UNITED STATES DEPARTMENT OF EDUCATION
OFFICE OF THE ASSISTANT SECRETARY
FOR SPECIAL EDUCATION AND REHABILITATIVE SERVICES

Dear Colleague:

I am pleased to invite you to participate in the "Economics of Disability II: Forum on Disability Policy" as a follow-up to the first "Economics of Disability" meeting held in Washington, D.C., April 1985. This national forum is the second of a series of planned meetings dealing with disability issues.

Congressional members/staff and Executive Branch personnel are invited to participate in problem-solving discussions in four specific policy areas. Discussions will be augmented by the participation of research personnel, practitioners, educators, and advocates in the disability field.

The Forum is to be held **Monday, February 24 and Tuesday, February 25,** 1986 at the Capitol Holiday Inn, 550 C Street, S.W., Washington, D.C. A block of rooms is being reserved at the hotel at special rates of $61 single and $76 double for those individuals with government I.D. and $75 single and $90 double without I.D. Reservations are to be made by calling the hotel directly at 202-479-4000 and indicating your participation in the national forum. Reservations must be made by January 31, 1986 to assure the above rates.

We would appreciate your calling Dr. L. Deno Reed at the National Institute of Handicapped Research to advise of your acceptance of this invitation. The telephone numbers are 202-732-1193 or 202-732-1182.

We look forward to your being with us to share your specialized knowledge, experience and interest in disability policy determination.

Sincerely,

Madeleine Will

Madeleine Will
Assistant Secretary

Enclosures

400 MARYLAND AVE., S.W. WASHINGTON, D.C. 20202

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NATIONAL INSTITUTE OF HANDICAPPED RESEARCH

"ECONOMICS OF DISABILITY II: FORUM ON DISABILITY POLICY"

CAPITOL HOLIDAY INN - 550 C STREET SW

FEBRUARY 24-25, 1986

MONDAY FEBRUARY 24

8:30 AM	REGISTRATION
9:15 AM	INTRODUCTION AND WELCOME
9:25 AM	OVERVIEW: INTERAGENCY COORDINATION
9:45 AM	KEYNOTE ADDRESS
10:15 AM	BREAK
10:30 AM	COMMUNITY CARE
12:30 PM	LUNCH
2:00 PM	EMPLOYMENT PROGRAMS
4:00 PM	ADJOURNMENT
5:00 PM	RECEPTION

TUESDAY FEBRUARY 25

8:30 AM	WORK DISINCENTIVES
9:45 AM	BREAK
10:00 AM	DISABILITY MANAGEMENT
11:30 AM	LUNCH
12:45 PM	ISSUES/REACTIONS/SUMMARY
2:45 PM	ADJOURNMENT

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COLUMBIA SOUTH ROOM

FEBRUARY 24-25, 1986

DRAFT ISSUE PAPERS

FOR

POLICY FORUM PARTICIPANTS

[PARTICIPANTS SHOULD BRING THE PAPERS TO THE FORUM;
PAPER I PROVIDES AN OVERVIEW OF THE FORUM THEME - THE NEED FOR
IMPROVED NATIONAL DISABILITY POLICIES - AND THE REMAINING PAPERS
EXPLORE SPECIFIC DISABILITY POLICY TOPICS]

400 MARYLAND AVE., S.W. WASHINGTON, D.C. 20202

PAPER I

STRUCTURAL PROBLEMS IN THE SERVICE SYSTEM FOR HANDICAPPED PERSONS

POPULATION AT RISK

Although the terms "disability" and "severe disability" are frequently used, there are wide variations in the meanings that different people attach to these terms. In consequence, there is much miscommunication among people, including among professionals in the field, much misinterpretation of existing data, and much misunderstanding about disabled people.

We begin with the concept of chronic conditions and impairments. The term, "chronic conditions," encompasses deviations from normal health that are expected to last for a substantial period of time, often for the person's lifetime. Examples of chronic conditions are tuberculosis, arthritis and rheumatism, diabetes, and psychosis. Although most chronic conditions are diseases of various types, mental retardation, which is not a disease, is considered to be a chronic condition. The term, "impairments," refers to anatomical limitations that result from disease, injury, or congenital conditions, e.g., deafness, blindness, missing all or part of a limb, etc. For convenience, we will use the term "chronic conditions" to include both chronic conditions and impairments.

Most people, professional and nonprofessional alike, implicitly, and sometimes explicitly, use the term "disability" as if it were synonomous with the term "chronic condition." If a person is mentally retarded, or missing an arm, or has arthritis, then he or she is regarded as disabled. When the term "severe disability" is used, most people envision severe chronic conditions, such as an I.Q. below 50, or multiple loss of limbs, or arthritis sufficiently severe to cause a person to be confined to a wheelchair.

Unfortunately, the term "disability" is often defined in technical ways which are inconsistent with the way most people use the term. For example, most disability surveys do not consider a person to be disabled unless he or she manifests some inability to carry on normal activities. For example, a person would not be considered as work disabled unless he or she was unable to carry on a job, or was seriously limited in the performance of one. As another example, the National Health Survey no longer reports on the number of persons with chronic conditions but only on persons with chronic conditions who report some activity limitation. This leads to the following types of problems:

o Periodically, we come across analyses of survey data which stress the finding that most disabled persons do not work, seemingly oblivious to the fact that the "finding" is an artifact of the definition: persons with chronic conditions who were working were not counted as disabled in the survey.

o More importantly, counting a person as disabled only if they manifest inability to perform some normal activities has made the term "disability" synonymous with failure in some people's minds -- an inference which has profoundly negative consequences for handicapped people as they seek to live normal lives.

The fact of the matter is that the majority of persons with chronic conditions report no limitations in their activities as workers, as homemakers, or in any other activity. Data from the National Health Survey for selected chronic conditions for 1979 (Mathematica, 1984) indicated that 70 percent of persons with visual or hearing impairments had no limitations and over 60 percent of persons with arthritis reported no limitations. Similarly, 60 percent of persons with heart conditions and 70 percent of persons lacking extremities or body parts reported no limitations. Even among groups whose chronic conditions are obviously severe, a surprising number reported no activity limitation and would not be counted as disabled in most surveys. For example, about one in every eight persons who reported paralysis reported no activity limitation, and 46 percent of persons with both hearing and visual impairments reported no activity limitation.

During 1979, data from the National Health Survey (Mathematica, 1984) indicated that about 14.6 percent of the noninstitutional population had some limitation because of a chronic condition. About one-fourth of these persons, however, reported that they were not limited in their major activity (working, keeping house, or going to school) and about half were limited, but not totally prevented from, performing their major activity. Only 3.7 percent of the population was so severely disabled that they were unable to carry on a major activity.

In all, a little over 23 million Americans not living in institutions reported that they were limited in the amount or kind of their major activity, or totally prevented from carrying on a major activity. Although this is a large number of persons, it must be emphasized that the majority of persons with chronic conditions are "successes, " not failures.

The prevalence of chronic conditions varies substantially by age. National Health Survey data for 1979 indicate that 8.8 percent of the population, 17 to 44 years old report some activity limitation, as compared to 24.1 percent of the

population aged 45 to 64, and 46.0 percent of the population aged 65 and over. The increasing prevalence of disability by age has important implications for the number of persons who are work disabled in future years, as increasing numbers of Americans live longer and as the age of retirement rises. Assisting aged, disabled persons to continue to be productive is a major public policy problem.

What is the prevalence of work disability among persons of working age? In a review of existing surveys on the prevalence of disability, Haber (1984) concluded that about 5.8 percent of the noninstitutional population, 18 to 64 years of age, is prevented from working because of a chronic conditon. Applying these percentages to the population 17 to 64 years of age in 1979 would indicate that about 7.8 million persons who were not in institutions were prevented from working. This compares with National Health Survey data which would indicate that about 3.8 million persons were unable to carry on a major activity, and that about 13 million persons were limited in, or unable to carry on, a major activity in this age range.

Why are some people with a chronic condition able to work and live normal, or near normal lives, while others, with similar conditions, become dependent upon public support? Part of the answer is clear. Chronic conditions are only one, among numerous, variables which determine how individuals will adjust to society. How well a particular individual will adjust depends upon the severity of the condition, his or her attitudes and training, the strength of the economy, the service system that provides income support, medical care, vocational and other services, and other variables, of which luck may often be the most important.

In the discussion to follow, we use the term "disability" to refer to any physical or mental condition that represents a significant deviation from what is normal. In effect, the term "disability" will be used in a way that is synonymous with the term "chronic condition." This corresponds to popular usage of the term and is consistent with current preferences among most persons who have a physical or mental condition. However, it must be kept in mind that the term may have a very different meaning when used elsewhere.

CAPACITY OF DISABLED PERSONS TO WORK AND LIVE IN THE COMMUNITY

In developing disability policy, it is essential that we keep in mind the immense variation in capacities and service needs that exist among persons with chronic conditions. The challenge, of course, is to devise public policies that are sufficiently flexible to meet these various needs. This is the basis of the concept of a "continuum of care."

One problem in developing public policy is that our understanding of the capabilities of disabled persons is rapidly changing, particularly for persons with severe disabilities. In consequence, programs tht were developed in the recent past with the best of intentions now become the obstacles impeding disabled Americans from achieving the level of social adjustment of which they are capable.

We are learning that very severely disabled Americans are capable of learning needed skills and improving their adaptive behavior, living in the community, and working on competitive jobs if given adequate services. In the past, persons with severe mental retardation (and even those with mild mental retardation) or mental illness were often confined to institutions, excluded from the educational system, and at best, placed in minimally productive workshops as adults.

Important policy changes reflecting this understanding of the capabilities of severely disabled persons have been made. For example, since the Education for All Handicapped Children Act of 1975, severely disabled children are no longer excluded from public schools. In addition, for 25 years, deinstitutionalization has been a major federal goal for persons with mental disabilities. During this time, institutional populations have declined substantially. For example, the number of residents in institutions for mentally retarded persons fell from 193,000 in 1967 to less than 120,000 in 1982. The number of persons in mental hospitals fell from almost 470,000 in 1969 to about 230,000 in 1979.

Currently, there is a growing commitment to place severely disabled persons, who have long been treated as unemployable, on substantial jobs in competitive employment.

These trends will continue and policies will need to be altered to support these changed social goals. A brief examination of some of the evidence for these striking changes in our perceptions of the capabilities of severely disabled persons will be helpful in explaining the need for a major reassessment of public policy toward disabled Americans.

Mental Retardation: Several current programs for persons with very severe mental retardation reflect the view that these individuals are incapable of work and need lifelong, medically-oriented support on a continuous basis. For example, an IQ score of 59 or less may be taken as sufficient evidence in Social Security programs that an individual is too severely disabled to work anywhere in the national economy (20 CFR 416.905 and Appendix 1).

An alternative view is emerging from professional research of the last two decades. We are rapidly becoming aware that many mentally retarded persons, who formerly were believed to be totally dependent on other and who were usually consigned to institutional care, are capable of working productively, living in regular dwellings, and participating in the normal life of a community.

Initial support for this alternative view was provided by research on the learning potential of persons with severe mental retardation. Beginning with demonstrations of successful acquisition and performance of rather simple manual tasks involved in work and self care (Bensgerg, Colwell, & Cassel, 1965; Crosson, 1969), the work progressed to basic academic skills and complex community living, social, and employment abilities (Bellamy, O'Connor, & Karan, 1979; Sailor, Wilcox, & Brown, 1980; Sontag, 1977; York & Edgar, 1979).

Reports abound of programs in which persons who earlier were considered too severely mentally retarded to benefit from vocational rehabilitation have entered the workforce at or above minimum wages after carefully designed training programs (Sowers, Thompson, & Connis, 1979; Wehman, Hill, Goodall, Cleveland, Pentecost, & Brooke, 1982). Other research and development programs have focused on people with even more severe disabilities, demonstrating successful employment, albeit below minimum wage, in small work crews, enclaves within industries, and small enterprises (Rhodes and Valenta, 1985; Boles, Bellamy, Horner, & Mank, 1984).

It is important to note, however, that most of these programs have offered at least some ongoing support at the worksite which is not available to other members of the workforce. Technically, therefore, the data support, not a simple assertion that persons with severe mental retardation can work, but rather a different formulation of the work disability issue that focuses on the level of difficulty in obtaining work and the level of support required to maintain it.

An analogous situation exists with residential services. Initial demonstrations of skill development gave support to philosophical and legal efforts to replace historical patterns of institutional care with smaller group homes, apartments, and family living situations (Gollay, Freedman, Wyngaarden, & Kurtz, 1978; McCarver & Craid, 1974).

The dramatic decrease in the number of mentally retarded persons in institutions is not due solely to a reduction in the number of mildly mentally retarded residents in institutions. According to a 1977 survey (Bruininks et al., 1981) of community residential facilities (excluding independent living

programs and foster care), almost one-third (32 percent) of those living in community placements are individuals with severe disabilities.

Traditionally, tenure in the community has served as a limited measure of success and re-institutionalization has represented failure. Studies have shown that the majority of community-placed individuals remain in the community and do not return to the institution. For example, the McCarver & Craig (1974) study demonstrates a success rate of 74 percent. Of those placed in the community, individuals with severe mental retardation were somewhat less likely than more capable individuals to return to the institution; this finding is explained by the perception that individuals with severe mental retardation had fewer behavior problems and were perceived to have adjusted to community living at least as well as their less mentally retarded counterparts (Gollay, 1981). These trends and research conclusions provide strong support for the capacity of persons with severe mental retardation to live in community settings.

A final question that arises is whether living in community settings, while possible and sustainable, provides worthwhile benefits to persons with severe mental retardation. Rotegard, Bruininks, Holman, & Lakin (1985) addressed this problem. On the basis of the few existing well-designed studies, they found that the adaptive behavior gains of persons in community settings, including individuals with severe mental retardation, was consistently superior to the adaptive behavior gains made by persons remaining in institutions. It is a reasonable interpretation of the data that the superior gains made by persons in community residences can be attributed to the effects of their less restrictive and more normalizing environment.

Mental illness: Many of today's treatment programs for persons with chronic mental illness view these individuals as "incurables" for whom psychotropic medication is the only effective means of intervention. Unfortunately, the side-effects of some medication may produce tardive dyskinesia and other conditions which interfere with the individual's ability to engage in substantial work activities. In addition, these side-effects are stigmatizing in that they draw the negative attention of others, including potential employers. Although psychotropic medication induces a remission of psychotic symptoms in the majority of psychiatric patients (Cole and Davis, 1969), about 40 percent relapse within a year of hospital discharge even when medication has been assured (Hogarty and Ulrich, 1977, Hogarty, et. al., 1979).

The development of improved methods of treating persons with chronic mental illness has been hampered by our inadequate understanding of mental illness. Anderson, Hogarty, and Reiss (1980) characterize the knowledge base for treatment of schizophrenia (the most common diagnosis underlying chronic mental illness) as "a host of very poorly understood biological, psychological, and environmental factors," whose inadequacy impedes specification of "some integrated psycho-social-biological position regarding an assumed pathogenesis from which a reasonable treatment formulation would follow." Despite the lack of a solid knowledge base concerning etiology, some interventions have recently been found to be more efficacious than others. One such approach maintains chemotherapy to decrease patient vulnerability to stress while offering a series of highly structured, supportive, psycho-educational family interventions which attempt to reduce high "expressed emotion" as reflected in criticism and emotional overinvolvement with the patient. According to Hogarty (1985), once families understand the disorder better and are taught how to modify their criticisms, patients fare better and the life of the entire family improves. In Hogarty's research, no schizophrenic patient had relapses for a year in families that had learned to reduce criticisms and expectations. After extensive preparation of the patient and family for six or more months, the patient is then assisted to return to work (Anderson, Hogarty, and Reiss, 1980). The importance of family support cannot be overemphasized.

The psycho-social rehabilitation model which was begun at the Fountain House in New York City and is now being replicated throughout the United States and in some foreign countries is another efficacious approach to stabilizing patients after discharge from a mental hospital. The transitional employment program (TEP) which is an integral part of the Fountain House program incorporates the ongoing support of staff "job coaches" for patients who are selected to share an entry-level job on a half-time basis or as preparation for eventual full-time employment without ongoing staff support. As of December 31, 1983, 604 employers throughout the country provided part-time work opportunities to 1,409 psychiatrically-impaired persons, whose average annual earnings amounted to $3,709. The estimated average cost for on-the-job support services was $1,500 per employee (Noble, 1984).

The efficacy and potential of the Fountain House psycho-social rehabilitation model for assisting discharged psychiatric patients to return to work is suggested by Virginia Department of Rehabilitative Services statistics. In contrast to a 16-19 percent rate of successful case closure with traditional vocational rehabilitation methods, the "Beach

House" located in Virginia Beach, Viginia, a replica of the Fountain House program, has achieved a 66 percent rate of successful case closures (Virginia DRS, 1985).

There is a great need to improve traditional methods of rehabilitating mentally ill persons. Anthony, Howell, and Danley's (1983) summary of the employment literature over the past 10 years indicates that earlier studies reported 20-30 percent of ex-mental hospital patients were either working full time or part time at the time of followup; more recent studies suggest a 10-20 percent employment rate, but some report zero employment. State rehabilitation agency statistics corroborate these findings, showing a 3 percent decrease between 1973 and 1977 in the number of persons with a primary diagnosis of mental illness who were vocationally rehabilitated. According to the National Institute of Handicapped Research (1979), mentally disabled clients (who make up the largest number of cases eligible for vocational rehabilitation services) have the lowest percentage of successful rehabilitations of the various diagnostic groupings that are represented.

