of alternative service models.

The problems for individuals requiring long-term care are complex. Many persons are in settings which do not suit their needs, in that services may be inadequate or lacking. Settings which permit a moderate degree of independence, such as community or group care, may not be available or may be financially infeasible. For those who require more intensive care, family resistance or financial factors may prevent additional care or institutionalization. Research into methods of screening, rehabilitation, and financing long-term care in the most appropriate but least intensive settings is needed. Disincentives to deinstitutionalization also need to be explored in this context.

Technology

Current technology for the disabled is quite sophisticated in some areas and very deficient in others. For example, large sums have been spent in the development of electronic implantation devices through which the blind may be able to see, but no one has developed a collapsible cane which does not vibrate. Vibrating canes disturb the blind person's sense of distance and are among the first priorities for research sited by blind consumers. Research on improved wheelchairs, canes, etc., could assist large numbers of severely handicapped who would not have access to the more sophisticated technology developed. In addition to basic research problems, problems in implementing new advances are posed by the cost of (1) design and production, (2) special modification for each individual, (3) adequate training of physicians and allied health personnel in their application, and (4) marketing and subsequent maintenance.

Consequently, there is a need for multidisciplinary interaction to enhance mutual exposure and interaction among workers in different specialties, in the following areas: (1) development of evaluation procedures to determine the total impact of both new and existing devices or techniques on the functioning of the user, (2) identification of the strengths and weaknesses of these aids, so that improvements can be made, (3) comprehensive analysis of the potential consumption market, and (4) primary research in the area of technology.

Transportation

One of the major requirements for receiving needed services, for employment, and for independent living was adequate and accessible transportation. However, even the providers of services which might lead to employment or independent living have generally relied on the disabled themselves to obtain the needed transportation to arrive at their facilities. Thus, there is a need to connect the provider and the consumer.

It is known that many factors affect the utilization of transportation services by the disabled, including physical limitations, psychological factors, income, and the performance of the transportation system itself. It is also known that different disability groups have different transportation problems, and therefore solutions to these problems will differ. A comprehensive study of the transportation needs, the impediments to using various transportation systems, and the current and expected utilization patterns for various types of existing and proposed transportation services for persons with different types of transportation problems is currently being proposed by the Department of Transportation. Results of that study should suggest a wide variety of options for resolution of the many transportation problems of the severely handicapped.

Architectural Barriers

Architectural barriers in the home and in public and private buildings limit or prevent the severely handicapped in employment, education, and in freedom of movement. In recognition of this, Section 502 of the Rehabilitation Act of 1973 provides a mandate for research into several aspects of what is needed for a barrier free environment. A study funded by VR in the early 1960s in Minnesota, as mentioned earlier in this report, concluded that architectural barriers were so self-evident that statistical documentation of the problem is for the most part superfluous. Study of the extent to which recently constructed buildings or other facilities which fall under the legislative requirements comply with laws regarding architectural barriers is possibly more relevant to current concerns. At issue is whether the buildings can be readily entered (e.g., ramps or street level entrances, doorways wide enough for wheelchairs, no revolving doors), and whether the facilities inside the building, such as washrooms, elevators, and drinking fountains, are usable. Further studies of this nature are required.

Even if all newly constructed buildings and other buildings which fall under legislative mandate were to be completely accessible, the severely handicapped would still be extremely limited in seeking housing and employment, as well as in carrying out normal activities such as shopping, going to the bank, or obtaining a driver's license. The costs incurred by the disabled because of their limited selection of accessible buildings, including excessive time and financial resources expended finding suitable housing or jobs, have not been thoroughly investigated. Research which addresses the cost of modifying already existing buildings would be useful in determining the feasibility of such modifications and the funding required for such efforts. A detailed analysis of the usual costs of different types of modifications, such as widening doors, lowering telephones and elevator buttons, introducing ramps and/or elevators, etc. is necessary for accurate estimates of this variety.

Barriers in the home may result in needs, for assistance in performing daily activities, or in increased time and effort being applied to tasks which could be better spent elsewhere. The major share of the costs of removing barriers in the home is currently borne by the disabled and their families. The VR survey findings indicated that the major reason for <u>failure</u> to remove barriers was the cost. In order for persons severely handicapped to have accurate information on the types, cost, and availability of devices and modifications to make housing accessible, research on the development and dissemination of such information is needed.

Geographical Constraints

In the process of contacting respondents for the VR survey, it was discovered that the proportions of persons rejected from large urban areas (e.g., population centers exceeding 100,000) was strikingly lower than for persons living in small urban or rural centers. This suggests that geographic locale or access to large urban centers with full employment services may be important factors in acceptance for services. Research which defines population size, services available in these population centers, and perhaps the employment situation in various locales is necessary to answer this question.

Lack of geographic mobility may hinder the severely handicapped in obtaining services, assistance, and employment. Demonstration projects which incorporate both information and direct services could contribute to the development of mobility strategies, in that the projects would generate information on demand patterns, permit the working out of cost-effective methods of implementation, and generate more accurate cost data.

Another option is to extend research into the actual mobility patterns and mobility needs of the severely handicapped. A geographic analysis of the accessibility of present and projected services to the severely handicapped population is also needed. Survey information on mobility and locational preferences of the most severely handicapped, when combined with on-going experience of the pilot program, should enable a reasonable legislative debate.

Social and Recreational Needs

The social and recreational needs of the severely handicapped should be investigated more thoroughly. Although these needs may be secondary in importance, it has been previously noted that the absence of "normal" life experiences results in deficiencies in personality development and in the ability to relate to people. This may, in turn, affect motivation to learn employment and intellectual skills, to seek a job, or to live more independently. Thus, in considering the design and implementation of a program for independent living, the effects of social isolation created by limited nonfamilial social interaction should be a program concern.

Existing recreational programs and facilities in local communities hold the potential for reducing the social isolation of the handicapped. Investigation of funding sources and program design, and implementation of efforts to integrate the handicapped into community-supported programs should be undertaken. The possibility of channeling tax dollars appropriated to Federal, State, and municipal agencies with recreational interests to the support of programs for the handicapped should also be investigated.

Education

Next to the family, school probably provides one of the most important influences in the average person's life. Many disabled people, however, are limited in or prevented altogether from acquiring the social, educational, and vocational preparation which is available to others. Many go to special classes or to schools where persons with physical disabilities, mental retardation, and sometimes emotional difficulties are combined in the same classrooms. Study of the effectiveness of various educational alternatives for the severely disabled, and of the methods by which these could best be implemented, is necessary for intelligent program planning for the variety of educational needs present in the severely handicapped population.

Consumer Involvement

Research and demonstration projects are needed to evaluate and explore alternatives for the relative effectiveness of consumer-run programs of community-based service delivery.

The impact of consumer involvement on the VR program itself requires evaluation. Are the severely handicapped better served by consumer involvement in planning, delivery, and evaluation of rehabilitation services, including proposal review, counselor sensitization through training workshops, peer counseling, advisory board involvement, and evaluation of service delivery?

Finally, consumer involvement in the policy planning and priority setting activities of the rehabilitation engineering research field may be helpful in orienting such research to the needs and economic constraints of the handicapped.

SPECIAL GROUPS

Certain disability groups having special problems to which R&D might give some assistance are presented below. This list is not exhaustive, but merely suggests some of the issues to be considered in addressing these groups.

The Mentally Ill

The mentally ill pose special problems with regard to definition and service requirements. Since they comprise a significant portion of VR applicants, and have a high acceptance rate but a low rate of successful rehabilitation, the R&D issues with this group will be treated separately. The major difficulties encountered in defining persons who are severely handicapped due to an emotional disorder are discussed more thoroughly in the report. One difficulty is the lack of adequate, objective criteria for severity, whether these are opinions of mental health professionals, psychological tests, or other methods. The unstable nature of emotional disorders, the fact that the pyschological condition and the functional and vocational limitations are not necessarily constant--present further difficulty. An individual may be severely impaired during a psychotic episode, suffer little impairment after the episode subsides, and yet be likely to undergo further disabling episodes. In addition, the effects of institutionalization may be just as handicapping as the effects of the individual's emotional problems.

One of the first research issues to be considered, then, is whether more accurate, reasonably efficient screening procedures can be developed which will define and identify those who are severely disabled because of an emotional disorder, and which will also indicate such factors as employment potential, ability to care for themselves unassisted, and likelihood of remission. Any increase in accuracy and greater efficiency in predicting employability or in placing persons in appropriate programs should be weighed against the costs and administrative difficulties imposed by such procedures. Research of this sort would necessarily require control groups, standardized VR selection procedures, and sufficient followup to determine whether the measures employed discriminate groups over a sufficient time period to warrant this implementation on a broad scale.

Previous research has only roughly indicated the numbers of persons who might be severely psychologically handicapped--HEW estimates range from 4.3 to 43 million. In order to do program planning which would encompass the needs of all severely disabled, the actual numbers of persons needing services must be more carefully estimated. However, if current rehabilitation efforts are any indication, a vast gap between the numbers of persons needing services and the number of services available will remain for some time, regardless of the precision of population estimates. A study in Vermont concluded that 70 percent of the institutionalized, chronic patients studied could be placed in the community if adequate transitional and vocational rehabilitation services are provided. The literature on programs providing such services is extensive regarding models and methods of implementation, but scant with regard to effectiveness. The best indications are that Halfway houses and other programs which assist with living arrangements, family and social relationships, and reentry into the vocational spheres are effective in the short term, particularly when workshop facilities or transitional employment possibilities are provided. Research and demonstration projects in addition to those already funded by RSA and NIMH are necessary to provide a substantial data base from which to base major policy decisions regarding expansion of the most promising projects of this type.

One of the major issues in terms of feasibility of implementation of programs designed to deinstitutionalize persons is cost. If the cost of these programs is significantly higher than current costs for institutionalization, we will probably see little expansion of such programs. Thus, research and/or demonstration projects should focus on programs which show low costs or high returns. Such demonstrations should be conducted in cooperation with Medicaid, Medicare, Social Services, and Public Health Service programs in nursing homes.

Any such research should address the weakest points in previous research -- lack of control groups and followup data. Rather than simply assessing progress at some later point in time -- say, 2 years after completion of the program -- demonstration projects should be designed which provide for followup services, since this population has a high risk of readmission to hospitals, termination of employment, and other setbacks. Research on long-term effectiveness may prove more promising if the need for continuing services or support is included in the program design.

The Mentally Retarded

There is considerable evidence to show that large numbers of even the severely mentally retarded can be deinstitutionalized and/or placed in employment or homemaking situations. However, the evidence also shows considerable variation in success rates between different States and different types of rehabilitation programs. It was suggested that this diversity is probably due to the diversity of populations used in the sample as well as the type of job placement considered. Counselor characteristics, including empathy, concreteness, familiarity with behavioral techniques, etc. could also affect the success of these efforts.

Research which was directed at determining the most fruitful types of placements and rehabilitation programs for individuals with different types of problems associated with retardation (e.g., employment, psychological, familial, independent living, etc.), might serve to point the way for comprehensive services to the retarded or towards more specialized services, depending upon the person's need and situation. If ADL services are to be considered as part of rehabilitation, prediction of the aggregate need for and usefulness of services is crucial. Definition of the boundaries between rehabilitation and Developmental Disabilities should be established. Research to ascertain the percentage of severely handicapped persons of different ages, with different levels of IQ, physical disability, and social maladaptation which would be helped by various types of vocational and independent living services such as sheltered employment, recreation, and domiciliary care, is now being done at one institution. This type of research requires careful followup study and analysis before drawing conclusions upon which to base policy-oriented decisions.

Study of the models existing for rehabilitating the severely handicapped retarded and the cost of such methods, such as reorienting institutions from custodial to rehabilitation facilities and the use of students, parents, and volunteers would be useful for indicating cost-effective ways to reduce physical and economic dependency in this group.

The Blind and the Severely Visually Impaired

People with severe visual impairments and the blind with multiple other impairments are among the most difficult to rehabilitate, and much research is needed to advance the state of the art. The principal areas requiring research are visual enhancement and visual substitution, information gathering, and formal informational display.

Extensive research should continue to develop hardware capable of providing rapid display of magnified print or other visual stimuli to the low-vision population. Techniques already available require study to determine optimal use. Aids which convert displayed information into tactile or auditory form need further development.

Studies should be conducted to determine the need, cost, effectiveness, and acceptance of the variety of special optical viewing devices, visual substitution devices, and computerized devices which translate the visual to the spoken word. Future research on visual substitution devices should stress more rapid assimilation of printed material.

Systematic investigations are needed to determine the most effective optical aids for independent mobility of persons with low vision. Development of visual substitution devices as an alternative for the blind and persons with low vision is also needed, to be followed by a systematic evaluation of the comparative benefits achieved by video inputs. Basic research designed to elicit information about the perceptual processes on which mobility depends is essential for adequate construction of mobility devices. We have already mentioned the need to develop nonvibrating collapsible canes.

Job development and training techniques need to be expanded for the blind. Research which incorporates current technological advancements with respect to the blind together with job development and training strategies could suggest employment paths for the future, rather than simply indicating existing solutions and programs.

The Deaf

The deaf constitute a special problem group since they do not necessarily have physical limitations, but their communication impairment can be sufficient to interfere with practically all aspects of life. However, the deaf cannot be readily spoken of as one group requiring similar services or having the same problems, since such factors as age of onset of deafness and presence of other physical limitations (such as blindness) can greatly affect the level of handicap and types of services necessary for rehabilitation. Despite the differences, however, some of the more general R&D issues for the deaf can be delineated.

Research on the best alternatives for providing quality education for deaf persons is limited. The deaf can easily become socially isolated, and the absence of opportunities to learn communication skills, to interact with others, and to become employable can be devastating. More basic research on the acquisition of language skills is fundamental for understanding and improving the educational system. Experiments in elementary education for teaching all students sign language and integrating the deaf child with his peers should be mounted to determine the costs and effects.

Adequate research indicating the time involvement and the costs of serving the deaf, as well as the availability of staff for such services, would provide some hard data for planning to meet the needs of the maximum number of such persons.

Job development strategies for the deaf will differ from strategies developed for those with limb impairments. Additional analysis of the effectiveness of various approaches to vocational training of the deaf and identification of appropriate vocational areas would be helpful for guidance in this area.

Improvements in technology for the deaf, such as hearing aids which screen out or control loud background noises and telephones which are usable by the deaf, await continued research development.

Persons with Other Disabilities

While there has been some research on the rehabilitation service needs of persons with cerebral palsy, epilepsy, arthritis, stroke, and so forth, the surface has barely been scratched. There has been extensive work in medical care and rehabilitation engineering for some of these groups, but considerably more information about their needs, potentials, and special problems should be systematically documented. Successful service modalities and innovations, together with the costs of these methods, should be investigated.

OVERVIEW

Much has been said about the need for R&D to determine the extent and characteristics of the severely handicapped, their rehabilitation needs, and the cost of such services. In order to achieve a more complete and realistic picture, large data file analysis, R&D on the characteristics of individuals successfully and unsuccessfully rehabilitated, and an assessment of the factors, including cost, which impinge upon the success and feasibility of rehabilitation efforts is needed. Factors which may relate to rehabilitation potential include physical limitations, age, education, work history, sex, geographic location, financial and motivational factors, and rehabilitation services received. The rehabilitation goals and/or outcome should be clearly specified in such research, since different characteristics or combinations of characteristics may facilitate rehabilitation towards different types of employment, homemaker status, continued education, or other outcomes. A wealth of data could be obtained from VR and other rehabilitation and social service agencies by delineating the research specifications in advance, thereby permitting study of the individual characteristics which, under current rehabilitation practices, contribute to a successful outcome.

Increased support of regional research centers to investigate the problems and needs of the various types of severely handicapped persons and to provide guidance to State agencies for research and demonstration efforts would help focus and disseminate the R&D efforts upon those issues most critical to the severely handicapped.