Traditional vocational services alone will not be sufficient to enable many persons with mental illness to return to work. People with chronic mental illness often require the ongoing support and stabilizing influence of either an understanding and accepting family or a Fountain House type of psycho-social rehabilitation program as the foundation on which vocational rehabilitation services can be built.

Physical Disability: It appears that some physically handicapped persons may be needlessly placed in nursing homes. Unlike many persons with severe mental retardation or severe mental illness, most severely phsyically disabled persons can live in their own homes or apartments and work on substantial jobs. In some cases, however, they will need to be provided with appropriate support and services in order to do so. The types of services that may be needed are:

o Attendant services. It is estimated that about 36,000 persons nationwide need in-home attendant services.

o Other home care services, such as assistance with shopping, transportation, medications, etc.

o Modifications of homes to make them more accessible to physically handicapped persons and enable them to live in them.

o Rehabilitation services to train physically handicapped persons attend to the everyday needs of living, such as being able to prepare their own meals, do laundry, etc.

o Vocational rehabilitation services.

THE SERVICE SYSTEM

There is a wide range of programs, both public and private, that offer support and services to persons who are disabled due to chronic physical or mental conditions. The White House Working Group on Handicapped Policy (1984) reported that there were over 150 federal programs funding services to disabled persons. And to this number must be added State and local programs that do not benefit from federal funding.

Some of the more important of these programs at a federal level are the following:

A. Income Support Programs
   i. Social Security Disability Insurance, including the Childhood Disability Program (SSDI/CDB)
   ii. Supplemental Security Income program (SSI)
   iii. Food Stamps
   iv. Railroad Retirement - Disability program
   v. Federal Civil Service - Disability Retirement program

B. Medical Support
   i. Medicare
   ii. Medicaid

C. Employment Programs
   i. State Employment Services
   ii. State-Federal Vocational Rehabilitation program
   iii. Targeted Jobs Tax Credit program
   iv. Job Training and Partnership Act

D. Social Services
   i. Social Services Block Grant
   ii. Head Start program
   iii. Maternal and Child Health Block Grant

E. Housing
   i. Medicaid Intermediate Care Facilities for Mentally Retarded persons program
   ii. HUD rent subsidy program

F. Education
   i. Special education programs
   ii. Regular education programs

There are many programs other than those listed above that provide services and/or support to disabled persons. Some programs, such as those managed by the Veteran's Administration and the federal workers' compensation program provide multiple

types of services and do not neatly fit into a classification by generic services. In addition, there are programs funded solely by state or local government, and programs funded by private organizations. It is not necessary to identify all of the programs which provide support and services to disabled Americans. In fact, this would be an almost impossible undertaking since disabled Americans have the same range of needs and wants as other Americans and almost any program that provides support and services to Americans will include some disabled persons in its clientele. Although most of the above programs are federally funded, it should be noted that services are often purchased from private providers - e.g., residential care, vocational training, etc.

Two points, however, must be emphasized. First, many disabled Americans, and the majority of severely disabled Americans, will utilize two or more of these programs. e.g., most persons on income support programs also receive assistance in paying medical bills. There will be some people who will simultaneously utilize SSDI/CDB as well as SSI, Medicaid, Medicare, food stamps, rent subsidies, vocational rehabilitation, an employment service, and social services. Sometimes services will be obtained from programs funded by the private as well as the public sector.

Second, these various programs must be viewed as comprising a system of services to disabled Americans. In assessing the effectiveness of public and private policies in achieving the most desirable goals for disabled Americans, we must examiné the combined and interacting effects of these programs. If a disabled person fails to achieve a goal, such as employment, it may not be due to a failure of the vocational rehabilitation program, but to work disincentives existing in public and private income transfer programs, or to problems caused by prolonged litigation, as sometimes occurs in workers' compensation programs. Although the importance of taking a holistic view in designing and evaluating programs for disabled Americans appears obvious, the sad truth is that most programs are developed, modified, and evaluated in isolation from the effects of other programs.

Several futher observations about the system of services will help place it into perspective. First, a large number of persons receive services from these programs. During 1984, about 2.7 million persons received SSDI because they were disabled workers or the disabled widows or widowers of workers who qualified for Social Security. In addition, about 1.2 million persons were receiving benefits because they were dependent spouses or children of SSDI beneficiaries. Also, during 1984, approximately 500,000 persons received benefits as

disabled adult children of Social Security beneficiaries (retired or disabled) or as survivors of persons who would have been eligible for Social Security benefits.

During 1984, approximately 2.4 million persons received income support from the SSI program because they were disabled and another 80,000 persons received support because they were blind. However, of this number, about 490,000 were age 65 or over so that there were about 2 million persons under age 65 who received SSI support because of disability. About one fourth of the SSI rrecipients under age 65 also received Social Security benefits. In consequence, there were approximately 5.9 million Americans under age 65 receiving benefits from the Social Security program, SSI program support, or both, because of disability during 1983.

During July, 1982, about 3 million persons were enrolled in Medicare because of disability and in Fiscal year 1983, 3 million persons were enrolled in Medicaid because of disability. During Fiscal year 1984, over 900,000 persons received services through the state-federal vocational rehabilitation program. During 1982, over 3 million persons received services from various veteran's programs because of disability, and over 700,000 persons received services from Railroad Retirement, the Black Lung Benefits program, federal Civil Service or other programs for federal employees because of disability (Social Security Administration, Statistical Supplement, 1984).

Although we are unable to devise an unduplicated count of the number of persons receiving support and/or services from these programs because of disability, the total is clearly very large, probably in excess of 6 million Americans. Many other Americans receive support and services from private programs and other public programs.

Our second observation is that the system of services for disabled persons is expensive. Berkowitz (1985) estimated that total expenditures for disability in fiscal year 1982 amounted to approximately $122 billion, of which 97 percent was used to fund cash transfers and pay medical bills. This total includes expenditures for a wide range of public and private programs. Berkowitz pointed out that disability expenditures have been rising rapidly in recent years. Expenditures per capita amounted to $211 in 1972 and increased by 65 percent in real terms (adjusted for inflation) by 1982.

Over half of the above estimate was funded through the private sector, primarily through worker's compensation and private insurance.

Our third observation is that the system of services is complex. This is partly a consequence of the large number of programs that comprise the system. But a more important cause of the complexity is that the various programs tend to be procedurally oriented and establish many rules governing who is eligible for the program, what services can be provided, and how these services can be provided. Sometimes program administrators themselves are unclear as to the capabilities of their programs. For example, Medicaid is prohibited by regulation from paying for educational or vocational services. A frequent complaint, however, is that there are no clear-cut definitions of which activities are educational or vocational in nature and not eligible for federal support. Although medical rehabilitation provided under a doctor's supervision is usually fundable under the ICF/MR program, vocational training, on-the-job support, and sheltered workshop services are likely to be regarded as ineligible for funding under Medicaid.

PROBLEMS IN THE SERVICE SYSTEM

There are numerous problems in the service system which lead to wasteful expenditures and which cause beneficiaries to achieve less desirable social goals than those which are within their capabilities. For example, disabled persons are sometimes inhibited from gainful employment, are sometimes inappropriately placed in excessively restrictive residential facilities, and are sometimes unable to obtain adequate medical protection if they return to work. In general, the service system has many features which foster dependency among beneficiaries rather than facilitate independence among disabled people..

In this, and the succeeding four papers, we will discuss many of the aspects of the service system which lead to dependency and for which attendees at this conference are being asked to develop solutions. Proposed solutions to these problems will invariably be controversial and it will be difficult to reach consensus on the changes that should be made in order to solve the interrelated problems that stand in the way of normalized living for severely disabled people.

There is, however, growing pressure to make changes in the various programs in the service system. We must begin to identify specific and actionable proposals for discussion and refinement. Continuing to lament about how one agency or another is not acting in the best interests of disabled people or of society provides little stimulus to improving programs.

Our focus will be primarily on ways to increase employment and reduce overly restrictive residential care among persons who are disabled. Much of the discussion will address problems of particular relevance to severely disabled persons.

In this paper, we will identify several overall system problems.

1. Lack of congruence of program objectives with national goals. A major problem in the service system is that the various public programs which comprise it frequently conflict so as to undermine the national goals of independence and self-sufficiency for persons with disabilities. The income support and medical care programs, for example, were not designed to encourage employment, but to provide financial support to dependent persons. Vocational rehabilitation programs, in contrast, were designed to assist people in obtaining jobs but not to provide income support. In consequence, although disabled people often need both services, these two programs have difficulty effectively complementing each other since they have different and inconsistent goals. As another example, social workers, lawyers, family members, group home operators, and others sometimes seem more concerned with assuring that disabled persons have a secure income and secure medical benefits from public funds than with returning them to work.

2. Lack of program coordination: Although the different programs serving disabled persons comprise a system of services, and should be conceptualized, developed, and evaluated as such, a lack of coordination and integration among the various programs has frequently been identified as a major problem in the provision of services. In effect, the programs do not operate as a system, but as a loose aggregation of independently functioning units which on occasion clash. There are a number of reasons for this.

We have already described one of the most important causes of poor coordination among programs; they project conflicting goals. A second reason is that programs were generally enacted to deal with specific problems, such as the provision of basic income support to persons unable to work with often inadequate consideration given as to how programs interact. Similarly, program administrators tend to focus on the goals, priorities, eligibility conditions, and operating procedures of their own programs and sometimes overlook the effects of their operations on the goals, priorities, eligibility condition, and operating procedures of other programs. Another problem is that the inherent difficulties of making these programs operate as a system are intensified because some programs are managed at a federal level (e.g., SSDI/CDB, SSI, and Medicare), others

at a state level (e.g., vocational rehabilitation, Medicaid), and still others at the local level (e.g., some social service and housing programs).

3. Distorting Effects of Federal Funding: A substantial proportion of the service system for disabled persons is financed by federal funds. In most cases, the federal government establishes rigid rules with which state and local governments must comply in order to be reimbursed for services.

State and local legislators have an obvious incentive to shift as large a part of the cost of operating the service system as possible to other levels of government. The most effective way of doing so is usually to place disabled clients in programs funded by the federal government. Thus, mentally retarded clients are often placed in residential facilities which qualify for ICF/MR funding although the clients could be placed in less restrictive housing. Clients with other forms of disabilities and mentally retarded clients who are not placed in an ICF/MR are often assisted to apply for SSI benefits to pay for their care. In effect, these federal funds are sometimes used as if they were a free good rather than a scarce resource to be carefully husbanded. In consequence, as we will discuss in separate papers, the federal income support and health financing programs contain serious work disincentives and the ICF/MR program contains serious disincentives to the deinstitutionalization of residents.

4. Lack of information. One of the most serious problems in monitoring, evaluating, and modifying federal programs is the limited and fragmentary information about the social adjustment of disabled persons and the services provided to them. Of course, a few programs, particularly the income support and health care programs, provide large amounts of information about the disbursement of benefits and the characteristics of the persons who receive these benefits. Unfortunately, these programmatically-oriented data bases provide only limited assistance in understanding the benefits of and the problems in the service system.

Despite the long-standing emphasis on community-based residential care, little information is available on the number and characteristics of persons in various forms of community residences, or the services that are provided, or the social adjustment of the residents. This is particularly true for persons who are physically handicapped or mentally ill. The Center for Residential and Community Services at the University of Minnesota has aggregated extensive valuable information on the residents of licensed residential facilities for mentally retarded persons. However, even this work is not as detailed

as would be desired. Nor are the financial resources available to assure that these data will continue to be collected in the future. It must be emphasized that data are most useful when they can be compared among states, treatment modalities, and over time. It should also be emphasized that there is a dearth of information in such crucial areas as methods of employing severely handicapped people and the provision of family services for all categories of disabled persons.

Without such information, policy is often developed on the basis of intuition and hunch rather than a careful assessment of existing problems, their causes, the number of people affected, and options for resolving these problems.

5. Lack of services: Despite the large amounts of money expended on the service system, it still lacks important and crucial services. Berkowitz (1985) reported that over 97 percent of the expenditures in the service system for disabled persons went for income transfers and medical care. Less than 3 percent was used to provide services to prepare disabled people for employment, raise their level of adaptive behavior, and to assist them and their families to cope with the environment. Examples of types of missing services are as follows:

o There is a serious lack of programs that provide long-term assistance to severely disabled persons who seek to obtain substantial jobs in regular job sites. Despite its many successes, the state-federal vocational rehabilitation program is primarily oriented towards providing the short-term services needed by many clients to obtain a job, after which relatively little, if any, support is available. This model of service delivery is unsuitable for many severely disabled persons (see paper IV).

o Lack of family support is another area in which there is a serious deficiency of services. Families with a seriously disabled member may face extraordinary burdens such as social isolation and/or rejection by kin or neighbors; the need to provide direct care, sometimes on a continuous basis which may create major financial losses and which will eventually wear down the most dedicated of parents; and the need to obtain and transport severely disabled persons to needed services (see Paper II).

IMPROVING THE SERVICE SYSTEM

The problems that have been identified, and which will be subsequently identified, are solvable. Changes will, however, need to be made in the service system. Options for change are sometimes viewed skeptically by policy makers. Their skepticism does not stem from unwillingness to improve services

to disabled Americans. One underlying fear is that some options may lead to a substantial increase in costs. A second concern is that the options will not prove effective in resolving the problems. Some policy makers may recall previous strongly supported changes in the service system that resulted not only in unexpected costs, but which today are considered the causes of numerous system problems.

The costs of making changes are extremely difficult to estimate. We emphasize, however, that many changes can be made and be limited to expanding one part of the service system and contracting another part. In effect, some changes will reallocate funds from one part of the service system to another. For example, if a disabled person is aided to achieve remunerative employment, then income support and health care expenditures funded by other programs should be lower than otherwise would be the case.

In evaluating proposed options, we should consider the effectiveness and costs of the overall system rather than the costs to individual programs. We believe that many options will cause overall system costs to decline as the system is made more efficient and clients are assisted in becoming more independent. Empirically, this decline in costs is difficult to measure since it is difficult to trace the relationship of a contraction in one part of the system to an expansion in another part of the system. this is particularly so since the contraction may not occur until many months after the expansion and the contraction in services may result from some persons never applying for benefits from other programs, e.g., someone placed on a job may never seek income support. In consequence, policy makers sometimes overemphasize those costs which are most directly apparent, i.e., the immediate increase in expenditures and overlook the important and longer-term savings elsewhere obtained. The problem may become particularly acute if government officials are less concerned about expenditures by other levels of government or even other programs on the same level than they are about the immediate impact on expenditures by the programs within their administrative responsibility. Options must be viewed in terms of effects in both the aggregate and in the specific.

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PAPER II

ENHANCING INCENTIVES FOR COMMUNITY CARE OF SEVERELY DISABLED PERSONS

Introduction

Many people who are aged or disabled are unable to live independently. They require protective oversight or help in activities of daily living, such as obtaining meals, taking medications, dressing, etc. Some need both protective oversight and help in daily living activities.

For purposes of developing public policy, it is essential to emphasize the obvious fact that the amount of supervision and support needed varies enormously from person to person. In consequence, the most efficient and effective public policy would result in the development of an array of types of housing arrangements providing different levels and types of supervision and services into which people could be placed according to their service needs. The benefits of such a policy would be measured in terms of the sustained or improved functioning, independence, and community integration that individuals would derive from appropriate placement. These housing arrangements would include some nursing homes, group homes, foster care, supervised apartment living, special services to enable disabled persons to remain with relatives, and probably a few institutional type facilities, i.e., facilities with minimal integration of residents into the community. Most persons would be placed in small and community based housing arrangements.

Unfortunately, despite major improvements in housing options since the 1960's, existing housing arrangements for persons in need of sheltered living arrangements fall far short of this ideal. Too often people are either placed in overly restrictive institutions or are placed in community residences with inadequate services (Dittmar, et al., 1983). These inappropriate placements exact a heavy social toll. Institutional care is often extremely costly and fosters dependency. Community care without appropriate services is often bleak and sterile (Mellody & White, 1978) and also promotes dependency.

Part of the reason for these unsatisfactory living arrangements lies in the conditions imposed on state and local governments for the receipt of federal funds that help support residential care arrangements for severely disabled people. Among the more important of the federal programs are:

1. The medicaid ICF/MR program which provides basic shelter, support, and comprehensive services to mentally retarded persons who need these services for health reasons or for habilitation;

2. The medicaid Home and Community Based Services

Waiver program which funds community services for persons who would otherwise be institutionalized in a skilled nursing facility (SNF) or in an intermediate care facility for mentally retarded persons (ICF/MR);

3. The medicaid program which provides nursing home services to aged and disabled persons who require such care for health reasons;

4. The SSDI/CDB and SSI programs which provide funds for basic support to eligible aged and disabled persons;

5. The HUD Section 202 and Section 8 programs which fund, respectively, construction and renovation costs of housing and rent supplements to elderly and disabled persons; and

6. A variety of social service programs which fund services to persons in residential care, or who are living with their families, or who are living in their own homes or apartments in order to make it possible for them not to be placed in residential care.

In this paper, we discuss problems in these programs that lead to inappropriate placement decisions and the provision of inadequate services.

Origins of the Community Care Movement

In earlier years, disabled persons who needed protective oversight and who could no longer live with relatives were usually placed in large, isolated institutions. In some cases, institutional placement was recommended by family doctors, educators, and other persons advising the families of disabled persons even though the families were able and willing to maintain these disabled relatives at home.

During the last twenty-five years, there has been a rising movement to provide community-based residential care for most disabled persons who are institutionalized or who are at risk of being institutionalized. The movement to provide community care for severely disabled persons has diverse origins. Studies conducted in Scotland, Italy, Canada, and other countries in the late 1940's and 1950's showed that prolonged confinement of persons with mental illness in an institution frequently led to deterioration of the patient's mental condition and earlier social skills. Hospitalization lasting one or two years often led to increased dependency, helplessness, and regression to the point of child-like behavior or silent apathy (Barton, 1966; Wing, 1970).