In view of the data from our surveys and the inputs from members of our advisory committee, a major shift in R&D emphasis toward a focus on the interaction of the individual and the barriers in his environment seems indicated. The chapter on employment underscores the fact that practically anyone who is not severely brain damaged can work, no matter how handicapped. The major problems seem to be not so much with the severely handicapped, as with the severely handicapping environment. R&D are indicated which would focus on the interaction of the individual with the labor market, the rehabilitation agencies, housing, transportation, attitudinal barriers, and legal sanctions. Research and demonstrations with control groups and sizeable, representative samples, are needed to focus on what actually works in reducing the environmental barriers that restrict persons who are considered severely handicapped.

DEMONSTRATION PROJECTS

Provisions of the 1973 Rehabilitation Act requiring demonstration projects in conjunction with the Comprehensive Needs Study clearly recognized that there would be areas of investigation which would not be answered on the basis of available data and experience. In this chapter we will describe the rationale for the areas to be examined, describe the two ongoing projects in a little depth, and describe the four remaining demonstrations to begin July 1, 1975.

The demonstration projects which are needed to adequately address all the issues far exceed the funds made available. A total of 21 percent of applications for demonstrations were received in the two requests made in late 1974 and early 1975. Six projects were funded, although almost all of the applications had merit. The two ongoing projects were funded by non-VR sources, whereas the four projects about to be initiated were VR funded.

Ongoing Projects

I. One of the ongoing demonstration projects concerns the role of the Comprehensive Medical Rehabilitation Centers. In the course of early discussions on demonstrations, it became clear that little was known about the possibilities of expanding the role of medical rehabilitation centers into delivery of independent living services. Most rehabilitation centers still operate primarily on the medical model, with the staff being available only at the facility, and discharge to the community marking the end of service. The extent to which a comprehensive medical rehabilitation center would be able to take severely handicapped persons all the way into the community, until it was certain that their adjustment was complete, and the relationship which the CMRC would have with VR or other ongoing programs in dealing with such problems as income maintenance, home finding, transportation, family counseling and the like, were basic concerns about the role of the CMRC's.

Examination of the expanded role which could be taken by the CMRC's was undertaken by the faculty and project staff associated with the University of Washington Department of Rehabilitation Medicine. The purpose of this demonstration project is to 1) conduct comprehensive evaluations as to the rehabilitation needs of persons with severely handicapping conditions, and 2) organize state agency activities as well as community resources in providing increased services and care to the handicapped.

The specific procedures to be used in this study include:

1) Interviewing the severely handicapped to determine their medical, housing, transportation, educational, vocational, economic and other rehabilitation needs;

2) Recommendation of appropriate rehabilitation services, based on the interview and further professional information. For example, if medical help is indicated during the interview, medical examination by appropriate specialists would be recommended. The same would be true if vocational help, speech therapy, psychotherapy, physical therapy or any other rehabilitation training or therapy is needed.

3) Since vocational training and counseling are frequently needed, two types of evaluations may be frequently used to plan for appropriate training and counseling. The first involves administration of interest, aptitude and achievement tests, and the second provides on-the-job observation. In addition, with the clients' permission, observations of the

work situation will be performed to see if there are any special rehabilitation problems which need to be solved. Assistance will also be provided, if needed, in job interviewing skills, resume preparation, and job seeking techniques. Such assistance will be given by a vocational counselor.

4) In order to see if the rehabilitation services are of help, interviews and evaluations such as those explained above will be re-administered after services have been provided. Rehabilitation services will continue as long as the need for them is present.

Data analogous to that collected by the Comprehensive Needs Study on client characteristics, service needs, severity profile, income, etc. and data on services provided, costs of care, interface with other programs and the like will be collected and analyzed. An outline of the variables to be studied and the timetable for the first year of operation are presented in Figures 1 and 2. As can be noted in Figure 2, the first task involves analysis of retrospective data, which may be used for control purposes.

II. The second ongoing project, also funded from non-VR sources, is at the Center for Independent Living (CIL). CIL, a consumer self-help organization, looks at the problems of the handicapped from quite a different theoretical perspective. They see the rehabilitation system as a network of public and private agencies in which several serious gaps exist. Psychological factors, for example, are often ignored or perceived as barriers to rehabilitation. In fact, in our survey of providers we found that the motivation of the severely handicapped person was often the major reason for their not being accepted into the program. Our surveys of individuals uncovered an extensive amount of despair and depression, extremely poor self-

Figure 1

OUTLINE OF RESEARCH VARIABLES TO BE STUDIED

(University of Washington)

I. Source of Population to be Included in Study

   A. Nursing home residents.

   B. Patients dismissed from Department of Vocational Rehabilitation because disabilities judged too severe for rehabilitation.

   C. Clients entering job station program at University of Washington Rehabilitation Center with full sponsorship.

II. Independent Variables

   A. Primary independent variables
      1. Population source
      2. Disability category
      3. Severe disability
      4. Non-severe disability

   B. Secondary Independent Variables
      1. Age
      2. Sex
      3. Social condition (alone, family membership, etc.)
      4. Psychometric characteristics

III. Dependent Variables

   A. Functional behaviors at onset of contact.

   B. Rehabilitation needs.

   C. Rehabilitation costs.

   D. Rehabilitation time involved.

   E. Rehabilitation outcome.

   F. Functional behaviors at discharge.

   G. Functional behaviors at follow-up.

Figure 2

COMPREHENSIVE NEEDS PROJECT

(University of Washington)

<u>Project Time Frame</u>

3/1/75 - 3/1/76

3/7/75	Data analysis (retrospective data)
4/1/75	Part-time staff started (retrospective)
4/7/75	Notification of grant approved by Commissioner, R.S.A.
4/14/75	Notification of grant award by University of Washington
4/15/75	Enhancement of community involvement begun
4/15/75	Preliminary data protocol completed
5/1/75	Revised budget submitted
5/7/75	Budget number provided by University of Washington Grant and Contract Services
5/7/75	University of Washington space and furnishings arranged
5/7/75	Full staff recruitment started
5/7/75	Final form of data protocol
5/15/75	Preliminary report to R.S.A. submitted
6/1/75	State Advisory Board formed
6/15/75	Patient flow begun
6/15/75	Computer capability programs initiated
7/1/75	Full staffing completed
7/1/75	Commitment from state DPA-DVR
7/15/75	Monthly data system evaluations.
8/1/75	Accomodate state staff
1/1/76	Re-adjust staffing for next grant year
1/1/76	Prepare and analyze prospective data for Year I report
2/15/76	First year report completed

image, and general isolation. The CIL program is based on the assumption that the best way to energize and motivate such persons is through role-modeling among the handicapped themselves. Peer counseling, aggressive advocacy for full integration into society and for attaining full dignity as a person, and provision of services only the handicapped themselves are likely to identify or provide, such as attendant pools, equipment repair, inventories of accessible housing, and picketing of the mayor until he agrees to put in curb cuts downtown, are all part of this energizing concept. Established formal agencies, both public and non-profit, often have traditions and limitations which result in gaps and occasional insensitivity to the needs and preferences of the handicapped person themselves.

There will always be those whose needs are such that no public agency can address them--it may take years to get a recently blinded or spinal cord injured person out of a depression and actively seeking to realize his maximum potential. Sex counseling, mounting lawsuits against landlords, and demanding action from public officials are some of the messy, controversial and essential activities for the real lives of those severely handicapped people with a passion for equality. The questions raised about the consumer self-help groups include how well does this approach work, what does it cost, and what are the dangers as well as the opportunities? The CIL project should shed light on this innovative, but controversial approach to service delivery.

The CIL project is designed to look at the progress of persons in the CIL program over time, and to compare this with the progress of comparable persons not accepted into their program. Key demographic, income, service, cost and process data comparable to that collected in the Comprehensive Needs Study are to be collected. Measurements of severity and reported limitations in various areas of functioning, such as self-care and transportation, will be recorded at several points in time. Eventually, these data can be compared with other projects to determine the degree to which CIL accomplishes the objectives of their program.

The principal objective of this project is to show that a consumer based organization can deliver services which would not otherwise be provided to severely disabled persons. A peer counselor approach to problem solving is the essential difference. Research and Demonstration will identify gaps in the services which are currently available, and will demonstrate how a consumer based organization can serve to supplement and to expand a comprehensive service delivery network. The project is designed to facilitate independent living for people with severe disabilities within the community as well as to provide assistance in vocational exploration and job placement.

The purpose for the existence of CIL can be reflected in its basic philosophy of "do for self". It is felt that a staff with a range of disabilities has unique advantages in understanding the problems which are faced by those persons who are disabled.

CIL has developed and expanded its services so that they help clients establish eligibility for services, find attendants and transportation, learn financial management and self-care, and find independent living situations in the community. The experience of staff members of CIL in serving the severely disabled will provide valuable information on the service gaps and economic and social barriers which confront the most severely disabled. CIL staff has identified many service gaps, in response to which wheelchair repair, attendant referral, financial advocacy, and employment services have been created. Peer counselors serve as the link between existing services, and identify new service areas where there is a need. With client involvement, they hope to see the development of new services, in close cooperation with the

Department of Vocational Rehabilitation and other service agencies. Possible examples of such services include housing, location, expanded housing programs, transportation services, and training of health professionals.

Project Activity

Project phasing is indicated in Figure 3. The procedures which will be employed at different stages of this project are described in the next section.

Client Selection Process

A client selection advisory committee is made up of the counselor coordinator, one peer counselor, an occupational therapy consultant, and a service counselor. The committee will evaluate and assist the coordinator in selecting clients from the referrals. Those who are rejected as clients will be referred to other agencies in the community or to other CIL services. The intake form has been designed to help document the status of services received from other agencies and the current status of the applicants' independent living situation. There are four general groups from which the clients will be selected.

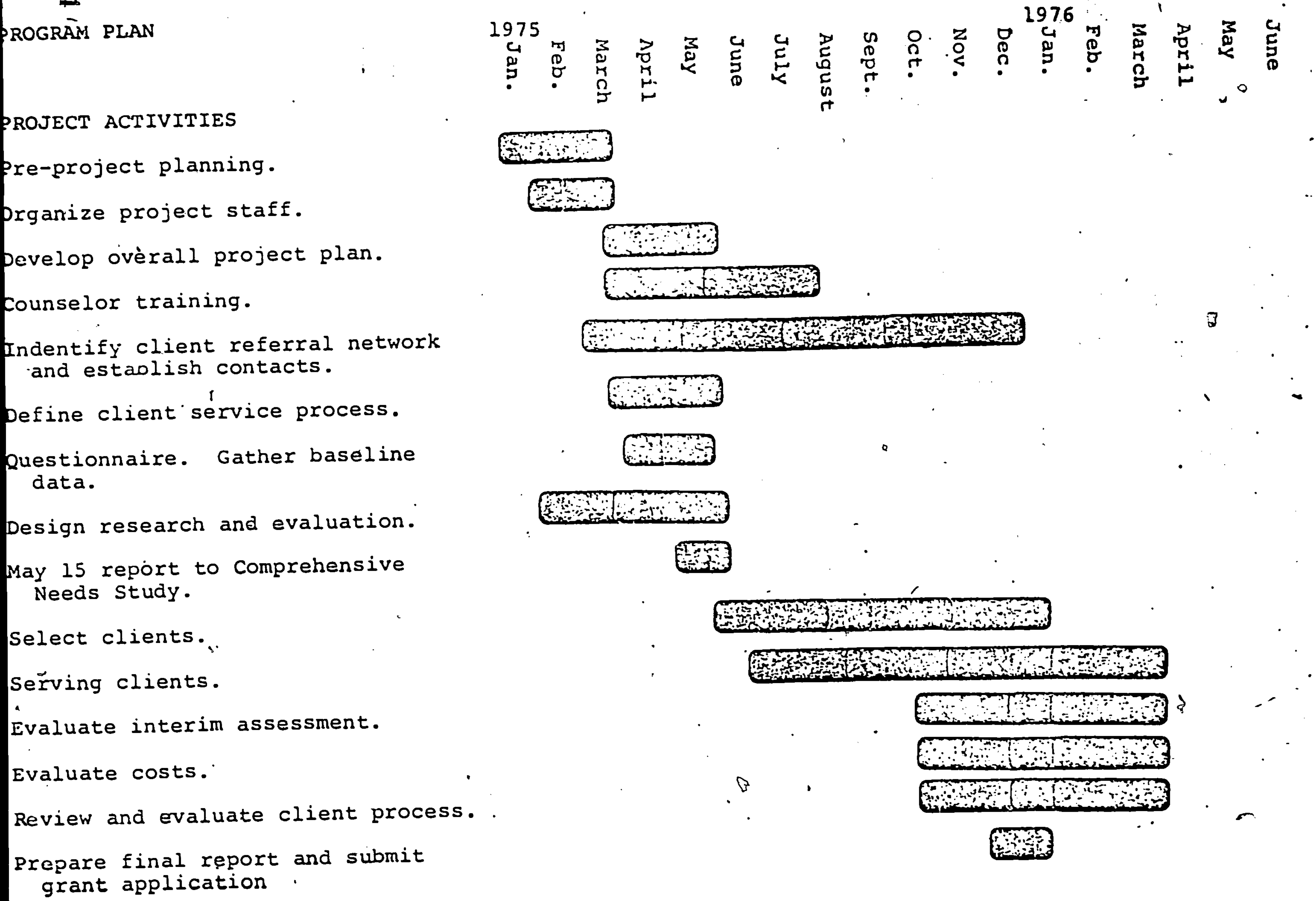
- Clients on rehabilitation but experiencing difficulties.
- The newly disabled with severe disability.
- The long disabled with no rehabilitation services due to severity of disability.
- Those that at present are not considered eligible for Vocational Rehabilitation (due to age, employment potential).

It is important that no specific disability should predominate in the initial caseload; where possible a reasonable distribution of age, sex and other characteristics will be attempted. Emphasis will be placed on serving those with high motivation who have been unable to receive satisfactory services through existing agencies.

Services

At the start of the project, counselors will have very low caseloads (one or two clients per counselor), and will be supervised closely by the counselor coordinator in order to a) monitor the counseling process, b) refine

Figure 3


PROGRAM PLAN
1975
Jan.
Feb.
March
April
May
June
July
August
Sept.
Oct.
Nov.
Dec.
1976
Jan.
Feb.
March
April
May
June
PROJECT ACTIVITIES
Pre-project planning.
Organize project staff.
Develop overall project plan.
Counselor training.
Indentify client referral network and establish contacts.
Define client service process.
Questionnaire. Gather baseline data.
Design research and evaluation.
May 15 report to Comprehensive Needs Study.
Select clients.
Serving clients.
Evaluate interim assessment.
Evaluate costs.
Review and evaluate client process.
Prepare final report and submit grant application

the program plan, c) identify service gaps, and d) identify unanticipated program stress. Coordination of the counseling program will include individual meetings with peer counselors on particular goals and needs of each client. Intensity of supervision will gradually reduce as the program makes a transition into full operation..

Services provided directly to clients by the peer counselor or other staff services will include:

- Individual counseling
- Group counseling
- Family counseling
- Sexuality counseling
- Occupational therapy
- Attendant management counseling
- Attendant placement-recruit
- Financial advocacy
- Housing information advocacy
- Mobility training
- Transportation
- Referral

An important component of service delivery is referral to other agencies for services the client needs but has not been able to obtain. Counselors will be responsible for following up on any in-service referrals, and for recording the services and benefits received from other agencies while a client of this program. Counselors will also record direct services for each client, and for entire caseload.

The objectives, services and assessment goals of the CIL project are illustrated in Figure 4.