About the same time, the discovery of psychotropic drugs permitted control of psychiatric symptoms and dangerous behavior and reduced the need for institutional confinement. Twenty years later, the U.S. Supreme Court in O'Connor v.

Donaldson (1975) declared that the State cannot constitutionally confine a non-dangerous person just because he is mentally ill, if the "individual is capable of surviving safely in freedom by himself or with the help of willing and responsible family members or friends."

People with mental retardation and physical disabilities equally benefit from care in the community and have the same legal protections as those with mental illness. The ideology of "normalization" that underlies much of today's consumer and professional expectations for mentally retarded persons was derived from the beliefs and practice in the Scandinavian countries (Nirje, 1969; Wolfensberger, 1970). In the United States, the concept has come to stress the creation of social environments that elicit or maintain normative behavior in people with disabilities with increasing attention being given to the "normative" nature of the environment and less on the normative nature of individual behavior (Willer & Intagliata, 1982).

Problems

Although most observers concede that the growth of federal funds has helped state and local governments to expand the array of community residential care options for handicapped persons, the following problems have emerged.

1. Institutional Bias of Federal Funding Programs: The ICF/MR program, which was created in 1971, has become one of the major federal sources of funding for both institutional and community care of persons with mental retardation. In part, this is because the ICF/MR program is open-ended. States are not limited in the amount of federal funds they receive as long as they meet program standards and provide the required matching funds. In contrast, all federally funded community programs limit the amount they will pay either by capping the entire program, as is done in the Social Services Block Grant, or by limiting the payment per person, as in the SSDI and SSI programs. In consequence, in FY 1985, the ICF/MR program accounted for 34.2 percent of the total of $7.773 billion in federal spending for mentally retarded and developmentally disabled persons (Braddock, Hemp & Howes, 1985). Since 1977, growth of the institutional care component of federal spending on persons with mental retardation has been explosive. The federal share of expenditures for state institutional services has increased from 23 percent to 45 percent, rising from $570 million in 1977 to $1.910 billion in 1984. In contrast, the state share of spending for institutional services from 1977 to 1984 has dropped from 73.7 percent to 53.8 percent (See Chart 1, Braddock, Hemp & Howes, p. 19). Clearly, there is strong incentive for state and local governments to shift the cost of institutional care to the federal government by taking advantage of the open-ended funding of the ICF/MR program.

At the inception of the ICF/MR program in 1971, the

states had to spend substantial sums of state money to upgrade staff, plant, and equipment of predominantly large institutions in order to meet the higher federal "active treatment" and fire and life safety standards. These expenditures in institutions thus represent a "sunk cost" which for the most part the states are reluctant to abandon--especially since the capital cost of developing community residential facilities that are not medicaid reimbursable must be entirely financed by state and local funds. In addition, the states must pay a larger share of the costs of operating community facilities that are not certified as ICF/MR facilities. Buttressed by unions and the families of institutionalized persons, the states have sought to maintain their ICF/MR funded institutions, despite the growing opinion and scientific evidence that adequately staffed community-based residences are superior to institutions (Conroy & Bradley, 1985).

Even when ICF/MR funds are used to finance community-based residences, the care is often institutional in character. A condition of eligibilty for the ICF/MR program is that the residents require 24-hour-a-day care. Lacking clear criteria to determine who does and who does not need this level of care, states have the option of placing persons who could be placed in less restrictive care in these facilities.

2. Funding arrangements between state and local governments: Where local governments, as in Virginia, do not share in the cost of institutional care but must pay some portion of the cost of community-based services, there is a strong incentive on the part of local governments to avoid development of community alternatives to institutional care of persons with mental retardation, mental illness, or physical handicaps.

3. Inadequate and inappropriate services: Whether or not appropriately placed, people in both institutional and community care settings often receive insufficient care and services. Recent reports by the U.S. Senate Subcommittee on the Handicapped (July, 1984) details many instances of non-compliance with the medicaid standards in ICF/MR facilities and public mental hospitals. There was lack of privacy in toilets and bathing areas. Residents lacked access to residential and program areas and to their personal possessions. The condition of clothing was poor, ill-fitting, and unseasonable. Too many beds were crowded into some sleeping areas--sometimes because there were too few staff to supervise residents at night unless crowded together. Living areas were barren and sterile and sometimes dilapidated. Residents had few, if any, personal possessions. Meals were bland and in some instances tasteless; there was no opportunity for residents to choose their food or make known personal preferences.

Medication was sometimes excessive and resulted in sleep or drowsiness and inability to participate in

programming. Contrary to federal regulations, medication in the majority of cases was being used as a substitute for behavior management programming. Protection against abuse and neglect was inadequate; in some cases, staff admitted that abuse occurred in one form or another on any given day. Locked time-out for behavior management was sometimes used. Many treatment deficits were apparent. Some residents received no programming at all and some never left their beds during the day. Some blind residents received no mobility training; some non-verbal residents received no alternative communication training; and some physically impaired residents received no training in use of adaptive equipment to feed themselves. Over one-half of the residents placed in one institution's vocational workshop were judged capable of work in a less restrictive job setting.

According to the superintendents of all of the facilities visited by U.S. Senate staff, there were many mentally retarded individuals who did not belong in the institution but were kept there because of the lack of more appropriate community alternatives. One superintendent was of the opinion that his entire resident population was inappropriately placed. At least some of these problems would not occur if federal ICF/MR standards were met.

4. Problems with federal oversight: Federal oversight has been weakened by lack of consistent standards and inadequate numbers of trained personnel to do the job. Standards have been particularly difficult to develop in such areas as quality of care and prevention of patient abuse. Nevertheless, the potency of federal oversight has been demonstrated by the recent "look behind" audits of ICF/MR programs throughout the United States. The Health Care Financing Administration (HCFA), exercising the expanded authority it received from the U.S. Congress in 1980, has targeted nearly one-third of the nation's ICF/MR facilities for close scrutiny. HCFA administrator, Carolyne Davis, noted the improvement in the quality of care that has occurred since the "look behind" audits began (HCFA Newsletter, March, 1985).

A major problem that faces HCFA in exercising its oversight responsibilities is the inherent conflict of interest which federal legislation has created by placing responsibility for monitoring compliance with the federal regulations in the state agency administering the medicaid program. It is problematic for the state medicaid agency to disallow reimbursements for the substandard practice of other state agencies. This is because disallowance of federal funding would increase total program costs to the state. Federal legislation should avoid policies which create inherent conflicts of interest and moral hazard for state and local governments.

5. Deinstitutionalization without sufficient community alternatives: Many deinstitutionalized persons living in the

community receive insufficient care and services. Looking back to the late 1950's and 1960's, when deinstitutionalization first began, there was a tendency to discharge younger, healthier mentally ill patients to boarding homes and older, more infirm patients to nursing homes (Denver Research Institute, 1981). Nursing homes became the primary resource within the health care system for the care of deinstitutionalized mentally ill persons. Their availability as established sources of federal funding through the medicare and medicaid programs and their status as facilities which most approximate the institutional environment made this inevitable. Persons habituated to institutional living are most easily moved from one institutional environment to another. The expansion of nursing home beds under medicare and medicaid to supplant more expensive general hospital care for recuperating medical patients provided further incentive. When the loss of revenues caused by the underutilization of general hospital beds reduced transfers of medical patients to nursing homes, nursing homes turned to the long-term care of ex-patients of mental hospitals (Valdeck, 1980).

The federal takeover in the mid-1970's of state categorical aid programs for poor blind, disabled, and elderly persons created the Supplemental Security Income (SSI) program with its national income support standard, and provided further impetus for deinstitutionalization by providing states with an alternative source of financial support for the maintenance of disabled persons in the community. Many states have selectively supplemented the basic federal SSI payment in order to pay for board and care arrangements which incorporate service provisions. However, the available funds were usually insufficient to purchase adequate services. Dittmar, et al. (1983) have observed that deinstitutionalized mentally ill and aged persons are more likely to receive inadequate services than persons with mental retardation.

The states have been able to reduce substantially their residential care costs by switching from institutional to community based care. These savings have been used in some places to improve the quantity and quality of community care, while in other places they have been used instead to provide taxpayer savings. The problem of "homelessness" among people with mental disabilities is partially the result of the failure to translate the savings from the reduced cost of institutional care into adequate community care for the deinstitutionalized population. To illustrate how taxpayer savings can be achieved at the expense of adequate community care, let us take the case of Virginia. In FY 1974, it cost Virginia $69.0 million at $15.63 per day to maintain 12,088 persons in its mental health and mental retardation institutions. In FY 1984, had the institutional population remained at 12,088 persons, it would have cost $400.6 million at $90.80 per day to maintain them in the institutions. Instead it cost $226.0 million at $90.80 per day to maintain an average daily census of 6,819. Even allowing for the increased cost of caring for a residual

institutional population of more severely impaired residents and for the loss of the unpaid services of higher functioning residents resulting from anti-peonage laws, the difference of $174.6 million between what it would have cost and what it actually cost in FY 1984 can be largely construed as savings. Of these savings, $103.0 million (59 percent) accrued to the state general fund.

The total community services budget for Virginia in FY 1984 was $82.0 million, of which $61.6 million consisted of state general funds. Consider the difference in FY 1984 alone of $92.6 million ($400.6 million - ($226.0 million + $82.0 million)) between actual state and local expenditures for mental health and mental retardation services and what would have been spent if the institutions had contained as many residents as in 1974. The bulk of the $92.6 million can be construed as savings, of which the state share of about 59 percent amounted to $54.6 million. Had the savings to the state which have accrued since FY 1974 been passed along to community mental health and mental retardation programs, the capacity and quality of Virginia's community programs would be substantially greater today and, consequently, the backlash against deinstitutionalization would probably be less. Of course, one can argue that neither the $92.6 million in FY 1984 nor the sums that accrued in prior years should all be construed as savings because it has become more costly to care for the increased severity of conditions among the institutionalized population without the benefit of the unpaid services of higher functioning residents. On the other hand, our rough estimate does not account for general population growth and the accompanying increase in persons with severe mental disorders over the 10 year period. There were savings that accrued from limiting new admissions from this group.

6. State and local cross-subsidy strategies: It is no secret among state and local government fiscal officers that the relationship between reimbursement charges and the actual cost of providing a reimbursable service is weak. In face of pressures to minimize state or local government expenditures, fiscal officers are ever alert to opportunities to spread the cost of non-reimbursable services over reimbursable service sectors. Euphemistically referred to as "cross-subsidization," the underlying principle is, "Wherever possible, spend the other fellow's dollar before your own." The use of the ICF/MR program by state and local governments to shift the cost burden of care to the federal government is a prime example of a cross-subsidy strategy. State and local governments also "make money" off of the ICF/MR program by failing to provide the level of service for which reimbursements are collected, pocketing the difference. Thus, it often happens that support staff who provide both reimbursable and non-reimbursable services are charged to the reimbursable cost center. Similarly, there are substantial opportunities to collect reimbursement for non-existent employees by delaying prompt replacement of employees who resign or are fired.

Any change in the reimbursement or funding rules by the level of government that is the object of cost-shifting threatens existing cross-subsidy strategies and could force painful budget readjustments. For this reason, among others, state and local governments seek to maintain the status quo.

Cross-subsidy strategies have the further effect of causing state and local governments to perceive and use federal funds as a "free good." Thus a program arrangement that is more expensive than some other alternative in terms of total program costs may be perpetuated because the state or local government share of the total costs of the more expensive arrangement is less than it would be in the alternative. This phenomenon, more than anything else, explains why local governments which often do not share in the cost of institutional care are willing to see the state and federal governments pay institutional costs running to $60,000 or more per year. Similarly, state governments may be more willing to sustain these very high costs when the federal government is paying the lion's share.

7. Policy-induced gaps in population coverage: Substantial gaps and inequities in the coverage of various categories of severely disabled persons have been created by the selective catering by federal, state, and local governments to constituency interests. Without denying the authority of the legislature to decide how to allocate public resources, one must recognize the results in the availability or non-availability of residential services that are equally needed by various categories of severely disabled persons. Two ill-served populations come to mind: the 1.7 million persons with chronic mental illness (Goldman and Manderscheid, 1984) and an unknown number of "dually diagnosed" persons with mental retardation and mental illness. The Congressional decision to exclude mentally ill persons between the ages of 22 and 64 from medicaid funding if they reside in an "institution for mental diseases" has caused great disparities in the quality of care available to persons with mental illness as compared to mental retardation. It has also created substantial distortions in the service delivery system as states have placed ineligible mentally ill persons in nursing homes. Substantial sums have been expended by state and local governments on legal fees in the attempt to overturn federal audit exceptions to a variety of stratagems to obtain Medicaid reimbursement for the excluded mentally ill population.

8. The dually diagnosed population: The "dually diagnosed" population, whose symptoms of mental illness are difficult to differentially diagnose in persons with mentally retardation, is often rejected by both mental health and mental retardation service providers and thus falls between the cracks of program coverage. Few, if any, public mental hospitals are staffed to offer the needed mix of mental retardation and mental health services. As a result, the dually diagnosed

population is denied appropriate care and the specialized treatment it requires for developmental growth and the alleviation of psychiatric symptoms.

9. ICF/MR program bias against work effort: Limitations on the use of medicaid funds for vocational purposes promotes the "helplessness" of ICF/MR residents instead of encouraging their highest level of functioning. The recent spate of audit exceptions involving the use of ICF/MR funds to pay for pre-vocational and vocational services demonstrates the disagreement that exists between the states and the federal government about the appropriateness of providing vocational services to persons in ICF/MR facilities. Ironically, rigid ICF/MR funding regulations are motivating the states to withhold community care and employment options from people who can benefit from the supported work technology that is being promoted by the U.S. Department of Education and the Administration on Developmental Disabilities in the U.S. Department of Health and Human Services. In places where ICF/MR funds are being used to pay for supported employment services, the program operators run the risk of audit exception and liability for paying back to the federal government many thousands of dollars.

10. Lack of in-home and community support for families with severely disabled members: Lack of community services influences many families to institutionalize their child. Families with a severely disabled member at home often sustain an extraordinary burden beyond the initial sense of shock, denial, grief, shame, guilt and depression that typically accompanies the discovery. These burdens include: social isolation and rejection by kin and neighbors; financial and/or opportunity costs associated with 24-hour caregiving; difficulty with physical management and ordinary family routines such as shopping, house cleaning, and finding ample recreational outlets; the acquisition of special parenting skills to cope with medical emergencies and to promote the child's adaptive behavior; stress on the parents and resulting poor physical health; and strained family relationships between siblings and parents (HSRI, 1984b).

A recent Maryland survey of family caregivers of mentally retarded adults quantifies the extent of these burdens (Black, Smull, Crites & Saks, 1985). About 20 percent of all the family caregivers were experiencing financial difficulties, poor health, or personal problems. About 12 percent had the burden of other child care responsibilities, an elderly or other disabled household member, or health problems in another household member. The pent-up demand for residential services among these families is substantial. Only 12.2 percent of the family caregivers could be sure that residential services were not then or in the future needed (Black, Smull, Crites & Saks, 1985). Thirty-nine percent stated a current need for residential services: 15 percent were in crisis; 11 percent had an urgent need but were stable for the moment; and 13

percent felt placement was highly desirable for the good of all concerned.

The lack of in-home and community support, including respite care, daycare activities, social/recreational programs, independence skill training, and financial assistance, exacerbates the burden of family caregivers and increases the likelihood of out-of-home placement. The Maryland survey disclosed that 32 percent of the mentally retarded adults lacked any regular daytime activity. Only 3.8 percent of them had a regular job, indicating that competitive employment was "a much less available option than the functional capacities of the group would suggest" (p. 9). Over 50 percent of the families expressed the need for social/recreational programs; 31 percent need for respite care; 28 percent need for financial assistance; 23 percent need for counseling; and 24 percent need for behavior management services. More than one-third of the caregivers made known their own need for personal relief, and 14 percent stated unwillingness and/or inability to provide continued care for their severely disabled family member.

11. Inefficiency in the use of public funds: Individuals with behavior problems living with foster-care families are more likely to learn age-appropriate personal and interpersonal behaviors than if placed in a group home (Willer & Intagliata, 1982). Individuals with deficits in community living skills, on the other hand, are more likely to learn these skills if placed in a group home. Moreover, the cost of family foster-care is significantly lower than for group homes (Gardner, 1977; Intagliata, Willer & Cooley, 1979; Novak & Heal, 1980). These observations emphasize the importance of placing severely disabled persons in homes that are appropriate to their needs. Unfortunately, our capacity to make these decisions is weak. Indeed, the community adjustment of many deinstitutionalized persons is jeopardized by the lack of precision in matching their characteristics with the setting most likely to maintain them successfully and to prevent their reinstitutionalization (Intagliata & Willer, 1982).

12. Policy-induced inappropriate placements: In general, financing arrangements determine where clients are placed. Historically, as medicaid funds became available first for nursing home care of persons with physical impairments, then for coverage in public institutions of mentally ill elderly persons and mentally ill children and youth under age 22, and then for care of persons with mental retardation in ICF/MR facilities, state and local governments sought to move as many people as possible into these covered services--even though some individuals did not meet the placement standard (Valdeck, 1980; Denver Research Institute, 1981).