Assessment

Clients will be assessed at the start of counseling, followed by at least two additional assessments--at the close of six months of CIL services, and/or at a time when services are judged as complete, and a follow-up assessment one year after leaving the services of the peer counselor. Assessment will cover the following areas of concern:

Figure 4

CIL Project Overview

Objectives	Direct Client Services	Data collection service input	Measures of change: from client assessment
acknowledgement, coping with disability self-esteem sexual awareness community/social awareness and mobility vocational/avocational goals	counseling: individual counseling sexuality counseling family counseling group counseling	hours and types of counseling hours and types of field work, phoning contact with other agencies, community organization, job development	counselor assessment emotional well-being questions education, employment income, satisfaction
self-care	occupational therapy	hours of occupational therapy time	independent living skills
physical mobility	mobility training transportation		physical travel pattern social activities
independent living situation	housing information and advocacy	housing services (hours, actual services)	living situation type of housing household
financial management	financial advocacy		economic resources, self-management
reducing service gaps	referrals	agencies where clients were referred, and record of services	service need service gaps.

-<u>physical assessment</u>
self-care
attendant management
physical mobility

-<u>emotional evaluation</u>: The counselor will discuss the following areas with the client:
acknowledgement/coping with disability
self-esteem
sexual awareness
community/social awareness and mobility
self-actualization

-<u>vocational/avocational plans</u>
vocational/avocational goals
vocational/avocational preparation
post-employment adjustment
employment stability
vocational/avocational development

The level of independent living skills and vocational or avocational skills desired and achieved depends on the <u>client's</u> stated goals and objectives. The counselor's function is not to become a necessary factor in the client's life, but to help the client realize his potential in recognizing and dealing with problems. The measure of success is the independence and self-reliance the client attains in recognizing and dealing with problems, in light of his own goals and objectives.

<u>Projects effective July 1, 1975</u>

Four demonstration projects, all funded by VR, will be described but briefly, since none of these projects are in operation at the present time.

I. <u>Demand for ILR Services</u> There is much concern but little data on the likely demand for ILR services once an authority is established. Some professionals in the field fear a demand so great as to swamp the vocational-oriented effort. Others feel ILR may be trivial, feeling that persons with ILR potential most likely can be shown to also have VR potential. One method of gaining some insight into the likely demand for ILR services is to implement a program of ILR, roughly comparable to that in the vetoed bills, in a small state or a bounded sub-state jurisdiction.

Such a project is essentially what the State VR agency in Utah proposed for demonstration.

II. Technology Application Great technological advances have occurred in many fields, but too often the application lags behind the technological breakthrough. Creative utilization of one of the advances in communication is proposed by the VR agency in Illinois.

This application would explore the feasibility of interactive cable television as a means of presenting training programs to the homebound, for establishing two-way communication with counselors or employers, and for assessing the ability of severely handicapped homebound persons to learn computer skills from a mode of media communication which permits feedback.

III. Expanded Agency Model Like the Seattle project, this project explores the possible roles of a CMRC, but the focus of this project is the coordination of the CMRC, other rehabilitation facilities, and other programs through the state rehabilitation agency itself. This essentially tests both the coordination and case management aspects of a potential independent living program. The New York State VR Agency, with Rusk Institute, ICD, Jobs, Inc., and other agencies working with the severely handicapped, are conducting this project.

IV. Multiply Handicapped Blind There are areas of reasonable concern about the state of knowledge regarding multiply handicapped persons. A blind cerebral palsied person, for example, must present more than the usual challenge to rehabilitation counselors. Demonstrations of progress with such individuals would remove that last doubt about whether methods for the rehabilitation of the severely disabled are available. Following up on its project for the blind retarded, the Texas Blind Agency has proposed to try some of the methods developed with that group on a dozen or more persons who are both blind and with one or more of the following secondary disabilities: chronically mentally ill, CNS dysfunction, multiple orthopedic disability, severe developmental disabilities, severe cardiac disorder, chronic pulmonary disease and/or severe auditory impairment.

Overview

There are numerous other areas ripe for demonstrations and numerous projects submitted which were not accepted due to lack of funds. For example, one agency proposed placing video cassettes on homebound TV sets in rural areas to provide step by step instruction for homebound occupations. Several proposed expanding rehabilitation into nursing homes and institutions, one proposed attempting family rehabilitation with the mentally ill and another proposed to deinstitutionalize the mentally ill. One would have tried a CIL type project, but with a somewhat more structured program. Several proposed testing service methods on specific disability groups such as arthritis, or the cerebral palsied. One non-VR agency project proposed having a group of clients not accepted by VR by reason of severity write their own rehabilitation plan, for up to $1,000 worth of service, to see how they would fare without the agency.

Among the areas not funded which are of special importance to get future demonstrations started include: Rehabilitation of the elderly, especially those in nursing homes, rehabilitation of the mentally ill in independent living to demonstrate how rehabilitation may differentiate its goals and activities from those provided by mental health centers, greater insight into how technology is diffused through the program, and exploration of different organizational arrangements and counselor incentives to assure that vocational objectives for the severely handicapped are not ignored in favor of independent living objectives. Along with our extensive suggestions for areas in which research would be fruitful, above and beyond the already important areas RSA is investigating, we feel that this program of demonstrations could lead to significant progress in defining the scope and accomplishments of programs for the severely handicapped. The knowledge needs in this regard are less for methods than for the most effective methods and arrangements. Results of such research and demonstrations should form the basis for sound development of rehabilitation programs for the severely handicapped.

Chapter 31

POLICY INTERPRETATIONS

A great many areas of investigation in this report have shown the existence of needs among the population of severely handicapped. Many suggestions are made in the several chapters. For the most part these are needs which we know how to meet: employment can be provided for the severely handicapped in a variety of ways; transportation can be supplied; medical services can be delivered, and equipment can be manufactured and repaired. Indeed, we believe it is possible to teach anyone who is alert and has some movement to do some task. The problem is that the labor market does not require the task from that individual at a price he is willing to accept. What seems called for is the will to provide resources, judicious decisions on the design of the delivery system and its accountability, and implementation of a commitment to full employment for all, including the most severely handicapped, who wish to work.

In this chapter we discuss some of the findings of the study and make some observations on the implications we see for the current program and for the deliberations over an independent living program. We provide these comments in a separate chapter because they are interpretive, drawing not only on our analytic findings but our understanding of the constraints involved in changing the present system of serving the severely handicapped. Throughout this chapter we make the assumption that only a modest increase in the level of direct funding to Rehabilitation is likely to be available for an expansion of services. Obviously, if this assumption proves to be in error, the judgments reflected below would have to be adjusted accordingly. We present some interpretation, which have potential cost complications for income and health financing programs, but these programs are already of such magnitudes that the percentage changes would likely be small.

Definition of Eligible Population

While a great proportion of the providers of rehabilitation services indicated that the definition used in the Vocational Rehabilitation Act is adequate for the purpose of defining severity, we feel that some more objective instrument or means should be developed so that applicants and evaluators will have objective criteria to judge the agency actions. We have indicated a number of options on these approaches, but we feel that further research is required to develop a screening instrument consistent with legislative intent to serve the severely handicapped. For the VR program, we feel that the primary source of variation in selection criteria should be the availability of local rehabilitation resources such as workshops or medical rehabilitation centers. Save for these, any severely handicapped person in any State should have the right to expect approximately equal probability of acceptance. We recognize that actual closures into the competitive labor market will vary depending on labor market conditions.

Concomitant with this we would suggest more stringent quality control, especially on cases closed for severity. We propose making a distinction in the VR reporting system which would allow "difficulty of placement" as a legitimate closure code. Such a closure code would more accurately reflect local labor market considerations. While one does not want VR to waste funds on futile efforts to place persons for whom the labor market will not make places, one also wishes to distinguish clearly between those reasons based on severity and those based on factors such as age and education combined with a disability. Efforts to place greater effort on services to these cases rather than assume difficulty may ha payoff. Considerable research in establishing standards and criteria for this screening activity we deem a very high priority. We would propose also a reviw of cases closed for severity or difficulty by a panel beyond the line supervisor. The panel might also include consumer representatives.

Estimates of the Disabled Population

Our efforts in trying to translate data files not intended for this purpose, to develop population estimates took a great deal of time and work, yet yielded less than optimal results. RSA should be granted funds and/or authority to work with Census or other parts of HEW to develop ongoing national samples of sufficient size to capture State-by-State estimates of the handicapped. These data will give both HEW and Congress touchstones on the incidence, prevalence, and performance of the States with respect to the population universe. Periodic surveys every 10 years or so which are intended primarily for other purposes do not yield the types of data necessary for program planning and for evaluation of the advances made in serving the population at risk.

As a corollary, RSA and the Social Security Administration should work even more closely in follow up of earnings records and of comparability of individuals both in and out of VR in order to get better data on mortality, earnings, and job retention. This would allow benefit/cost analyses predicated more on hard data than on assumptions.

Follow up studies should be mounted, not on an after the fact basis, but prospectively. A sample of clients now applying to VR should be followed for periods of up to 10 years to determine outcomes, along with a non-VR cohort studies of this type on the elderly, and RSA would be well served in doing the same.

Implications of Client Surveys

The findings of the VR survey suggest strongly that considerable value should be placed on expanding the follow up of clients who cannot be vocationally rehabilitated on a number of fronts. Repair and replacement needs in equipment, while certainly not great, appear to require some public help. Health insurance would be the preferable place to lodge such financing mechanisms. Ongoing contact with VR, though, might permit reintroducing those with the drive to work back into the program. In view of the extent to which we found that the most severely impaired needed assistance of a medical nature, they should be part of the planning for any further developments in health insurance.

As we point out in the following sections, many of the findings have implications for expanding the VR role in housing, transportation, and the like. Here we present some rough estimates of the cost of providing a modest level of services for attendant care, counseling, education, homemakers, meal preparation, and some transportation.

One method of developing such cost estimates would be to consider a program to serve the 18-64 group of 68,000 closed in 1972 for severity. Making modest assumptions of care needs--two round trips per week in a taxi, 1 hour per day for an attendant, 1 hour per week of a home health aide, 1 meal per day brought into the home, 4 hours of personal and adjustive counseling per year, and (for 10 percent) $1,000 toward college tuition--the cost of such a program would be $115.1 million. Table 31-1 summarizes these estimates.

Table 31-1

Annual Cost Estimates of Modest Program
to Serve the Handicapped Rejected by VR

Service	Unit Cost	Units	Persons	Costs ($millions)
1. Homemaker/attendant	$ 3.00 per hour	365	37,400[1]	41.0
2. Home health	$11.00 per hour	52	27,900[2]	16.0
3. Meals on wheels	$ 1.55 per meal	365	37,400[1]	21.2
4. Transportation/taxi	$ 6.00 per round trip	104	37,400[1]	23.3
5. Counseling	$25.00 per hour	4	68,000	6.8
6. Education	$1,000.00		6,800	6.8
TOTAL				115.1

1. 55 percent of our sample were dependent, a proportion used here.
2. 41 percent were moderately to totally dependent.

An alternative approach is to ask what the authorization of $80 million would have purchased, this being the high-level authorization had independent living rehabilitation become operated. Average Federal shares of counselor time in direct salary and fringe benefits, not counting office space and support costs, for FY 1973 was approximately $20,000 per counselor year.[1] Diagnosis, evaluation and restoration ran about $600 per client. If each counselor did nothing but serve 100 clients per year for these two services, $80 million would permit services to 100,000 clients.

Put another way, to cover costs of 100 clients per year per counselor (or a total counselor time per client of 20 hours), diagnosis and evaluation, restoration at costs comparable to the average caseload, $80 million would have paid enough to cover the 68,000 persons rejected for severity reasons and to send about 13,300 of them to rehabilitation centers or workshops for about 2 months each.

Architectural Barriers

A role for the rehabilitation agency in the advocacy for a barrier-free environment was described following the experience in Massachusetts. An expanded role for the VR agency in being the source of information on methods to modify the residence and providing financial and technical assistance to persons in need of such services would be desirable. This service could as well be established through one of the voluntary sector agencies with public funds. Lack of compliance with State and Federal accessibility, legislation is recognized as a major concern. The role of the Architectural and Transportation Barriers Compliance Board should be strengthened by providing the Board with sanction authority and additional resources.

Geographic Mobility

Relocation assistance essentially assumes an inventory of accessible housing,

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[1] FY 1973 Program Data Book, RSA.

working agreements with movers, and other information on services and opportunities. This would permit a severely handicapped person to get a notion of what is available in the community to which relocation is desired. While this could easily be a role for a unit of the rehabilitation agency, it could also be contracted out to a consumer-run organization or to a voluntary agency.

Transportation

Greater emphasis on barrier-free public transportation, including curb cuts on the way to it and other efforts to enhance mobility would be a major assist for many of the severely handicapped.

While we do not expect the rehabilitation agencies to start major alternative transportation systems, we feel that the agencies can make greater efforts as advocates for accessible transportation and in providing support for paratransit systems to be set up and operated by the handicapped themselves. The essential costs of such systems include the initial capitalization of the vehicle and costs of insurance. If the handicapped tap their network to increase utilization, the costs per trip could be considerably lowered compared to some present experiences.

Employment and Labor Force Participation

The prospect for employment for the majority of the most severely handicapped in the competitive labor market under today's conditions and without major subsidies to either the employer or employee seems dismal. Affirmative Action efforts will probably extend opportunities somewhat to the less severely disabled. Without major legislative changes, the present employer attitudes, the effect of perceived and actual increased insurance premium costs (an area worthy of greater investigation in itself), job requirements for flexibility of schedules, and modifications to places of employment, all suggest that labor force participation is a faint hope for all but a few of the severely handicapped. Legislative changes could include the elaboration of the authority in the Vocational Rehabilitation Act for new careers into a public employment program for the severely disabled, with funds for ongoing support of positions. In addition, the number of workshops and facilities should be expanded, as an estimated 1,000,000 could benefit from such placements.

Long-Term Care

If there is one priority area in which rehabilitation might make substantial contributions to both public policy and the severely handicapped, it is in working with clients in nursing homes and long-term care facilities. It would be desirable to work out more of the issues in demonstrations before moving ahead on legislation for Independent Living, but on the face it appears a very valid concept. Long-term care vendors, especially those in the for-profit sector will have few incentives for permitting rehabilitation to occur in their facilities. The most rehabilitatable individuals are probably those who require the least care and, hence, are most profitable. Turnover of beds is itself a cost to the vendor. Reluctance to easily cede profit is understandable. Similarly rehabilitative goals for this population are difficult to achieve because of a lack of community resources. Group residence facilities and other supportive settings which allow more independent living than nursing homes are not widely available.

This should be a very fruitful area to pursue. An HEW interagency task force on long-term care mounting research and demonstrations on such projects should be created.

Casefinding and Followup

We were struck by the difference that the source of referral made in the acceptance of clients and the probability of success once accepted. Since the bulk of clients are referred from hospitals or other agencies, greater efficiency of referral could be achieved if outstationing or some other form of improved referral procedures were accomplished. Some method for follow up of closed cases or cases not accepted could easily be developed through a variety of means: mail back forms, counselor follow up at periodic intervals, etc. The issue here is not the method, since that can be developed easily, but the services and resources to be delivered after the follow up. If there are to be few services so that the individual is not particularly better off, agency resources spent in the follow up might get greater return spent for individuals on the waiting list.

One of the possibilities for expanding the program, however, is to expand the services which can be available to people without vocational objectives: equipment replacement, generally referring the individual to various advocacy or consumer organizations, family counseling, etc.

Health Coverage

Our investigation was not able to assess the extent to which all of the severely handicapped have health care coverage. Since about 67 percent have Supplemental Security Income (SSI) and Disability Insurance (DI) benefits, they would have some coverage under Medicaid or Medicare. Another group would have Veterans Administration benefits. The CMRC clients had their services covered by third party vendors in 97 percent of the cases. The VR population reported a high degree of coverage as well. Thus the coverage for acute health care seems less problematic than the coverage for certain services. For example, after the initial device is supplied, the cost of repairs or replacements are largely borne by the individual. Coverage for items such as attendant care or home health aides even in the public programs is very limited.