The Home and Community Based Services Waivers program, enacted in 1981, gave states the flexibility to receive Medicaid reimbursement for non-medical community-based services for persons who would otherwise have been institutionalized in

the absence of these services. The responses by the states are indicative of the extent to which disabled persons are inappropriately placed. Many waivers were sought for the purpose of assisting people with varying degrees of physical and mental disabilities to be transferred from nursing homes and ICF/MR facilities to community facilities. Even more revealing was the fact that some states sought to use the Home and Community Based Services Waivers program to transform community-based ICF/MR facilities into group homes. This permitted States to meet less restrictive residential care standards and thereby to reduce costs and, hopefully, to improve the quality of care. Finally, some states sought to extend the waivers program to non-institutionalized persons whose community placements were unsatisfactory because of a lack of appropriate services.

13. The uncertainty of the Title XIX Home and Community-Based Services Waivers demonstration program: A basic problem with the program is the uncertainty of its future existence. The reimbursement model of funding that characterizes the medicaid program requires service providers to capitalize and establish programs in advance of obtaining reimbursement for rendered services. Many not-for-profit providers are not sufficiently credit-worthy to borrow construction and initial operating funds. Others capable of borrowing the needed funds, including many for-profit providers, are reluctant to make an investment in the face of the program's uncertain future.

14. Other problems in the Home and Community-Based Services Waiver program: The underlying rationale of the Home and Community-Based Services Waivers program is that if community based care is less costly than institutional care, and equally or more effective, as proponents of community-based care argue, then medicaid support of community-based care is justified on both economic and programmatic grounds. However, the use of the Home and Community-Based Services Waivers program to develop residential alternatives to institutions is severely limited for a number of reasons.

First, total medicaid expenditures under the waiver may not exceed what medicaid expenditures would have been in the absence of the waiver. In consequence, states with low cost institutional programs have sharply limited funds with which to develop community residential alternatives.

Second, the program is limited to persons who would reside in medicaid certified facilities in the absence of the waiver. In consequence, states which realize financial savings by placing institutionalized or institutionalizable persons in community care are not allowed to use the reduction in medicaid expenditures to expand services to other medicaid eligible persons. States are not even allowed to use the savings to expand services to medicaid eligible persons receiving substandard community-based residential care unless it can be

shown that they would otherwise be placed in medicaid certified facilities. This limitation takes away part of the incentive that the states might have to economize on the cost of providing community residential alternatives (although it must be remembered that about half of any savings accrues to the states).

Third, it becomes increasingly difficult over time to determine who would have been placed in medicaid certified facilities. For the immediate future, the medicaid program can rely on evidence of reductions in the institutional population, or data on empty institutional beds, or cancellation of the proposed construction of new medicaid certifiable facilities. In these cases, it is incontrovertable that the people involved might well have been placed in these institutions. But several years from now, what kind of evidence will there be? The number of institutional beds will probably be far less as the waivers take effect, and unused institutional capacity is phased out without replacement. At that point, it will no longer be possible for the states to argue that, in the absence of the waiver, certain people would otherwise be institutionalized since the institutional bed will not be available.

Fourth, since the program is limited to medicaid eligible persons, it does not assist in the development of community residential care for persons who are not medicaid eligible but who nevertheless need such care yet cannot afford it.

15. Lack of funds for construction and start-up operating expenses: A major impediment to the establishment of community-based residential services is the difficulty of obtaining capital funds for construction and refurbishing small group homes, as well as operating funds for start-up costs. This was true of the original ICF/MR program, the HUD/HHS Demonstration Program for the Chronically Mentally Ill, and currently hinders the Title XIX Home and Community-Based Services Waiver program. The original ICF/MR program led to the conversion of the predominantly large state institutions to ICF/MR reimbursable facilities. In the process, the federal government accepted state plans of correction, which in some instances were many years overdue, before final implementation took place. The delays largely resulted from the need to generate large amounts of capital to modify existing physical facilities.

The HUD/HHS Demonstration Program for the Chronically Mentally Ill attempted to meet the problems of limited capital funds by combining the HUD Sections 202 and 8 programs to build or rehabilitate housing and subsidize the rents with Social Security Act Section 1115 waivers to pay for services. However, complexities in coordinating the receipt of funds arose that were beyond the capacity of many interested service providers to unravel--particularly the extensive paper work and

long delays in obtaining HUD approvals. The Title XIX Home and Community-Based Services Waivers program has limited capacity to stimulate the provision of new in-home and community support services because of its extensive documentation requirements and lack of start-up operating funds.

It appears that the small size of community-based residential facilities makes lenders less willing to risk large sums to build or renovate them for a handicapped population. Although nursing home operators have had less trouble raising capital funds, this is probably attributable to their much larger size. Lenders apparently feel less troubled about the stability of future income if there are 50 or more residents as compared to four or five.

16. Insufficient attendant care and independent living services: Successful placement and maintenance of persons with severe disabilities in community-based housing and employment are dependent on what occurs in the workplace and environs. Housing, transportation, peer support, advocacy, personal care attendants, and other everyday living and support elements are all necessary for some severely disabled persons.

Independent living centers (ILCs) are designed to provide ongoing support services to persons with severe physical and mild to moderate mental disabilities. The ILCs develop options for housing, transportation, attendant care, recreation, and the like. Some ILCs extend their services beyond assistance in the acquisition of community living skills to the provision of pre-vocational and vocational training. A few work with employers to obtain jobs and to maintain program participants in them. What distinguishes the ILCs from most other programs is the emphasis on having the program participants take charge of their own lives--making their own decisions, taking responsibility, and asserting control. This is accomplished through peer support or advocacy in relation to the special problems that program participants encounter as they strive to attain a normalized existence.

An ILC with a budget ranging between $20,000 and $200,000 may employ between 3 and 40 handicapped and non-handicapped persons to serve an average active caseload of about 500 clients. The typical ILC has been operating an average of 5 years.

In terms of type of disabling condition, 86 percent of the ILCs serve persons with cerebral palsy; 80 percent persons with brain injuries; 70 percent persons with spinal cord injuries; 76 percent persons with mental retardation; and 56 percent elderly persons with severe disabilities. Recently, the ILC network has begun to serve persons who have contracted AIDS because the fear of contagion has limited access of AIDS victims to more traditional sources of assistance.

A number of problems exist in the ILC program. First,

existing programs cannot serve the entire population in need of ILC services. At present, there are about 320 ILCs nationwide. Of these, 156 are federally funded and serve about 77,000 severely disabled clients (Jones, Bolx & Petty, 1983). In contrast, there were an estimated 2.9 million adults in 1977 who needed some assistance with personal care from another person (DeJong & Wenker, 1979). Second, there is a problem of distribution. Many states, like Alabama and Alaska, have only a single, token ILC located in their capital city. Third, obtaining affordable transportation for program participants is almost always a problem.

Another source of funding for attendant care is the medicaid program. However, such care under the medicaid program is broadly variable among the states due to the eligibility criteria, its medical orientation, and the opposition in some states of the nursing lobby to non-nurse attendants. Although some states have sought and obtained attendant care coverage under the Home and Community-Based Waivers program, many other states have not. Unfortunately, persons who are fortunate enough to obtain medicaid covered attendant care have a strong incentive not to accept work lest they lose it. What is more, S. 843 (the successor bill to S. 2053), known as the Community and Family Living Amendments of 1985, only provides attendant care coverage for persons whose disabling condition is manifest before age 35 and thus fails to cover the entire population of severely disabled persons in need of attendant care.

17. Lack of a strategic plan and incentives for converting state service systems dependent on larger institutions to ones which use smaller community living arrangements: The findings of the longitudinal study of court-ordered deinstitutionalization in the case of Haldeman v. Pennhurst State School and Hospital (Conroy & Bradley, 1985) should leave no doubt about the conditions that must be met to promote the development of persons with severe handicaps. Significantly greater developmental growth occurs among formerly institutionalized persons who are placed in small community living arrangements, and the cost of achieving these greater benefits is roughly equal to the cost of institutional care after taking into account the salary differential between unionized and non-unionized employees (HSRI, 1984a).

There is no national strategic plan and incentives for converting state service systems dependent on larger institutions into ones which use smaller community living arrangements. Without a strategic plan and incentives, it is difficult to envision how the disparate programs which now fund residential care and support services can be coordinated to implement a coherent strategy that encompasses the activities of all levels of government--federal, state, and local.

In view of the multi-faceted nature of the problems

that prevent the delivery of appropriate residential and support services to severely disabled persons, it is difficult to design single options that can adequately address the various aspects of the problems. Experience suggests that piece-meal solutions often interact with parts of the problem which are left untouched to frustrate desired goal attainment and sometimes to create new problems.

Options for changing the present system of financing and managing residential and support services should be designed to enhance the incentives for placing or maintaining severely disabled persons in need of protective oversight in community residences. These residences include living with parents and relatives for as long as it is possible and appropriate, or in a variety of supervised living arrangements--foster family-care, supervised apartments, group homes, etc.

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PAPER III

WORK DISINCENTIVES

INTRODUCTION

The service system for disabled Americans is derived from public policies that because of the process by which they were formed contain and perpetuate unintended consequences which result in major work disincentives for many beneficiaries. How many people do not work because of these work disincentives cannot be determined, but we believe that the number is substantial. As described in the first chapter, there are increasing indications that most disabled Americans of working age are capable of finding, or of being placed, in employment that pays substantial wages. On the other hand, there are about 5.9 million working age adults who are receiving disability benefits from the Social Security Disability Insurance or Supplemental Security Income programs because they have been evaluated as being too severely disabled to work on jobs paying $300 or more per month. We believe that work disincentives and lack of appropriate vocational services are major factors contributing to the large number of Americans receiving benefits for total disability.

In this paper, we will identify the major work disincentives that exist in the service system. Our discussion will be limited to four programs, the Social Security Disability Insurance program including the Childhood Disability Beneficiary program (SSDI/CDB), the Supplemental Security Income program (SSI), and the Medicaid and Medicare programs. Other programs providing income transfers and health care benefits to persons who are disabled (e.g., Federal Civil Service, Railroad Retirement, private insurance) often have similar work disincentives. Most work disincentives confronting disabled Americans arise from the income transfer and health care programs. The pervasiveness of work disincentives is made manifest when we recall Berkowitz's conclusion (1985) that 97 percent of the expenditures made through the service system are used for income transfer and health care benefits.

A BASIC MISCONCEPTION

For the most part, the existence of work disincentives in the service system derives from the belief that disabled persons can be evaluated and neatly divided into those who are capable of substantial gainful activity (SGA) and those who are not. This belief provides the basis for determining who is, and who is not, elgible for benefits in the SSDI/CDB, SSI, Medicare, and Medicaid programs. Both the SSI and the SSDI/CDB

programs, for example, define disability as "inability to do any substantial gainful activity by reason of a medically determinable physical or mental impairment which can be expected to last for a continuous period of not less than 12 months."

Persons are currently considered capable of substantial gainful activity if they are capable of earning $300 or more per month. This amounts to approximately $1.75 per hour or about 50 percent of the Federal minimum wage for beneficiaries employed on a full-time basis. Special provisions are made for blind persons in both the SSDI/CDB and the SSI programs which will be discussed below.

The Social Security Administration has developed a long list of impairments and conditions, which in the absence of other evidence (such as having had earnings above the SGA level after becoming disabled), are considered sufficiently severe to prevent a person from being able to work at an SGA level. The level of earnings considered equivalent to SGA (currently $300 per month) is set by regulation and not by law. This SGA level is not indexed to inflation and has not been changed since 1979.

Persons do not have to be actually earning over $300 per month to be declared ineligible for SSDI/CDB or SSI. They must only be evaluated as capable of working at some job that will pay this level of wages. It is immaterial whether such work exists in the immediate area, or whether a specific job vacancy exists, or whether the applicant for an income security program would be hired if he or she applied for work. Economic conditions, discrimination, and cost of relocation do not mitigate a determination of capability to earn SGA and therefore ineligiblity for SSDI/CDB or SSI disability support.

There are two problems with this criterion of eligibility for SSDI/CDB and SSI. First, it assumes that a reasonably accurate technology exists with which to determine who is not able to earn at an SGA level on the basis of a listing of conditions or a direct assessment of an applicant for benefits. Consider the following:

o Few people who work with severely disabled adult persons agree that they have the capacity to make this earnings capacity assessment with acceptable accuracy.

o The enormous percentage of cases litigated in workers' compensation (Conley and Noble, 1979) and the high percentage of appealed cases among denied applicants to SSDI/CDB and SSI further attest to the uncertainty in making evaluations of work capacity.

o The increasing number of severely disabled persons who are working above the SGA earnings level futher indicates the potential capacity to work of severely disabled Americans.

o There is not a close relationship between the type and severity of an injury or illness and the liklihood of work disability. Whether or not disabled people obtain employment and earn substantial wages depends upon many interacting factors, of which the disability is only one, and frequently not the most important impediment to employment. Attitudes, age, education, and other variables have major effects on the liklihood of obtaining a job. In consequence, attempts to use a schedule such that a given disability is presumptive proof of work incapacity is certain to result in many errors as is evidenced by the fact that some people with a given condition are substantially gainfully employed and others with the same general condition are unable to obtain substantial employment.

The second problem in the eligibility criterion is that it overlooks the great difficulty that many disabled people will encounter in locating work, and of finding new employment if they lose their job for some reason (such as cyclical unemployment, technological changes, or the misfortunes of the firm for which they work). In consequence, disabled persons who are judged as capable of substantial work are often denied the income support and health care benefits they need during the process of locating suitable employment.

Despite restrictive eligibility conditions, we believe that the practical problems of determining if a person is capable of working at an SGA level result in many people being declared eligible for benefits who could, in fact, be employed on jobs paying more than the SGA earnings level. This will become increasingly true as our knowledge of how to assist severely disabled persons to obtain and retain substantial jobs grows.

FACTORS AFFECTING WORK DISINCENTIVES

To measure the work disincentives facing an individual beneficiary, it is necessary to sum the value of all of the program benefits that must be given up as a consequence of accepting substantial employment. The number of benefits that may have to be given up is often large. Many persons receiving SSDI/CDB also receive SSI. Most persons receiving benefits from one of these programs also receive either Medicare or Medicaid benefits and sometimes both. Some persons receive food stamps and rent supplements. In addition, some persons may receive private benefits, particularly persons receiving SSDI/CDB where the private benefits would not reduce their monthly SSDI/CDB benefit. Persons receiving SSI would have their Support reduced by the amount of the private income

transfer benefits received. Public income support and health care programs create work disincentives in at least three different ways: (1) by reducing the net gain from work; (2) by fostering dependency and negative attitudes toward work; and (3) by offering greater income security to persons who continue as beneficiaries of these programs than could be obtained in regular employment.

Reducing Net Gain From Work: A major incentive for beneficiaries to return to work is the prospect of increasing their standard of living. If their living standard is increased only slightly, or even falls by their returning to work, they may feel little inclination to do so.

The potential for reducing incentives for a beneficiary to return to work is particularly strong in the SSDI/CDB program. Under current law, SSDI/CDB beneficiaries who accept substantial work are entitled to a nine month trial work period (TWP). At the end of the trial work period, the beneficiary is re-evaluated and if he or she is found capable of earning $300 or more per month, after deduction of extraordinary impairment-related work expenses, then benefits are terminated. At that point, in order to determine the net gain (or loss) among beneficiaries who return to work and lose their benefits, the following items must be subtracted from earned income.

o The benefits formerly received from the SSDI/CDB program. Theoretically, these benefits may exceed $2,000 per month in the case of families, and $1,000 per month in the case of individuals. However, the majority of beneficiaries receive less. During the first quarter of 1985, the average monthly payment for disabled workers was about $470. For childhood disability beneficiaries and children aged 18 to 21, the average amount was much lower - about $130 per month.

o Any income taxes that must be paid. In almost all cases, these will include Social Security and Medicare taxes of approximately 7 percent in addition to Federal and possibly State and local taxes. Social Security, SSI payments, and private disability insurance are not taxable.

o Any work-related expenses, such as special clothing costs, transportation, lunches, child care, etc., which are not fully deductible.

o Any other benefits that may be lost as a consequence of returning to work (such as medical benefits which will be discussed below).

In some cases, the benefits under SSDI/CDB actually exceed the level of earnings at termination of benefits. Moreover, the working former beneficiary will pay taxes on earnings of at least 7 percent for Social Security, in addition to Federal and State income taxes. Finally, normal work expenses are sometimes substantial, and often not fully deductible, particularly in the case of disabled parents who must pay for child care in order to return to work.

Potential work disincentives are generally less dramatic in the SSI program, partly because maximum benefits are lower, and partly because of the effects of major legislation passed in 1980. In determining the monthly benefits to be paid to SSI beneficiaries receiving Federal benefits only, the following steps are followed:

o The first $20 of earned or unearned income and the next $65 of earnings are exempt from consideration.

o The amount of any extraordinary impairment-related work expenses are deducted from earnings.

o Thereafter, payments are reduced by $1 for every $2 of earnings over these exempted amounts. Payments are reduced by $1 for each $1 of unearned income over the exempted amount.

Beginning in 1985, the basic SSI cash payment to disabled recipients is $325 per month for eligible individuals and $488 for an eligible couple. At these levels, all Federal SSI payments will cease when earnings reach about $735 per month for a single individual (without any non-earnings income) and $1,061 per month for an eligible couple.

Prior to 1981, an SSI recipient who began to work on a substantial job would be placed on a nine month trial work period. At the end of the trial work period, the recipient would be re-evaluated and if found capable of earning more than $300 per month, SSI payments would cease.