We would suggest further investigation of the potential costs of separating health care coverage from income maintenance, extension of health coverage to all severely handicapped persons regardless of employment or income (but with reasonable cost-sharing provisions), and expanded scope of services covered to include ongoing needs for equipment maintenance and replacement, attendant care, interpreters, readers etc. At present, good data on utilization patterns and cost factors are unavailable.

The objective of separation of health coverage from income maintenance is to reduce loss of health benefits for those who wish to work. As pointed out in the discussion on disincentives, the fear of being burdened with major costs of care discourages many from seeking the highest level of social and vocational functioning of which they are capable. Coverage of the acute and ongoing medical, home care, and equipment needs of this group seems warranted without regard to labor force participation. We feel that the coverage should not be through the rehabilitation program, since the needs and purposes of such coverage are broader and most consumers of these services should be reasonably competent to procure their own. Rehabilitation should, however, be able to counsel those with difficulties. Similarly, we feel that existing public programs financing health care services should be required to take the burden of costs for such care off the rehabilitation program. If the medical care financing programs were broad enough and responsive enough to cover the necessary services promptly and at reimbursement rates that assured quality care from vendors, then the rehabilitation role should focus primarily on case management, monitoring, quality control and other activities. The substantial funds available to provide restoration could then be placed back into other rehabilitation services.

Another similar area for investigation is the relationship of private insurance and Health Maintenance Organization rules with respect to the severely handicapped. Man[illegible]vate insurance plans equate disability with sickness and raise insurers' rates. It is alleged by consumers that these rates are raised without the vendors having done experience studies to see if the increase is warranted or, if warranted, whether the premium is related to the costs. Employers perceive the possibility of such increases as a cost if they hire the handicapped. One consumer on our advisory committee reproted that an HMO turned down her request to join because of her handicap. Others complain that the clauses excluding pre-existing conditions leave them uncovered in the area of their impairment where they may need assistance.

As the debate on various forms of national health insurance proceeds, we would urge examination of the special concerns of the severely handicapped for the coverage in such a program. If private vendors are to be used extensively, special requirements (e.g., reimbursement arrangements) should be included so that the severely handicapped are not further penalized by their impairments.

As a minimal proposal we would suggest that Congress eliminate the rule requiring 2 years of receipt of Disability Insurance Benefits before persons are eligible for Medicare coverage. It is an unjustifiable barrier to many who might like to be vocationally rehabilitated.

Income Maintenance

Small legislative changes in SSI and DI could make big differences to the severely handicapped and to their motivation for rehabilitation. We are unable at this time to estimate the likely impact on caseload and expenditures of some of these suggestions, but given the high proportion of severely handicapped already covered (67 percent) we feel that a significant increase in the billions currently expended is not likely. The results, however, in encouraging the severely handicapped to attempt greater self-realization would, we think, be commensurate with the costs. We would propose that the definition of disability used for eligibility in SS and DI be based entirely on the severity of the disability as measured by some objective instrument and earnings history to distinguish between the programs. This instrument should be scaled at the level of severity of the current SSI-DI caseload. Then reference to Substantial Gainful Activity should be dropped and instead a provision for exemption of reasonable costs of employment and the present SSI 50 percent tax rate on earnings be substituted. This would have to parallel the separation of health benefits from eligibility for income maintenance, since even working without income maintenance may cause severe dislocation if health coverage is also lost.

Altering the income maintenance programs in this way would offer several advantages to rehabilitation as well as to the severely handicapped. More persons would have some incentives to try to work to improve their incomes. This should permit rehabilitation to receive more motivated clients. Secondly, this allows individuals with some income to work and should reduce the amount of maintenance expended by VR itself, again permitting greater investment in other services. Given the limited demand for severely handicapped labor, we cannot presently estimate the behavioral effects (which may be minimal and result in minimal costs), but we suspect the morale effects will be substantial.

Coordination of HEW Programs

The problem of coordinating HEW programs for the handicapped is considerable. These programs have differing purposes, objectives, and target groups. Some are federally administered, some State administered, and some administered at the local level. Initiatives designed to pull such programs together, such as Services Integration and the Allied Services proposal have so far reported limited, if any, success. Within HEW itself are the bureaucratic realities of the differences in size and influence of the Social Security Administration relative to the office of Handicapped Individuals and RSA. We are growingly convinced that if Congress seriously expects coordination then it will itself have to make major efforts to reconcile differing legislative purposes and to mandate more authority to the Office of Handicapped Individuals in order to gain the full cooperation and participation of the various agencies.

Among the service programs which should be investigated to reconcile both coordination and boundary problems are programs for the developmentally disabled, mental health, aging, and social services. If rehabilitation is to take a greater role with handicapped children, then greater interrelationship with the special education programs of the Office of Education will be necessary. Given the $16 or so billions spent by HEW on the severely disabled, with a larger amount going to all disabled, it may even be useful to think about pulling all of these programs into a single organizational entity, althouth such a move would have to be carefully designed to minimize the dislocations which would result from such bureaucratic changes.

In some program areas we suspect that the Federal level may not be the appropriate place for coordination at all. In some programs, even State-level coordination may not accomplish much. For example, when Congress created Title XX of the Social Security Act as the mechanism to provide social services to the poor, there was an explicit reduction in the degree of Federal prescription on the shape of the State program. Services, eligibility, allocations of funds, even types of services, questions of who supplies the service and priorities for service are to be left largely to State bureaucratic and political processes. Groups such as the developmentally disabled, who have been favored in the past may or may not do well in capturing resources from this program. Rehabilitation agencies may be able to move in on some share of the activity depending upon their agressiveness, standing in the State, and interest. Yet it is clear that if the process of allocation in a State is not favorable to the disabled as a key target for social service attention and resources, there may be little to coordinate. In this instance, either a return to the Social Security Title VI approach or a new social service authority may well have be authorized. In testimony on the Independent Living Provisions of the 1961 proposed act, The American Public Welfare Association pointed out its concern that Social Services authorized in the public assistance titles and ILR services would overlap. This overlap might, they testified, cause confusion wit clients and fragmentation of services. They argued for a coordination mechanism to avoid duplication and confusion. Giving only one agency responsibility for rehabilitation would be, they thought, a backward step. If such a coordinated mechanism wer possible then, its implementation with Title XX seems to require stronger mandates than presently are in that program.

While much can be done through policy and legislative changes to improve the interrelationship and coordination of these programs, ultimately the most effective means for assuring that the severely handicapped have the services they need is the active and aggressive effort they themselves exert. As with all of us, the key responsibility for getting the range of our needs met rests with us as individuals and the organizations which we use to exert influence. It is reasonable to expect, therefore, that the severely handicapped should bear the final responsibility for insuring the satisfactory coordination of programs designed to serve them.

Consumer Involvement

While there are considerable problems in defining who is a consumer and who really speaks for whom, we were struck throughout this study by the growing number of consumer-run organizations and the growing awareness and advocacy of many of the individuals. Organizations like the Center for Independent Living fill a role as perhaps no other organization can. Emerging organizations of consumers for advocacy and political activity may be an important sign of a turn away from despair among the disabled.

Rehabilitation needs to make greater use of these individuals and organizations. It is they, after all, whose lives are affected for good or ill, who can say what is in their interests and what is not. Certainly this is a problem for many professionals, even in rehabilitation, to accept an ungrateful or a critical client. But we feel that by utilizing consumers in rehabilitation, a more effective rehabilitation program can be established, especially in the area of coordination of services. We have heard of a case, for example, when a client would not sign off on his Individualized Written Plan because he thought the workshop was overcharging for the program that he was to enter. Consumers are uniquely able to make this type of assessment.

Recognizing the interest in consumer involvement reflected in this report, research and demonstration projects could increase knowledge in several areas. For example, projects with councils of organizations of the handicapped might explore the feasibility of different disability groups cooperatively developing information and referral services, paratransit systems, equipment repairs, reading services, and so forth. The most effective means for consumers to seek and coordinate needed services in a manner appropriate to their realistic capabilities should be demonstrated.

We would encourage greater effort in implementation of the provisions of the Vocational Rehabilitation Act for consumer committees and some legislative mechanism for funding CIL-type organizations should the demonstration project prove their worth.