Let us consider two cases based on the payment levels which exist in 1985, but apply the rules governing payments which existed prior to 1981. The first case involves an SSI recipient who accepts a job paying $250 per month and the second relates to an SSI recipient who accepts a job paying $350 per month. At the end of the trial work period, the higher paid person would lose the entire $325 SSI payment and end up with a net increase in gross income of only $25. The worker making $250, on the other hand, would still receive an SSI payment of $242 per month and end up with a gross income of $492 per month. The lower earning recipient would actually end up with almost $136 more per month than the higher earning

recipient. This example illustrates the substantial disincentive that existed for relatively small increases in earnings.

Clearly, there is an incentive for the SSI recipient to choose the job paying the lesser wage if possible. It is doubtful if the recipient would feel the higher paying job was worth accepting, particularly since taxes and normal work expenses would also have to be paid. Of course, even if the beneficiary chose the lower paying job, the Social Security Administration could re-evaluate the person and conclude that he or she was capable of earning over $300 per month, which might make a beneficiary skeptical of accepting jobs paying less than the SGA level.

Recognizing these problems, Congress authorized a special three year demonstration program beginning on January 1, 1981 (incorporated as Section 1619(a) of the Social Security Act) which permitted working SSI recipients to continue to receive SSI payments as long as their earnings were below the Federal breakeven point, based on a $1 reduction in payments for each $2 in earnings. The recipient making $350, for example, would continue to receive an SSI payment of about $192 and his or her gross income would be about $542 per month, an increase of about $218 in gross income over the SSI suppor level without working. This special demonstration has been extended to June 30, 1987 (1984 Social Security Act Amendments).

The above calculations are based on the receipt of Federal SSI payments only. About half of the states supplement Federal SSI payments. These supplements usually increase work disincentives by an amount that depends upon the size of the supplement and state practices, e.g., some states terminate the entire supplement when Federal payments end, while other states continue the $1 reduction in payments for each $2 in earnings.

Continuation of health benefits is often as important, and sometimes more important, to disabled persons as continuation of income payments. Medical expenditures are frequently unpredictable, and sometimes very large. For some recipients and beneficiaries, the value of health benefits exceeds the value of income support. The importance of continued health coverage under Medicare (available to SSDI/CDB beneficiaries after two years of receiving SSDI/CDB benefits) or Medicaid (available to almost all SSI beneficiaries) is increased because some SSI recipients and SSDI/CDB beneficiaries who return to work are unable to obtain health care coverage either as a fringe benefit where they work or as an individual.

What happens to Medicare benefits if SSDI/CDB beneficiaries return to work? Prior to 1981, a return to a job paying the SGA wage or more led to termination of cash benefits and loss of eligibility for Medicare after a trial work period. During 1980, however, Congress changed the law so that SSDI/CDB beneficiaries would continue to receive Medicare coverage for 36 months after a determination that the beneficiary is capable of working at an SGA level. In addition, Congress eliminated the 24 month waiting period for Medicare coverage in the case of former SSDI/CDB beneficiaries who become re-entitled to SSDI/CDB benefits within a five year period after cessation of cash benefits.

What happens if SSI recipients who receive Medicaid return to substantial work. Prior to 1981, many recipients who lost their eligibility for SSI also lost their Medicaid coverage (Some States maintained a medically needy program that could continue Medicaid benefits for some persons. However, eligibility for federal support is limited to persons whose income is less than 133 percent of the highest money payment that ordinarily would be made in the State AFDC program to an individual in a family of comparable size.). In 1980, Congress authorized a three-year demonstration program (incorporated as Section 1619(b) of the Social Security Act) to provide continued Medicaid coverage to SSI recipients who return to substantial work even if their income is too high to qualify for Federal SSI payments. In order to qualify for this program, it was stipulated that the recipients must: (a) continue to have a disabling condition; (b) have difficulty maintaining their employment without medical coverage; and (c) lack earnings high enough to pay for benefits equivalent to the combined value of federal and state SSI payments, and the Medicaid coverage that they would have continued to receive. This demonstration has been extended to June 30, 1987 (Social Security Act Amendments of 1984).

SECURITY OF INCOME

People make decisions about when and where to work (or whether to work at all) not only on the basis of the amount that they can earn, but also on how secure a job is. People will often forego a higher paying but less secure job to remain in employment that is protected by union rules, seniority provisions, tenure, civil service, or has some other type of buttressing against the swings of the business cycle.

The desire for income security creates a strong work disincentive among beneficiaries of public income support and health care programs. Why should we expect that beneficiaries of these programs will easily give up what appears to be a

secure monthly cash income and assured medical care in exchange for jobs that often are temporary or insecure (and that may pay little more, or even less, than their monthly benefits).

Recent changes in the Social Security Act serve to reduce the fear that beneficiaries who return to work might have about the loss of their jobs. for both the SSDI/CDB program and the SSI program, the 1980 Amendments provided for a 15 month re-entitlement period following the trial work period and an determination that the beneficiary is capable of working at a SGA level. In addition, the extension of Medicare coverage for 36 months after cash benefits cease and the elimination of a second 24-month waiting period for Medicare for persons who become re-entitled to SSDI/CDB benefits within five years should also reduce the insecurity of beneficiaries who return to work.

Attitudes Toward Work: A third major work disincentive arises from the need for applicants to prove that they are unable to engage in substantial gainful activity in order to establish eligibility for SSDI/CDB or SSI. The process of determining eligibility may last for two months to a year and during that entire period applicants are compelled by the system to prove that they are unable to engage in substantial work.

Assistance in documenting work disability is usually obtained from vocational specialists, doctors, lawyers, social workers, family, friends, and others. The process may convince applicants of their inability to work and the folly of attempting to work. In this regard, it is noteworthy that one study of workers' compensation shows that claimants who do not need to prove the extent of their injuries generally fare better in re-employment than claimants with comparable injuries who become involved in litigation over the extent of their work disability (Ginnold, 1984).

SPECIFIC TYPES OF WORK DISINCENTIVES

These recent changes in the laws governing the Federal income transfer and health care programs are of great importance, not only because they may reduce work disincentives in these programs, but also because they indicate increasing recognition that the process for determining eligibility for these programs may be faulty. However, numerous problems remain. Among these problems are:

1. We have already described the potentially large income loss that beneficiaries of SSDI/CDB will incur if they return to work, not only because of a loss of benefits, but also because they must pay taxes and sometimes incur large normal work expenses.

2. Some SSDI/CDB beneficiaries may be concerned about the loss of Medicare benefits that will occur three years after they lose entitlement to cash benefits.

3. Some SSI recipients may fear that the special cash payments and the special Medicaid demonstration projects (Sections 1619(a) and 1619(b)) will not be forever extended. In fact, there was a nine month period between the time the authority for the initial three-year demonstration projects ended and the time at which they were statutorily renewed for another three years. Although the program was adminstratively continued during this time, some recipients of these programs were undoubtedly concerned about their continuation.

4. According to Social Security regulations, SSI recipients are eligible for extended Medicaid benefits under 1619(b) if their income is below a threshold amount. This threshold amount differs from state to state and is equal to the Federal breakeven amount (calculated on an annual basis) to an individual living in his or her own household plus 2 times the State supplement for one year plus the average Medicaid expenditure for disabled SSI beneficiaries in the state. In 1984, this threshold amount varied from $8,500 to $21,500. If the earnings of an individual exceed this threshold amount, the Social Security Administration checks to see if actual or anticipated Medicaid expenditures are higher than the state average. If they are greater, then these higher Medicaid expenditures, rather than the state average expenditure, are used to calculate the threshold amount for the individual. Two problems exist with these threshold amounts. First, there are obvious inequities among states. More importantly, work disincentives will continue for SSI recipients whose income exceeds the threshold amount, but who cannot obtain medical insurance privately or as a fringe benefit of their employment.

5. Not everyone receiving SSI is automatically entitled to Medicaid or Section 1619(b) benefits. Twenty of the states in early 1985 used their own definition of who is entitled to Medicaid benefits.

6. The 15 month reentitlement period for SSDI/CDB and SSI may not be sufficiently long for some beneficiaries.

7. Even more importantly, beneficiaries may fear that engaging in substantial gainful activity for an extended period of time may lead to the finding that they are no longer disabled if their case is reevaluated and that they would then no longer be eligible for SSDI/CDB benefits, regular SSI payments, or even Section 1619(a) provisions. Earnings above the SGA level are a specific indication that the case should be reconsidered. Moreover, some cases are slated for periodic reevaluation because medical improvement is expected. If their

cases are reevaluated, SSI recipients may find that they are no longer eligible for regular SSI payments or for Section 1619(a) provisions by virtue of their earnings above the SGA level. In fact, they may also lose their fifteen month re-entitlement period.

Even SSI recipients who lose their jobs may have their payments terminated unless they can show that the job loss was due to their disability. If however, their job loss is due to factors such as cyclic swings of the economy, use of new technology by the employer, loss of business by the employer, or any of a number of reasons causing non-handicapped workers to lose their jobs, then the worker will probably lose his or her SSI payments if the case is reevaluated. Despite the fact that the recipient has shown a capacity to earn the SGA wage under certain circumstances, it may be a long time, if ever, before he or she can find another job.

8. The Social Security Administration has interpreted Section 1619(a) to mean that after the trial work period and fifteen month reinstatment period, a person is eligible for a special SSI payment only if he or she received an SSI cash payment during the previous month, either a regular SSI payment, a Section 1619(a) payment, or a State supplement. Similarly, a person continues eligible for Section 1619(b) only if he or she received a SSI payment or a 1619(b) payment during the previous month.

If a recipient does not receive a SSI payment during the previous month, then he or she loses the program connection and all SSI including Section 1619(a) provisions. The former recipient may reapply for SSI payments, but only for the basic program, not for Section 1619(a) payments. In these cases, the former recipient must be evaluated as too severely disabled to earn the SGA wage in order to be declared eligible for any SSI payments, a virtual impossibility for someone who has been receiving Section 1619(a) provisions because they are earning above the SGA level, and sometimes even above the Federal breakeven point if the state pays a supplementary award. Similarly, a person who becomes ineligible for 1619(b) also loses the program connection and must be recertified as eligible for the basic SSI program before further health care coverage can be provided.

These administrative provisions can result in substantial hardships and major inequities. As examples:

o Section 1619(a) recipients can lose eligibility to special SSI cash payments because of a relatively small one time gift or bequest, often less than $300.

o If an individual accumulates savings in amounts greater than $1600 ($2400 for a couple), he or she may lose eligibility to both Section 1619(a) and Section 1619(b) provisions. These amounts are for 1985 and are scheduled to rise by $100 in 1986.

o If an individual is entitled to SSDI/CDB benefits and SSI payments, then the breakeven point at which he or she loses eligibility to SSI may be considerably lowered. Consider a case where an individual receives $300 from SSDI/CDB and $45 from SSI. Suppose the person accepts a job paying $250 per month. The SSI payment will be terminated. Total income will be $550 ($300 + $250). But suppose the person subsequently obtains a "merit" increase to $350 per month. After the trial work period, he or she is reevaluated and found not eligible for SSDI/CDB because earnings are above the SGA level. Total income declines to $350. In contrast, a person who received SSI only and who had the same job history would end up with a total income of $542.50 under Section 1619(a) - $350 in earnings and $192.50 in SSI payments.

9. We should mention that under current regulations, recipients will lose entitlement to SSI if their assets, other than a home, automobile, burial plot, insurance, and personal effects, exceed $1600 for an individual and $2400 for a couple. Although it is unlikely that this constitutes a serious work disincentive, it may seriously discourage thrift. To avoid a severe penalty, a Section 1619(a) or 1619(b) recipient must maintain strict limits on his or her bank account, refuse gifts, and avoid windfalls such as a lump sum settlement on his or her injury.

10. The intent of the trial work period is often nullified since any month in which the earnings of SSDI/CDB beneficiaries or SSI recipients are $75 or more must be considered part of the trial work period. Moreover, the trial work period need not be continuous and only one trial work period is allowed per worker. Sometimes the trial work period is exhausted while recipients are in sheltered workshops, before they have an opportunity to test their ability to work on regular jobs.

11. In determining whether a person's earnings constitute substantial gainful activity, extraordinary impairment-related work expenses are deducted from earnings both for applicants to, and beneficiaries of, the SSDI/CDB program. Extraordinary impairment-related expenses are also deducted from the earnings of SSI recipients in determining the payments they receive. However, they are not deducted from earnings when evaluating the eligibility of applicants to SSI which not only creates inequities, but may discourage some disabled persons from seeking work.

12. Significant inequities arise because benefits from the Section 1619(a) and Section 1619(b) demonstration programs are available only to persons who have established eligibility for SSI payments by convincing a disability determinations unit that they are incapable of working at an SGA level. Not only does this create work disincentives for persons not yet receving SSI, but it also results in obvious inequities if some disabled people receives Section 1619(a) and 1619(b) provisions while others do not even though they have the same earnings.

13. Federal regulations governing reimbursement for care in Medicaid approved inpatient facilities stipulate that the Federal payment made to these facilities must be reduced by any amount of income in excess of a personal needs allowance which may be as low as $25 per month.. This provision may greatly reduce the incentive to work since it may amount to virtually a 100 percent tax on earnings. For some people with severe disabilities who need personal care, a skilled nursing facility or an intermediate care facility may be the only practical provider and yet the individual may be able to earn something as say, a writer, or by going to and from work in a wheel chair.

14. Under current policy, once SSI recipients become eligible for 1619(a) because earnings are in excess of the SGA level, then they lose eligibility for basic SSI provisions. If their earnings fall below the SGA level, then they become ineligible for 1619(a), and they must be reevaluated to determine if they are still eligible for SSI. If they lost their job for reasons not related to the disability, e.g., their employer went out of business, they will probably be found to be not eligible for basic SSI provisions and will have permanently lost their Sectional 1619(a) eligibility. The problem may become significant since many severely disabled persons work on jobs that are temporary or insecure.

BLIND BENEFICIARIES

Persons who are blind receive much more favorable treatment from the income transfer programs than persons with other disabilities. For blind persons who receive SSDI/CDB, the SGA level is $610 in 1985 and is adjusted upward annually to reflect changes in the cost of living. Blind persons who apply for or receive SSI are not even subject to an SGA determination. Eligibility is based solely on the existence of a medical condition (blindness).

The payments of employed SSI recipients who are blind are reduced according to the same formula as for other SSI recipients with one exception. Extraordinary impairment-related work expenses are deducted from what would otherwise be the deduction in the SSI payment as a result of

earnings, instead of earnings as is done for other beneficiaries. The effect of this is that the SSI program pays the full cost of these expenses for blind recipients and only 50 percent of the cost for other disabled recipients.

In the case of persons who are blind, SSI payments continue as long as earnings and other income are below the point at which all payments are offset. Thus they have the same provisions as other disabled recipients under Section 1619(a). Unlike other SSI recipients after a period when no benefits are made, blind persons are not re-evaluated to determine if they still are disabled. Instead, payments are suspended and resumed if income declines to a point where the recipients is again eligible for payments.

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PAPER IV

RESTRUCTURING PUBLIC PROGRAMS TO IMPROVE EMPLOYMENT FOR DISABLED PERSONS INCLUDING INDIVIDUALS REQUIRING SPECIAL SUPPORT

INTRODUCTION

A number of changes in Federal policy have sought to stimulate the employment of severely disabled people. Substantial changes have been made to reduce work disincentives for persons receiving income support or health care benefits. In addition, the Developmental Disabilities Act of 1984 established "employment related activities" as one of four priority services to be provided under the Basic Support Grants portion of the Act. By 1987, it will become mandatory that "employment related services" be provided under the State Developmental Disabilities plan. The Department of Health and Human Services instituted an initiative for the employment of developmentally disabled persons during 1984. The goal of this initiative was to place developmentally disabled persons in substantial jobs in regular places of employment. Finally, the U.S. Department of Education in cooperation with the U.S. Department of Health and Human Services recently funded 10 grants to states to develop supported employment for severely disabled persons in integrated work settings.

Most disabled Americans are capable of substantial work. Whether they achieve this goal is dependent upon the incentives to work that exist and the availability of programs to help them attain jobs. Policies and programs are also needed to reduce discrimination and negative perceptions about the work capacity of severely disabled persons (Hahn, 1985).

This paper identifies gaps and limitations in current programs providing vocational, supportive, and affirmative services to disabled persons.

New Groups of Disabled Americans Considered Employable

In fact, most disabled Americans have long been regarded as employable. Yet, it is true that some severely disabled persons have traditionally been considered unemployable and, in order to become employed, require more extensive services than less severely disabled Americans.

Reasons for the recent, strong emphasis on employment are the following:

1. There have been numerous programs around the country that have demonstrated not only that severely disabled persons can work, but that they can work on regular jobs. Some outstanding examples of these programs are the Physio-Control enclave (Olympia, Washington),

the TRW Developmental Disabilities Demonstration Project (Torrance, California), the Specialized Training Program (Eugene, Oregon, and the Transitional Employment Enterprises program (Boston, Massachusetts). These, and many other similar projects, are in process of developing a new rehabilitation technology for severely disabled Americans.

2. Success in educating disabled Americans and assisting them to living in the community is creating increasing pressure to take the next step in helping them to obtain meaningful work. In many cases they have difficulty obtaining appropriate services. Often they are placed in day care. This does not meet the expectations of parents who have struggled to maintain their severely developmentally disabled children at home and to send them to school so that they can prepare for useful lives as adults. Neither does it meet the expectations of young developmentally disabled adults who themselves share their parents' views. Parents who have become trained advocates for children during school years are more informed and assertive advocates for their children when they apply for adult services.

3. In addition, large numbers of disabled Americans are being placed in community residences who would otherwise be institutionalized. Most of the persons in these community residences are not employed, or are underemployed in workshops (Dittmar, et al., 1983).

4. A number of consumer organizations have developed which emphasize the need for more extensive employment services. In addition to developmental disabilities, groups represented by these organizations include persons with brain injuries, chronic mental illness, cancer, learning disabilities, and persons who have undergone organ transplants. Consumer and advocacy organizations have become better informed about the work capacity of disabled Americans, the availability of employment-related services, the nature of bureaucracies and political processes. They have become more articulate in specifying the needs of their constituencies.

Where Should Disabled Americans Work?

Whenever possible, disabled Americans, including persons with severe handicaps, should be employed in regular, integrated job sites.

Why should disabled Americans be employed in regular job sites rather than under sheltered arrangements? If properly placed, most handicapped persons can earn for more on regular job sites than in workshops. Moreover, disabled workers interact with and observe non-disabled people in regular work settings, which has been shown to be of significant value in improving productivity and social skills (Conte, 1983).

In the past, placement of severely disabled persons in extended sheltered employment has often been justified on the grounds that their productivity will be low. This belief was based on the falla-

cious assumption that productivity varies directly with severity of disability; hence the more severe the level of disability, the lower is productivity.

What determines a worker's productivity? At least three variables must be considered.

(1) The values of the items or services that are being produced. Workers cannot be paid any more than consumers are willing to pay for the products they produce.

(2) The efficiency of the productive process. The greater the number of units of output produced by a given number of workers, the greater the revenue from sales and the more that workers can be paid.

(3) The appropriate placement of the worker. Workers must be placed on jobs which take advantage of their unique physical attributes, aptitudes, training, and other characteristics. Place a learned professor on a job using a pick and shovel and he or she may be hard pressed to earn the minimum wage; place a severely mentally retarded person on a job washing dishes, assembling electronic equipment, or working in a nursery, and he or she may be as productive as anyone else.

Why are the earnings of most sheltered employees lower than what they could make in regular job sites? Extended sheltered employment programs often have difficulty obtaining adequate and appropriate work. Often they engage in salvage operations which are possible only because workers are paid low wages. Frequently they are unable to obtain a sufficient quantity of, or an even flow or work, to enable employees to engage in continuous production.

In addition, sheltered facilities have inherent characteristics which prevent most of them from achieving the efficiency of private sector organizations: (a) their small size makes it difficult to achieve economics of scale; (b) they must use large numbers of severely limited workers on production activities that normally would use workers with a wide range of skills; and (c) workshops usually lack the capital, experience, technical knowledge, employee skills, and marketing capacity that make private firms highly successful.

Sheltered employment settings are also disadvantaged by their narrow range of job types and thus have difficulty in placing severely disabled clients in jobs that are suitable to their capacities. This constricts the range of jobs for which severely disabled workers can be trained, a fact of particular importance given the need to transfer acquired job skills to other settings.

These criticisms apply primarily to the use of facilities to provide long term employment. A major function of rehabilitation facilities is to prepare clients for employment in regular jobs. However, a recent literature review of studies of sheltered employment programs concluded that "there is little disagreement that these organizations have a very poor record of performance in achieving

either rehabilitation or employment outcomes" and "the vast majority of documents reviewed are critical of the roles and functions currently manifested by these organizations" (Conte, 1983).

Rather than blame the low productivity of sheltered employees on their disabilities, it is more reasonable to believe that their low earnings should be attributed to the inherent inefficiency of the sheltered employment setting.

Why should placement of disabled workers on regular jobs be expected to be more successful? The regular job market consists of thousands of types of jobs, each requiring a different combination of reasoning ability, strength, dexterity, experience, training, and other traits. Most severely disabled persons can be expected to find, or can be helped to find, jobs which make use of their intellectual and physical capacities in the regular job market and which will enable them to make a substantial contribution to the firm's production.

In addition, placing disabled workers on regular job sites puts them in establishments that have stood the test of competition. They have products or services desired by consumers. They use production methods that can produce goods and services efficiently. These firms bring together disabled and non-disabled workers that embrace the range of needed skills.

Another advantage of regular job sites is that disabled workers can be trained directly for the jobs that they will be performing.

In some cases, jobs must be modified in order to adapt them to the limitations of the workers who seek to fill them, e.g., the expected hourly level of output may be reduced, part-time work permitted, special tools provided, special supervision maintained, etc. Even in these cases, we expect that the productivity of disabled workers placed on regular jobs will be greater than it would be if the workers were placed in workshops.

Range of Employment Services Needed

Because of the great variation in capabilities and service needs among disabled Americans, the most effective employment policy is one that provides a wide range of different types of employment services. Several different types of more intensive services have been developed for severely disabled workers to assist them in entering and maintaining employment.

1. Supported Employment. Supported employment is a combination of employment (20 or more hours per week in an integrated setting) and ongoing services provided from public funds. It addresses the needs of severely disabled persons who have little prospect of employment if long term services are not provided to them. There are a number of different models used to provided long-term support (Virginia Commonwealth University and University of Oregon, 1985).

a. Dispersed work with long-term support. After training and placement, clients are provided long-term follow-up, counseling, and additional services as needed. Extended follow-up services are available and may last indefinitely. Training is provided at the worksite on the job the client is to fill. Job coaches and trainer advocates train and monitor workers placed in independent, dispersed jobs under this model.

b. Enclave model. Physio-Control, a Seattle electronics firm, trains mentally retarded employees to do assembly work. An experienced worker, initially paid by the state, supervises the work of these retarded employees. Jobs are located on the main assembly floor within the firm.

c. Crew model. Workers are transported to different job sites under the supervision of a trainer-supervisor employed by a public or private agency. In Tucson, for example, Beacon Foundation supplies a large car dealer with a clean-up crew of eight mentally retarded workers who are supervised by a Beacon Foundation employee. The crew model has been applied to hotel work, yard work, and similar labor intensive work.

d. STP model. These small programs were initially developed by the Center on Human Development at the University of Oregon. They maintain severely mentally retarded clients in an employment oriented alternative to adult day care and work activity programs. They generally involve electronic assembly performed on a subcontractal basis. These projects hire non-disabled employees to work along with and assist disabled workers. Disabled clients are continuously involved in productive work and achieve higher earnings than when placed in either work activity or day care programs. The managers of these programs are astute and competitive business managers who are also talented in working with severely disabled persons.

2. Transitional Employment Programs. Transitional employment programs (TEPs) are time-limited interventions that seek to place disabled persons in competitive jobs at or above the minimum wage, subsidized by temporary job credits and other incentives to hire people with disabilities. Emphasis is placed on developing job readiness at the work site while in the TEP program.

The Projects with Industry program funded by the Rehabilitation Services Administration is a TEP program. Some examples of TEPs are: (a) Bay State Skills Corporation, a quasi-public economic development agency established by the Massachusetts Legislature to administer work programs to persons with programs at worksites; (b) the Washington State Division of Developmental Disabilities Food Service Program at the University of Washington; (c) the Structured Training and Employment Transitional Services (STETS) program of the Manpower Demonstration Research Corporation of New York; (d) the "Vendor Services" model of the Virginia Commonwealth University's Research and Training Center, Richmond, Virginia; and (e) the Fountain House psycho-social rehabilitation program for persons with mental illness in New York City.

3. Affirmative Industries. Affirmative industries are typically integrated programs which are based on the "non-profit business" model. They hire both disabled and non-disabled workers but are primarily established to provide employment opportunities to disabled workers. These establishments are organized and operated primarily as a business. They make extensive use of modern business techniques and production methods, use "model-workers" as positive role models for disabled employees, and need little external funding (Conte, 1983).

4. Sheltered Employment. Despite the advantages of placing disabled persons in regular jobs, extended sheltered employment will continue to play a major role in the employment of severely disabled workers where better alternatives do not exist. Facilities in the future can be expected to play a major role in the development of transitional and supported employment opportunities at regular job sites. Many facilities have already begun to diversify and establish programs to train, place, and support workers at job sites in the community. There is need to expand these endeavors in view of the superior outcomes that result.

Supported Employment Alternatives: Earnings and Costs

In this section, data on the costs and earnings of severely handicapped persons in supported employment are compared to the principal alternatives to supported employment - day care and sheltered employment. Data are from the following sources:

o 19 extended sheltered employment programs in 15 community mental health and mental retardation services board jurisdictions in Virginia which employ persons with a wide range of physical and mental impairments of varying levels of severity (Virginia DRS, 1985);

o The Virginia Commonwealth University Rehabilitation Research and Training Center supported competitive employment program (VCU-RRTC, 1985);

o The University of Oregon Specialized Training Program sheltered employment and sheltered enclave programs (STP, 1985);

o The Structured Training and Employment Transitional Services (STETS) demonstration program (Kerachsky, et al., June, 1985).

Data from these programs are summarized in Table 1. The following observations are made.

1. The adult day care programs yield no earnings at a public cost per participant of $493 per month.

2. Participants in the Virginia extended sheltered employment programs within the 19 sheltered workshops earned an average of $103.87 per month, ranging from a total of $1.60 to $709.45, at an average public cost per worker of $289 per month when paid for by the Virginia Department of Rehabilitative Services (DRS). Participants paid for by the Virginia Department of Mental Health and Mental

TABLE 1

DAY ACTIVITY PROGRAMS AND ALTERNATIVE SUPPORTED WORK MODELS COMPARED

	Adult Day Care[a] (15 CSBs)	Virginia Extended Sheltered Employment[b] (15 CSBs; 19 sites N=378 clients)	VCU-RRTC Supported Competitive Employmt.[c] (N=186 clients)	STP Sheltered Employment[d] A.Workshop (18 sites) 213 clients	STP Sheltered Employment[d] B.Enclave (1 site; 7 clients	STETS Transitional Employment[e] A.5 Experimental Sites (N=203 clients)	STETS Transitional Employment[e] B.5 Control Sites (N=192 clients)
A. Benefits							
1. Average monthly Earnings (range)	NA	103.87 ($1.60 - $709.45)	$401.48 ($72.58 - $854.53)	$42.00 (0 - $754)	$452.60 ($320 - $664)	$388.38 (0 - $1100)	$275.97 (0 - $1248)
2. Average monthly hrs. worked (range)	NA	84.7 hrs.	123.4 hrs.	28.7 hrs.	127.8 hrs.	125.5 hrs.	119.7 hrs.
3. Average productivity (% of non-handicapped worker's wage in same job) (range)	NA	35% (1 - 146%)	NA (paid at least Fed. min. wage)	28%	68%	NA (paid at least Fed. min. wage)	UNK
4. Average monthly SSI/SSDI reduction	NA	NA	$33.45	UNK	UNK	$20.76[g]	-
B. Public Costs		DRS / DMHMR					
1. Average monthly cost (days attended)	$493 (UNK)	$289 (17.0) / $312 (UNK)	$287 (15.4)	$355 (18.9)	$30[f] (16.0)	$666 (16.4)	UNK (15.0)
2. Targeted Jobs tax credit (2 years max.)	NA	NA / NA	$155	NA	-0-	$ 23	UNK
Total	$493	$289 / $312	$442	$355	$30	$689	UNK

[a] IQ's unknown
[b] IQ's unknown
[c] Mean IQ = 50;range = 25 - 78
[d] Mean IQ = 30;range = untestable - 45
[e] Mean IQ = 64
Borderline (IQ 71 - 85) = 38%
Mild (IQ 56 - 70) = 50%
Moderate (IQ 40 - 55) = 13%
[f] Physio Control, Inc. pays for supervisor
[g] Average difference between experimental and control clients

Retardation (DMHMR) cost $312 per month. Work productivity, as measured by the Department of Labor (DoL) sheltered workshop standard for what a fully productive worker would earn at the same job, was 35 percent, ranging from one to 146 percent.

3. Participants in the Virginia Commonwealth University Rehabilitation Research and Training Center (VCU-RRTC) supported competitive employment program earned an average of $401.38 per month, ranging from $72.58 to $854.53. Their IQs averaged 50, ranging from 25 to 78. All participants in the VCU-RRTC program received at least the federal minimum wage.

The public cost per participant in the VCU-RRTC supported competitive employment program averaged $442 per month. The monthly cost has two components--$287 for supportive services and $155.46 for tax credits under the Targeted Jobs Tax Credit (TJTC) program to 61 percent of the employers of the VCU-RRTC program participants. TJTC tax credits are available only to for-profit businesses which are making a profit subject to taxation. The earnings of participants in the VCU-RRTC program lead to an estimated $33.45 reduction in the Social Security Supplemental Security Income (SSI) benefit that would otherwise have been paid.

4. Participants in the Specialized Training Program (STP) directly operated or franchised by the University of Oregon earned an average of $42.00 per month, ranging from no earnings among persons in training to $745. STP employees in both sheltered workshop and sheltered enclave sites have IQs which average 30, ranging from untestable to 45. The public cost per participant in the sheltered workshop sites averages $355 per month. No TJTC tax credits are payable to the non-profit STP programs. Productivity is 28 percent of the DoL standard wage.

STP employees in the Physio-Control, Inc. sheltered enclave earned an average of $452 per month, ranging from $320 to $664. The public cost of the Physio-Control, Inc. sheltered enclave is $30 per month because the STP supervisor was hired and is paid for on site services as a regular employee of Physio-Control, Inc. Physio-Control, Inc. elected not to seek TJTC tax credits for its STP employees.

5. Participants in the Structured Training and Employment Transitional Services (STETS) program were randomly assigned to an experimental group which received special services and a control group. Unlike the foregoing programs, the STETS program had a true control group with which to compare the effects of program treatment.

STETS participants had an average IQ of 64, ranging from 40 to 85. In the 22nd month after enrollment in the STETS program, participants (all but 16 percent of whom had transitioned from their initial training job into regular or sheltered workshop jobs) earned an average of $370.31 per month, ranging from $1,100 to no earnings among those who were unemployed at the time of followup. In contrast, the control group members earned an average of $263.14 per month, ranging

from $1,248 to no earnings among those who were unemployed at the time of followup. Thus, participation in the STETS program had the effect of increasing average monthly earnings by $112.41 ($388.38 - $275.97).

The public cost per STETS program participant averaged $689 per month, consisting of $666 for services and $23 in tax credits to employers under the TJTC program. The public cost of services incurred by members of the STETS control group are unknown. However, they were probably substantial because 14 percent of the control group members were employing sheltered workshops and 14 percent were enrolled in training programs at the time of followup. In consequence, public services may have contributed to the earnings of both the experimental and the control groups at the time of followup.

What accounts for the reported differences in earnings and costs among these program alternatives for persons with severe handicaps? Comparisons among these different approaches to providing adult services are difficult to make. Information was not available on IQ levels in all cases. Nor was information available on the severity of associated disabilities. It is known, for example, that many persons in the Virginia extended sheltered employment program do not have severe disabilities. Also, a substantial proportion of these sheltered workshop employees are physically handicapped as compared to persons in supported work projects who have severe mental retardation. Moreover, the lack of a common accounting system for measuring benefits and costs means that the differences among the different work and care programs as measured may not reflect the "true" differences.

In addition, the data from the STP workshop sites included persons with no earnings, some of whom were in training. This obviously causes an understatement of the earnings of workers who are in sheltered long-term employment in these sites. Earnings from the other projects were reported for persons with earnings.

One conclusion from these data is that it cost more to maintain disabled people in idleness than to place them in jobs. The average monthly cost of adult day care was $140 to $460 higher than for any of the work programs except the STETS program, which may be biased upward because all of the experimental group was initially receiving services to prepare than for work. The least expensive approach to adult services was clearly to place severely disabled persons in regular job sites. The sheltered enclave site involved little public cost and served severely mentally retarded clients as compared to the sheltered employment which served large numbers of less severely disabled persons.

A second conclusion is that, given appropriate long-term services, most severely disabled workers can work in substantial jobs. Surprisingly, the clients in supported work models had earnings significantly greater than the clients in the Virginia extended sheltered employment sites who were less severely disabled. The only exception was the STP workshop sites which serve very severely disabled clients. Even in these sites, a number of clients had wages

as high as were earned in the other sites. As we noted, the average earnings of clients in STP workshops are biased downward because of the inclusion of clients in training.

Everything else being equal, it is fair to say that VCU-RRTC supported competitive employment for persons with moderate mental retardation yields between $125.41 ($401.38 - $275.97) and $297.51 ($401.38 - $103.87) more than the monthly average earnings in an ordinary sheltered workshop in Virginia. The low estimate is based on a comparison with the $103.87 average monthly earnings in Virginia extended employment programs. The high estimate is based on a comparison with the $275.97 average monthly earnings among STETS control group members.

Considering the average IQ level of the seven STP workers at the Physio-Control, Inc. sheltered enclave, their reported average monthly earnings of $452.60 is remarkable. They surpass the average monthly earnings reported by all the other program alternatives being compared. What is more, they are made possible by a public outlay of only $30 per month. One should contrast these data with the $493 average monthly cost that is incurred by government each year for maintaining in adult day care many thousands of persons with similar levels of intellectual functioning.

Kerachsky, et al. (June, 1985) concluded that the STETS program was a worthwhile social investment:

> From the perspective of society as a whole, it cost $6,200 per participant to provide the STETS intervention. During the 22-month observation period, this investment yielded increases in participant output and reductions in the use of other programs by participants that offset about 85 percent of this initial investment. . . . However, trends observed for the impacts on earnings and the use of sheltered workshops suggest that benefits will persist and are likely to outweigh costs in the long-run. If the earnings and reduced alternative program benefits continued for as little as seven months beyond the 22-month point, social benefits would exceed the costs.

In summary, the evidence at hand argues that all forms of sheltered employment are more productive in terms of earning potential and less costly to provide than adult day care. Moreover, supported competitive employment for persons with moderate mental retardation appears to be more productive, albeit somewhat more expensive because of the employer tax credits involved, than employment in sheltered employment.