Functions of Rehabilitation

The primary areas of strength we observe in the rehabilitation program lie in case management, counseling, and coordination. Future expansions of the program, especially with respect to independent living rehabilitation should focus on these as their key service orientation. We caution, however, that counselors who have only these skills and a pile of referral slips will have a low sense of involvement and most probably a low level of accomplishment. Yet expansion of the program into independent living areas will require considerably greater advocacy and use of existing programs. We have made numerous suggestions of ways Congress could modify programs to make them more responsive to the rehabilitation needs of the severely handicapped. Should those programs in fact be the primary financing and delivery mechanisms, then rehabilitation could have full play in its case management, counseling and coordination role. The role would include responsiblity for ongoing, long-term case management for the severely handicapped, assuring proper information and counseling is availabe to the individual, and coordinating other programs to meet the needs identified. Only the long-term case management aspect is new, since VR is primarily a time-limited program. This change would necessitate new procedures and orientation, but they are, we feel, within the capability of the program managers to accomplish with ease.

In developing a program of independent living for severely handicapped individuals, it is imperative that duplication and conflict in the way of service provision, evaluation, funding, etc. be minimized. To gain insight into this matter, we asked providers of rehabilitation services for their thoughts as to who should be held responsible for particular functions.

While only 28 percent of the providers responded to this question, those that did respond showed a high degree of uniformity of opinion. For example, of the top five ranked agencies that were considered most suitable for conducting a program of independent living, 80 percent of all respondents though that VR should be responsible for evaluating the rehabilitation potential of individuals. An additional 12 percent thought that comprehensive rehabilitation centers should be in charge of this task. Less than 5 percent thought that a social service agency or public health agency should perform this activity.

In every programmatic area--funding, service provision, coordination, information and referral, training, advocacy, case management, and case finding--VR was the first choice of the respondents in our sample of providers. This result may be explained by the fact that 54 percent of the respondents are employed with VR agencies. Nevertheless, we can safely summarize that VR is the most preferred agency by the respondents sampled to conduct independent living services for severely handicapped individuals.

Financing

From the point of view of the VR program itself we are concerned that the number of expectations placed on the program far exceed the resources available to meet them. Rehabilitation budgets for the past few years have been virtually constant, without considering the effect of inflation. The Congress and the Administration have made little in the way of unequivocal statements that they expect the natural concomitant of this fiscal constraint and the efforts to move toward the more severely disabled to result in fewer rehabilitations, higher cost rehabilitations, and greater incident of closures which are either unsuccessful or in non-wage occupations. Such a signal would assure the program managers in the States and probably make the job of facing the State legislatures for the State share of rehabilitation funds somewhat easier.

If the Congress is desirous of an independent living program we would think authorization levels far in excess of those included in the previous bills would be called for, if only to cover those persons presently closed for severity. We would think that an authorization of $30 to 80 million dollars would be most usefully spent on a project grant program modeled after the Innovation and Expansion Grant Authority which would establish a series of projects to investigate various approaches, assess the most effective and efficient means for providing such services, and work out the optimal interrelationships with other delivery systems before a large formula grant program is introduced.

We would think that much of the financing of both VR and an ILR program should be accomplished through the general health and income maintenance programs as pointed out previously.

Lastly, in financing of a formula grant program of independent living, some consideration should be given to the possibility of client cost sharing since some services provided under a program of this type might include those normally provided by the individual--meal preparation, homemaking, recreational activities, etc. Client cost sharing should include (1) payments associated with inclusion in the program and (2) payments associated with use of the program's care benefits.

Independent Living Rehabilitation or Not

As contractors we can only suggest that the need for independent living rehabilitation is there and that the rehabilitation system as it currently exists could provide such services as may be authorized. We were struck, however, by the potential cost of such a program and the minimal authorizations proposed in the previous bills. Given the focus in VR on the severely disabled, we would suggest not beginning a formula grant program of independent living until a minimum of $150 million per year can be assured to provide coverage just for those currently in contact with VR and not served due to severity. Any lesser funds would be well spent in VR as it presently is structured. Congressional interest in an independent living program might be effectively expressed through first mounting demonstration projects to work out the service delivery issues until such time as funding for both VR and ILR is available. Another option for modest funding levels is to expand use of extended evaluation. Such approaches, in a time of fiscal constraints, permit some movement while avoiding many of the sticky problems of eligibility and relationship with other service systems described in the study.

The way to most easily accommodate a very modest program of independent living is through expansion of extended evaluation. As we pointed out in our discussion of this option, one small step would be to have all persons thought to be infeasible due to the severity of their impairment go through a full program of such services. We would exclude those who are not actually severely handicapped, but whose closure is based on other characteristics which make competitive placement difficult, such as age or inadequate education or skills. As we pointed out, most of these persons seem to have few limitations in self-care and mobility.

When so limiting the program, it is important to also establish new measures of success. At present a client closed from extended evaluation without vocational rehabilitation is counted as a non-success despite the benefit received from services. Certainly measurable, successful independent living outcomes can be defined: no longer needs attendant, can now travel alone, reduced need for assistance in homemaking, and so forth.

If the ILR program were limited to those severely handicapped who get to a VR Agency but who cannot be vocationally rehabilitated, it is possible to avoid many programmatic issues concerning which services to provide, how to interface with other delivery programs and, at the same time, recogize the limitations of resources in dollars, facilities, and manpower. For $80 million, an average counselor, administrative, and case service cost of $3,000 would be available for the nearly 27,000 persons who, based on the 41 percent in our survey, are moderately to severely dependent because of their impairment.

If any initiative is to be mounted in new areas, we would propose it be in the rehabilitation of persons in nursing homes and related long-term care facilities. While many persons in these institutions need some level of care and supervision, there are some who could be rehabilitated to their homes or more congenial community settings if they got some rehabilitation services. Movement to these settings could reduce outlays in Medicaid and Medicare for these individuals and offset costs of rehabilitation services. Demonstrations of the possibilities of such an approach prior to legislation would be desirable, but if the reform of health and long-term care programs proceeds rapidly, we feel the State-Federal rehabilitation program and/or CMRCs should be written in, based on the face validity of the accomplishments in the field.

Summing Up

When we began this study VR loomed large. At the end we found that it accounted for about 2 percent of Federal expenditures on the severely disabled. While its influence far outstrips that modest proportion, we wondered at the expectations people placed on the program without the corresponding willingness to provide the resources.

Any exercise which approaches a population from the perspective of "needs" is very likely not only to find needs but also to find the associated costs of meeting those needs to be very expensive. To have a comprehensive program for the severely disabled that comes anywhere near to living up to its name and expectations would cost billions. The Congressional authorizations, much less appropriations, belie the impulse. The $30 million first-year authorization could be spent entirely on demonstration projects. The Nixon Administration was, perhaps, more honest in saying it chose not to put up the resources, but it failed in dealing with the consequences.

When Congress turns to VR to deal with the more severely handicapped, several things happen. Whatever the merit of digging into the pool of more severely handicapped, some of the traditional clients must be abandoned. These are clients whom many consider quite worthy of services. But to serve the more severe, given no additional resources, means something or someone has to go. The next thing that happens is that the risk of failure mounts, not so much because VR does not know how to rehabilitate but that the labor market does not easily accommodate the more severely handicapped. The number of closures drop. No matter that Congress may not mind, nor that good is done anyway. While Congress may be willing to watch the number of rehabilitations drop with some satisfaction that the more severely handicapped are better served, there is little to indicate that State legislatures and governors are so sanguine. And it is a State-Federal program. Indeed, there is little to say that the Administration is so inclined. When rehabilitation declined in the first part of the year, the Secretary of HEW wanted to know why.

No one can fault the desire to actualize the potential of every disabled person. However, the realities of resource constraints require responsible public officials both in Congress and the Administration to make the hard choices and not make grand pronouncements of humanitarian concern, while leaving it to the local counselor to turn away the specific individual at the door.

Much technical knowledge exists to allow the severely handicapped to realize their potential. Design of a goal oriented program and significant financial commitment is required. This commitment must be undertaken if the promise of providing comprehensive services is to be fulfilled.