Despite the success of the STETS program, 55.3 percent of its participants were left without any kind of paid work at followup in the 22nd month. Many of these persons might have done better than this, had they been able to receive ongoing supported competitive employment services instead of only the transitional services provided by the STETS program. The point is that no one work modality is successful for all severely disabled persons. A variety of programs must be maintained if the majority of severely disabled Americans are to be productively employed.

EXISTING PROGRAMS

United States Employment Service (USES)

The Employment and Training Administration, U.S. Department of Labor, funds local USES offices throughout the country. Each of these offices is required by law to assign at least one staff member to provide disabled persons with special employment assistance such as evaluation, counseling, training program information, and referral to suitable jobs. USES programs often refer unskilled workers who have disabilities to vocational rehabilitation or to Job Training Partnership Act programs.

Vocational Rehabilitation

The federal Rehabilitation Services Administration funds state rehabilitation agencies, whose primary purpose is to assist disabled Americans to enter gainful employment. An individualized written rehabilitation program (IWRP) must be developed for each disabled individual accepted for services. Rehabilitation counselors determine eligibility, jointly develop the IWRP with the client, and coordinate the multidisciplinary services which most often are purchased from private sources.

State rehabilitation agencies successfully rehabilitated 225,722 persons in FY 1984, a gain of 4.4 percent from 1983. The number of severely disabled persons rehabilitated in FY 1984 increased by 6.8 percent from the prior year to 132,665. Severely disabled persons accounted for 58.8 percent of all rehabilitations in FY 1984 compared to 57.4 percent in the prior year.

The total funding available for basic state grants in FY 1984 was $1,037,800,000. The act requires states to match federal funds on the basis of $1 for every $4 federal funds. Additional programs operated through the Rehabilitation Services Administration include:

(a) $6,000,000 awarded to 50 states for the Client Assistance Program (CAP). The CAP advises clients and client applicants of all available services under the Rehabilitation Act and assists them in their relationship with projects, programs, and facilities that provide needed services.

(b) $22,000,000 awarded to rehabilitation training programs (e.g. continuing education, in-service training) in FY 1984.

(c) Special Projects for Severely Disabled Individuals that demonstrate innovative services for persons with blindness, deafness, spinal cord injury, and other disabilities totaled $6,235,000 in FY 1984.

(d) Projects With Industry (PWI) made grants totaling $13,000,000 to corporations, labor organizations, trade associations, foundations, and voluntary agencies to expand job opportunities for disabled persons.

(e) Centers for Independent Living were awarded grants which totaled to $19,400,000 in FY 1984. Over 150 centers serving more than 20,000 individuals were funded by this program.

Sheltered Workshop Programs

The Wagner-O'Day Act of 1938, as amended, uses the purchasing power of the federal government to promote the goals of higher wages and increased employment opportunities for blind and other severely disabled employees in sheltered workshops. Designation of selected commodities and services for the workshops to produce, and procurement actions for the actual work, are the responsibility of the Committee for Purchase from the Blind and Other Severely Handicapped. This Committee publishes a list of goods and services which qualify for the program, determines a fair market price for items on the list, and revises the list and prices as markets and needs change. The Act originally authorized purchase from workshops for the blind, but amendments to the Act in 1971 extended authority to workshops for other severely disabled persons.

To implement the Wagner-O'Day Act, two additional organizations have been established.

The National Industries for the Blind (NIB) was established in 1938 to act as the designated liaison between workshops for the blind and federal procurement representatives. Its main function is to allocate purchase orders among qualified workshops and to provide training and consultation to workshop boards. About one hundred workshops are associated with NIB in producing goods and services.

The National Industries for the Severely Handicapped (NISH) was organized in 1974 to act as the designated representative between workshops for the severely handicapped and federal procurement representatives. It also identifies commodities and services which are feasible for production in sheltered workshops, and assists workshops to obtain and fulfill federal contracts. More than eight hundred workshops are associated with NISH.

Another federal law which regulates many sheltered workshops as well as private employers is the subminimum wage provisions of the Fair Labor Standards Act. This law allows subminimum wages to be paid to severely disabled persons who are unable to compete for regular minimum wage jobs because their levels of productivity are substantually below those of non-disabled candidates. A certificate may be issued to to a profit-making company or nonprofit sheltered workshop, or directly to eligible individuals. In all instances certificates are only issued for workers whose earning capacity is impaired by physical or mental disability. Generally the certificates provide for 75% of the statutory minimum wage (currently $2.41 hr.). The subminimum wage program is administered by the U.S. Department of Labor, Employment Standards Administration, Wage and Hour Division.

Targeted Jobs Tax Credit (TJTC)

A Targeted Jobs Tax Credit is available to employers of qualified disabled individuals referred by state vocational rehabilitation agency personnel. The credit also applies to individuals referred by certain public assistance and training programs. The credit is for up to $3000 of the first $6000 of wages paid to a certified worker in the first year of employment and up to $1500 on the first $6000 of wages paid in the second year of employment.

Education Programs

The Education Amendments of 1983 authorized the Secondary Education and Transistional services for Handicapped Youth Program. This program supports projects that strengthen and coordinate education, training, and related services to assist youth in the transition to competitive and supported employment, postsecondary education and training, and adult services; and projects that stimulate the development and improvement of secondary special education programs.

Educational services to older (secondary and post-secondary) disabled students have increasingly stressed the goals of increased employment and improved independent living skills (Will, 1984). There has been an increasing emphasis on transition programming between high school programs and postsecondary placements such as further academic education, vocational training, and employment (Wilcox, 1983; Harold Russell Associates, 1984).

Transition programs are being established in some communities to improve services and outcomes for the severely disabled population. These programs include work experience programs; work skills preparation; employer focused initiatives; rehabilitation engineering; assistance in accessing community resources, occupational information; job seeking skills preparation; and, transition planning.

Although national data on the number of disabled secondary students are not currently available, child counts from all 50 states show that the number of postsecondary disabled students (18-21 years old) served by the public schools has increased by over two-thirds in the last five years, with 186,393 served under the Education for All Handicapped Children Act in school year 1983-1984. Twenty-eight states had mandates in 1984 to serve disabled youths through age 21 if they have not graduated from high school.

Job Training Partnership Act

The Job Training Partnership Act (JTPA) is designed to encourage businesses and state and local governments to work together to train and place dislocated, economically disadvantaged, and handicapped persons in permanent private sector jobs. JTPA programs operate at the local level through a Private Industry Council (PIC) which consists of representatives of the private sector (at least 50% of the membership) and representatives of educational agencies, rehabilitation agencies, organized labor, and community-based

organizations. JTPA programs can establish programs to prepare handicapped youth and unskilled adults for entry into the labor force, including job training. Supportive services such as transportation, health care, materials, temporary shelter, meals, financial counseling, and other reasonable expenses required for participation in the program can be provided. Rehabilitation facilities are recognized as "community-based organizations," which are eligible to participate in job training programs.

SSDI and SSI Vocational Rehabilitation Programs

Sections 222 and 1615 of the Social Security Act provide for the payment from special federal funds of the costs of vocational rehabilitation services to disabled SSI and SSDI/CDB (Childhood Disability Beneficiary) recipients and beneficiaries. In FY 1980, $113 million and $55 million were available respectively for the SSDI and SSI rehabilitation programs. However because of significant legislative change, funding has decreased significantly under these provisions to about $2.2 million in FY 1983 and 1984.

The Social Security Administration is developing and carrying-out demonstrations and experiments to test alternate ways to encourage SSDI beneficiaries and SSI recipients to return to work and to demonstrate whether transitional employment training is a cost-effective means of helping mentally retarded SSI recipients get and keep nonsubsidized, private sector jobs. SSA has awarded $2,655,000 in grants to eight nonprofit organizations to conduct the training between April, 1985 and April 1987.

PROBLEMS

Despite this array of services to assist disabled persons to obtain and maintain employment, a number of problems remain which hinder the achievement of substantial employment by many disabled Americans. Among the problems are:

Lack of Adequate and Stable Funding for Long-Term Vocational Services. Activities that provide extended vocational services, such as supported work, transitional employment programs, enclave programs, etc., generally are funded through project grants lasting one to three years. There is no assurance that they will be funded beyond this time.

There is no Federal program that has a mandate to assure that this type of vocational activity continues to be funded. Although Federal law permits vocational rehabilitation funds to be used for long-term vocational support, there is little incentive on the part of counselors or State agencies to use funds for this purpose. It should be observed that a few States have made a commitment to funding supported work activities, but funds are limited even in these States (Hill, Hill, Wehman, Revell, Dickerson and Noble, 1985).

The lack of funds for long-term vocational support is particularly important since a major impediment to hiring severely

disabled persons is the employer's fear of the "hassle factor" (Vardergoot, 1985). These "hassles" may refer to the problems of smoothly integrating the severely disabled worker into the job site, assuring no loss in productivity or increase in cost, confusion in understanding and complying with disability laws, and so forth. Job site based employment services, such as a job coach model, greatly increase the human competence of disabled workers while greatly reducing these employer fears (Wehman and Melia, 1985).

Disincentives to Providing Long-Term Vocational Support. There are serious disincentives to providing long-term vocational support in employment programs for disabled persons.

In the vocational rehabilitation program, there is for the most part an emphasis on rehabilitating as many disabled persons as possible. Counselors may be given informal quotas. In consequence, there is an emphasis on time-limited services leading to closures which can be counted. Moreover, counselors sometimes avoid cases which require a substantial amount of time, which have a low probability of being successfully rehabilitated, or which will be costly in view of limited case service budgets. Finally, there is no incentive to place workers on the most productive job of which they are capable - a small weekly check counts as much as a large one. Although the Rehabilitation Act of 1973, as amended, requires State vocational rehabilitation agencies to give priority to persons with the most severe handicaps when determining how to ration services, the definition of who is severely disabled is judgmental and a great deal of leeway in deciding who is, and who is not, feasible for services remains with the vocational rehabilitation counselors, particularly since many more people apply for services than can be served.

The current Federal allocation formula disburses rehabilitation funds on the basis of the relative size and per capita income of States, and has no way to reward the States which serve the most difficult clients or which achieve superior service outcomes.

The emphasis on time-limited services applies to most manpower development programs in the United States. Time-limited employment services have been the traditional response to meeting the general population's need for help in preparing for and securing jobs. Time-limited services have distinct beginning and ending points, and do not continue after the client has been placed on a job (Hill, Hill, Wehman, Revell, Dickerson, and Noble, 1985). The time-limited perspective is built into manpower development programs' operating policies, procedures, and systems of accountability. Thus, manpower development programs provide statistics on applicants, acceptances, and "successful" and "unsuccessful" case closures. The statistical accounting systems do not permit categorization of cases of individuals who require ongoing assistance to remain on the job. Some manpower development programs, including the state-federal VR program, provide post-employment services on a strictly time-limited basis if the service need is the same or closely related to what was addressed in the original services plan.

The SSDI/SSI Beneficiary Rehabilitation program was radically altered by the Omnibus Budget Reconciliation Act of 1981 in a way that created severe disincentives to serving severely disabled persons. Prior to this Act, vocational rehabilitation agencies were reimbursed for services provided to SSDI and SSI enrollees, regardless of outcome. The 1981 Act, however, changed this to a performance reimbursement system so that vocational rehabilitation agencies are paid only if the client is sustained in employment paying SGA wages for a continuous period of 9 months.

Unfortunately, the reimbursement system has several drawbacks. It creates a long time period between the provision of services and reimbursement to the States. It also creates a severe disincentive for serving severely disabled persons who take longer to rehabilitate and who are less likely to be able to earn above SGA level and who may require extensive long-term vocational support. In consequence, services to SSI and SSDI beneficiaries have been severely cut back.

Medicaid Restrictions on The Provision of Vocational Services. The Intermediate Care Facilities for Mentally Retarded (ICF/MR) persons program is limited to persons with mental retardation and associated conditions. It funds residential care and services. It differs from the basic Medicaid program in that services can be provided for the purpose of providing either health care or habilitative, i.e., developmental services.

The ICF/MR program has been growing rapidly. Between 1973 and 1983, it grew from $400 million annually to $3.9 billion. By June 30, 1982, 58 percent of all residents of public and private residential care facilities for mentally retarded persons were in ICF/MR certified facilities. Overall, there were 243,669 mentally retarded persons in 15,633 residential facilities so that approximately 140,000 mentally retarded persons were in ICF/MRs covered by the ICF/MR program (Bruininks, 1985).

Most ICF/MR residents are in large institutions. In June, 1982, over 162,000 of the persons in residences for mentally retarded persons were in residences with 16 or more persons. It is anticipated that the number living in large residences will decline steadily in future years.

The ICF/MR program discourages employment for clients in several ways. In order to be eligible for ICF/MR care, clients must be in need of 24 hour a day supervision and must be engaged in an active treatment program. Since the ICF/MR program has generous funding provisions (all reasonable costs of care are eligible for Federal matching funds), States have a powerful incentive to place mentally retarded persons in this type of facility. Lacking clear criteria as to how to determine who is in need of 24 hour a day supervision, it is frequently alleged not only that states place persons in ICFs/MR who do not need this level of care, but also that many of these beneficiaries could work on substantial jobs if given an opportunity. The restrictive eligibility requirements make it unlikely that substantial employment will achieved. Persons defined as able to work

would probably be construed as not needing 24 hour a day care. What is more, if the person were actually employed, he or she would probably not be regarded as being in an ICF/MR reimbursable active treatment program.

The second problem with the ICF/MR program is that Medicaid regulations specifically prohibit the use of Medicaid funds for vocational training (CFR 441.13 (b)). However, Medicaid regulations also specifically require that "active treatment" be provided to all residents of ICFs/MR (CFR 442.494). These ICF/MR requirements appear contradictory since work, in the view of most people, is one of the highest social functions that people perform. In effect, Medicaid funding is precluded from providing the services that may be needed to achieve future independence on the part of the residents. In consequence, many residents of ICFs/MR are placed in adult day care which is eligible for Medicaid funding.

A third problem with the ICF/MR program is that the Health Care Financing Administration has never indicated how it expects the state to distinguish between habilitation services and vocational training for purposes of Medicaid reimbursement. Nevertheless, there are a number of States which have had Medicaid claims challenged by the United States Department of Health and Human Services Inspector General's Office on the grounds that they were using habilitation funds for vocational training purposes (Consortium, 1985).

Medicaid prohibition against vocational training has recently been extended to the Home and Community Based Services Waiver program. This program, which is approximately 4 years old, was designed to permit states to provide home and community services to eligible Medicaid beneficiaries who would otherwise require long-term care in Medicaid certified facilities. The purpose of this program is to reduce the costs of caring for aged and disabled beneficiaries and to promote their independence.

> In the preamble to the final waiver regulations, HCFA states:
>
> We do not believe that prevocational and vocational training and education activities are commonly furnished as a means of avoiding institutionalization. Individuals would not, in the absence of services, require institutionalization. Therefore....we have interpreted Section 440.180 as excluding these services because they are not cost effective alternatives to institutionalization (Federal Register, March 13, 1985, Vol. 50, No. 49, p. 10020).

Not only are the vocational services prohibited that could enable clients to return to work, but states, parents, and advocates may fear that if these clients are assisted to enter the labor force, they may become ineligible for Medicaid since the fact of employment could be construed as indicating that they are not potential candidates for institutional care.

The Transition from School-to-Work (Aging-Out) Problem:
The "aging out" problem refers to the difficulties encountered by some severely disabled persons in making the transition from school services to adult services. Many young severely disabled persons are unable to obtain adult services after they leave school, or can only obtain inappropriate services. In particular, the lack of long-term vocational services means that many young adults lack an opportunity to engage in meaningful work. They often end up in a day activity center, a work activity center, or a sheltered workshop. This is particularly true of individuals who have been impeded from entering the labor force by the lack of services from agencies providing "time-limited" vocational services.

Arrangements are Available for Purchase of Sheltered Work and Day Activity Services but not Transitional and Supported Employment Services: Although sheltered employment and day activity programs may obtain financial support from state VR agencies, state Medicaid agencies, and state and local government mental health, mental retardation and /or developmental disabilities, and social services agencies, methods of financing transitional and supported employment services are not readily available. Thus, there is little incentive for these programs to change their operating methods to encompass transitional employment and supported employment approaches. Also, sheltered employment and day activity programs often have substantial capital committed to buildings and equipment, the amortization of which is dependent on maintaining the status quo (Bellamy, Rhodes, Bourbeau, and Mank, 1982).

Staff need to be Trained to Provide Direct Services in Supported and Transitional Employment. There are too few people trained in supported and transitional employment approaches to meet the needs of all severely disabled people. Most persons who have been trained to provide services to severely disabled persons through transitional and supported employment approaches have been trained in short-term institutes or internship programs provided by "pioneers" in these fields (Wehman and Melia, 1985). There are too few existing training programs to meet an expanded demand for direct services personnel. There is also a need for more leadership personnel to organize training programs. Although some sheltered workshops and day programs might become providers of services, the competencies needed to assist severely disabled persons at work sites using supported and transitional employment are different from the skills currently associated with most sheltered employment programs and day care programs (Harold Russell Associates, 1985). The personnel in sheltered workshops and day activity programs are also concerned about retaining their jobs, but to retrain them for new jobs will require significant role transitions (Nicholson, 1984).

Need for Improved Administrative Efficiency in Vocational Rehabilitation:
In recent years some private rehabilitation service providers and consumer organizations have criticized state rehabilitation agencies and the Rehabilitation Services Administration for spending too much on administration and thus reducing the amount of resources available for direct employment-related services.

There is evidence to suggest that some federal and state requirements for case management and documentation do not assist successful rehabilitation outcomes, e.g. the detailed requirements found in the preliminary, and thorough diagnostic study, and individualized written rehabilitation program sections of the Rehabilitation Act and regulations. The University of Georgia's Management Control Project found that many administrative and supervisory control systems have no positive impact on successful rehabilitation client outcomes and may have a negative impact on agency productivity and counselor morale. (Rehab BRIEF, 1984)

Dwindling Fiscal Support for Vocational Rehabilitation: Rehabilitation program appropriations have not kept pace with inflation since 1972 although state VR programs are now serving an increasingly severely disabled population. This apparently explains the decline in the number of persons served. During the 5-year period from 1975 to 1979, for example, the number of cases served by state VR agencies declined by Ø.71 percent for each percentage point reduction in 1975 constant dollar purchasing power. Erosion of the purchasing power has continued into the 198Ø's. The budget crunch decreases the feasibility and willingness of state VR agencies to take chances with new clients and new service technologies (Noble, 1984).

Two-Year Limitation on the Targeted Jobs Tax Credit (TJTC) Program. This program contains a perverse incentive (Conley and Noble, 1985). The current two-year limitation on the tax credit that can be paid to employers stands as a disincentive to the continuous employment of the same individual; employers who turn over their handicapped workforce will reap more tax credits than those who stabilize it. [NOTE: as this paper is prepared, the future of the TJTC is uncertain; the basic TJTC legislation has expired and is under Congressional consideration for renewal.]

"New" Populations are not Served Effectively by Rehabilitation Agencies. Increasingly, the vocational rehabilitation program is being asked to serve persons with disabilities that have not traditionally been served, e.g. persons with severe mental retardation, persons with brain injuries, learning disabled persons, persons who have had or currently have cancer, persons who have undergone organ transplants, and chronically mentally ill persons. The methods of serving these populations often differ from traditional service methods. In consequence, vocational rehabilitation counselors do not always know the most effective ways of rehabilitating these new populations. Even when effective service methods are known, availability of services is often limited or requires new service arrangements. For example, individuals with chronic mental illness fail in sustained employment due to both individual and societal factors. Mental health programs have traditionally lacked resources to assist persons with chronic mental illness (CMI) to enter the work force. There are few vocational evaluation methods which have proved of value in describing, predicting, and prescribing for improved employment outcomes for psychiatrically disabled persons (Anthony, 198Ø; McCue and Katz-Garris, 1983).

Few rehabilitation or employment service staff have special training for interacting with and assisting persons with schizophrenic disorders, affective disorders, and personality disorders. Few methods exist for exchanging information on successful practices and implementing cooperative programs for such purposes; the most successful programs, as noted above, have been transitional employment programs (TEPS) such as the Fountain House.

Eligibility Problems. Eligibility criteria for programs such as vocational education, and United States Department of Labor training programs often require that individuals be "job ready", "have vocational potential", or "demonstrate capacity to participate in the program as offered." In many instances, these pre-requisites are defined in terms of an unmodified job. The readiness test is applied before individual accommodations such as task analysis to breakdown a job, special assistance by "job coaches" or "vocational resource educators" (VRE's -members of vocational educatators who are trained in special education) and other methods of making it possible for the disabled person to perform the job have been considered (Wehman and Melia, 1985). Vocational evaluation approaches intended to predict performance on a job rely on traditional psychometric approaches are used to screen individuals out while also failing to account for gains in performance that will be achieved in doing the job (McCray and Blakemore, 1985). As might be expected human competence increases when provided such individual attention (Gilbert, 1978; Bellamy, Horner, and Inman, 1979; Virginia Commonwealth University and Specialized Training Program; University of Oregon, 1985).

PAPER V

DISABILITY MANAGEMENT IN THE WORKPLACE

Despite important advances in the development of employer programs to assist workers to remain productive after the onset of disability, many workers do not have access to these services. Even many Fortune 500 firms do not have disability management programs. Moreover, many disability management programs that are in place do not provide a full range of disability services to workers nor extend these services to all employees/applicants (Schwartz, 1986).

Disability management is a comprehensive effort by employers to prevent or avoid disabilities, to minimize absence from work due to disability, and to enable employees whose impairments require major changes in work or personal functioning to return to work and maximum productivity in the most efficient manner possible (Mitchell, 1980).

In different firms, these policies and practices may differ dramatically among different disabled persons according to whether they are employees of the firm with a work-related injury, employees of the firm with a non-work related injury, or if they are applying to the firm for work. Components of a comprehensive disability management plan often include:

o Provision of Fringe Benefits. Almost all large employers, and many small employers, provide benefits to employees who become disabled that are in addition to required Social Security, Medicare, and Workers' Compensation benefits. These fringe benefits vary widely in coverage and amount. In some cases, they assure workers of income support and medical care for as long as they are disabled. In other cases, benefit levels are limited as to time or amount.

o Employment Policies. Ultimately, employers must modify hiring practices if many handicapped persons are to be employed. This may take many forms. At the simplest level, it may consist only of being willing to give disabled workers a chance to prove that they can perform a job at an acceptable level. More positive actions would be:

a. arranging for the transfer of disabled workers to jobs within the firms that are within their capabilities.

b. assisting handicapped workers to locate jobs in other firms.

c. modifying jobs to bring them within the capabilities of disabled workers.

d. providing special training for disabled workers.

e. providing special supervision for disabled workers, or permitting outside organizations to provide such supervision.

o Employee counseling and other services to reduce the effects of disabling conditions. Increasing numbers of companies are establishing Employee Assistance Programs (EAP) which provide services before the effects of a handicapping condition become sufficiently serious to cause job loss. Initially, EAP's were developed primarily for the purpose of assisting employees who were alcohol abusers (McMahon and Shaw, 1983). However, these programs have expanded so that some firms now provide counseling and other services to employees who are under stress, or to employees after a handicapping condition occurs to prevent job loss or to assist them to return to work. During 1982, there were an estimated 5,500 EAP programs in the United States (Bierman, 1982).

Employers can provide a wide array of services, beginning with counseling services to prevent conditions such as alcoholism and drug abuse from worsening. Counseling can also be provided after the onset of a injury or disease to help the employer adjust to the condition and to prevent deterioration of attitudes toward work. Vocational training and restoration are sometimes available, as well as other services such as counseling to families of disabled workers.

These employer based programs have several major advantages over conventional vocational rehabilitation services: (a) In most cases, they provide services earlier than State vocational rehabilitation agencies would provide services; (b) they can provide reasonable assurance of employment if the employee makes reasonable and satisfactory progress; and (c) they can integrate a range of income support, medical care, vocational, and other services that are provided by the employer.

o Prevention of the onset of Industrial accidents and diseases. Each year, almost six million people receive a workers' compensation award because of an industrial accident, disease, or cumulative trauma (e.g., the cumulative effect of noise on hearing, or lifting on the back) (Worrall and Butler, 1985). In most cases, the conditions are not serious and workers' compensation pays for medical treatment only. However, over one million workers receive indemnity benefits for wage loss or as compensation for the injury or disease. Of these persons receiving indemnity benefits, about 325,000 suffer permanent disability in the sense that there is a permanent functional loss. Although the great majority of these permanent disability cases are rated as permanent partial disability, a significant number will stop working because of their condition. In one study, it was estimated that one-fifth of the men with permanent partial disability ratings of 10

percent of higher were not working four to seven years after their injuries because of the effects of their injury and/or problems generated by the system for obtaining compensation (Conley and Noble, 1979).

These workers" complensation claims understate the full extent of permanently (or temporarily) disabling conditions caused by workplace exposure since an unknown, but potentially large, number of persons develop occupational disease (e.g., black lung disease) or injuries resulting from cumulative trauma (e.g., prolonged back strain, or exposure to noise)) for which workers' compensation benefits may not be claimed. Barth (19) has summarized evidence indicating widespread existence of occupational disease (see also Conley and Noble, 1979).

Employer efforts to provide assistance to disabled workers in order to avoid their separation from the labor force are of relatively recent origin, and have yet to be adopted by large numbers of employers. In general, the reaction of employers to disabling injuries or illnesses among employees has been to refer them to workers' compensation carriers if the condition was work related, or to pay (usually through an insurance carrier) medical benefits, income support, and other benefits to which workers are entitled. Administrative efforts have largely been devoted to adjudicating claims, assessing disability, and determining benefit amounts. Vocational rehabilitation services are generally not available to employees until the disability is clearly established and the workers have left the work force.icating

This approach to disability among workers has been appropriately termed the "disabling system" (University of Minnesota Medical School, 1984). In effect, most employers "wrote off" disabled employees, paying compensation claims and other benefits as a cost of doing business. For example, Wickersham (1983) stated that before the 3M company adopted a disability management system, the company paid "...benefits to anyone who presented satisfactory proof of a disabling condition." This led to the following types of problems:

o "Writing off" disabled employees increased the cost of doing business and the long-term disability benefit rolls;

o Disability and rehabilitation policy among employers has largely focused on workers' compensation claims;

o Little capacity has been developed to manage rehabilitation and prevention programs at worksites;

These disability problems are likely to grow in the future as the retirement age rises.

MOTIVATION FOR DISABILITY MANAGEMENT PROGRAMS

What has led numerous companies to adopt a more proactive posture to prevent disability, to respond at the workplace to the needs of disabled workers, and to facilitate rehabilitation and return to work (Menninger Foundation, 1985; Wickersham, 1983)? Some of the reasons are as follows.

1) Cost Considerations. During the last 15 to 20 years, the costs to employers of disability among workers has been rapidly rising (Galvin, 1985; Schwartz, 1980). In part, this is due to increasing liberalization of the benefits provided by workers' compensation. Workers' compensation benefits generally pay all medical costs of work-related injuries and illnesses and pay indemnity benefits that may amount to as much as two-thirds of wages and, in some cases, be lifelong. In part, this is due to the growth of fringe benefits providing medical care, income support, and other benefits for non-work related benefits. In some cases, fringe benefits will supplement benefits paid under workers' compensation.

Some indicators of the high costs faced by private firms due to illness and injuries are as follows:

a) In 1983, AT&T's health care bill totaled $2 billion for 3 million beneficiaries - employees and their dependents - and will increase to $3 billion by 1986 if provider practice patterns and fee schedule trends remain the same.

b) Lee Iacocca reported in his autobiography;, "When I came to Chrysler, I saw that Blue Cross/Blue Shield had already become our largest supplier. They were actually billing us more than our suppliers of steel and rubber! Chrysler, Ford, and G.M. are now paying $3 billion a year for hospital, surgical, medical, and dental insurance plus all pharmaceutical bills. At Chrysler, that comes to $600 million or about $600 per car."

c) The Social Security Administrations reports that in less than ten years, workers' compensation benefits paid to injured workers more than tripled from $5.1 billion in 1973 to $16.1 billion in 1982.

d) The Bureau of Labor Statistics estimates that approximately 8 million musculoskeletal workplace injuries occur each year, translating into 20,000 injuries each work day. Back injuries alone cost an estimated $14 billion a year.

The costs incurred by private industry in individual cases can be staggering. Schwartz (1984) provides an example. "Take the case of a 50 year old truck driver working for a large company in the state of Washington who has an accident. He

fractures his neck and can no longer continue his present job. If he qualifies for an average weekly benefits of $294, receives a yearly 7 percent cost-of-living increase, lives for another 20 years, and does not resume employment, this individual would receive total benefits of $627,000. The amount would obviously increase dramatically if the employee in the example were younger and if the cost of medical care were added. Cases involving $1 to $2 million in benefits may become increasingly common.

Cost incentives vary dramatically among different groups of workers. Probably, in most cases, these cost incentives are strongest for persons covered by workers' compensation since employer liability is virtually universal and benefits are prescribed by law. They are generally less strong in the case of non-work related injuries and illnesses among employees who are covered by a companies fringe benefits since these benefits, which are not prescribed by law, may be more limited in amount and duration than workers' compenstion (occasionally they may be more generous). Many workers are not covered by fringe benefits, particularly workers who are newly hired, employed by small firms, or who have pre-existing conditions. There is, of course, no cost indemnity or medical cost consideration in the case of disabled workers who apply for employment to a firm. In consequence, the incentive to provide disability services to disabled job applicants, as well as to employees not covered by fringe benefits, is limited. This bias against disabled job applicants is particularly important in an economy in which changing technology is constantly destroying some types of jobs and creating other, in which firms are subject to going out of business, and in which mobility is often the swiftest way to job advancement.

2) Training. If workers are separated from the labor force, employers must incur the expense of recruiting and training workers to replace these disabled workers.

3) Worker Capabilities. Employers are becoming increasingly aware that many disabled workers can become outstanding employees. Numerous reports have indicated that absenteeism and turnover are no greater among handicapped than among non-handicapped workers, and frequently are less. In industries, such as the fast food industry, these can be important economic considerations that can result in substantial cost savings. This can be a major incentive to hire disabled workers who apply for jobs.

4) Employer Knowledge. Employers are becoming increasingly aware that permanent disability need not lead to job separation if counseling, services, and other support services are provided as soon as possible after the onset of, or the worsening of, a physical or mental condition. Employers

are beginning to recognize that to delay rehabilitation is to jeopardize rehabilitation. In consequence, it may become cost-effective to place more resources in assisting the employee to maintain his or her employment, than in attempting to settle a claim.

5) The Corporate Culture Factor. The attitudes of business establishments toward employees is changing. The "Corporate Culture" being adopted by more and more progressive employers indicates a growing concern for, and commitment to, one's employees. Kiefhaber and Goldbeck (1983) note "...it has become possible to humanize issues that were previously viewed only in economic terms." The importance of this shift in orientation cannot be overstated. Jane Belau, Vice President of Control Data Corporation states "I think the corporate culture in any company is probably the one single factor that contributes most to the success of the employment of an individual with a disability..." Peters and Waterman (1982) reported "We were astounded, as we did our research, by the sheer number of people programs we encountered and the frequency with which they are replenished...these programs are neither lip service nor gimmickery - many of the best companies really do view themselves as an extended family."

EXAMPLES OF DISABILITY MANAGEMENT AND REHABILITATION PROGRAMS

It is obviously imposible to do more than highlight a few of the programs that private firms have established to prevent accidents and diseases, promote health, and assist workers to retain employment after the onset of disability. More elaborate analyses of these programs can be found in the works of Galvin (1985), Hood and Downs (1985), and Davidson (1985). The following examples were summarized from Galvin (1985).

A number of companies have established close contacts with state vocational rehabilitation agencies. The New York Office of vocational rehabilitation assigns a vocational rehabilitation counselor half time to the Eastman Kodak plant in Rochester. One advantage of this relationship is that it is much easier to work with a client's existing employer than to find new employment elsewhere. In addition, services can be provided before employees become unable to work.

The Herman Miller Corporation, a furniture manufacturing firm, uses a Transitional Work Center to ease injured workers back into their old jobs or an appropriately modified job. Injured employees may be referred to the Michigan Rehabilitation Service for services if necessary.

The Burlington Northern Railroad developed a Medical Management Team consisting of a physician, a rehabilitation counselor, appropriate insurance claims representatives, and

the immediate supervisor. All employees who are injured and off work for more than 30 days are referred to the Medical Management Team. Through the efforts of this Medical Management Team, the number of employees unable to return to work was cut in half and the number of lost work-days was reduced by almost 3000 days.

The Control Data Corporation has a policy of guaranteeing absolute return to work to every disabled employee. The company maintains a home based operation which permits severely disabled employees to learn computer programming and work in their homes.

The 3M Corporation was one of the first American firms to adopt a comprehensive approach to disability management. The company has appointed disability program coordinators who serve all facilities in a given geographic area.

The John Deere and Company program was established through a labor-management agreement. The company provides education on health management, physical restoration, and work therapy. A nurse coordinator facilitates and monitors the worker's progress. Any Deere employee may participate in this program, regardless of whether the injury/illness is work related or not.

We should also observe that some workers' compensation carriers have been providing disability management services to their clients for many years, particularly in the area of prevention. Progressive workers' compensation carriers originated the rehabilitation nurse program which was characterized by early intervention after a disabling injury. Often the rehabilitation nurse would begin talking to the injured or ill worker about a return to employment within a day or two of the injury. The rehabilitation nurse was sometimes in a good position to coordinate income support, medical care, and vocational, family, and other services to the injured or ill worker since most of these services were provided by the workers' compensation carrier.

PROBLEMS

There are many obstacles to the continued development of disability management programs. Among these obstacles are the following:

1. Small firms. Most documented and successful disability management programs have been implemented by large corporations. This is hardly surprising considering the relatively infrequent risk of serious injuries or illnesses encountered by many small firms and the amount of professional expertise needed to implement a successful disability management program. In general, small firms would not find it

economic to mount their own programs unless they were subject to an unusual number of disabling conditions. This barrier to the development of disability programs takes on special importance in view of the fact that the majority of U.S. employees work in small firms.

2. Role of state vocational rehabilitation agencies. To date, the state-federal vocational rehabilitation program has played a minor role in the activities of employer disability management programs. In fact, many such employers express reservations as to the helpfullness of the state vocational rehabilitation agency. Frequently one hears charges that state agency personnel all too often devise expensive, long-term service efforts which frequently do not result in reemployment for the injured worker.

Another problem in utilizing state vocational rehabilitation agencies is that many disability management programs provide services before a disabling condition has progressed to the point of causing job loss. It is unlikely that vocational rehabilitation agencies would regard many of the persons receiving early intervention services as eligible for vocational rehabilitation services.

The resources and expertise of the state vocational rehabilitation agencies may be crucial to the successful implementation of many disability management programs, particularly in the case of small firms which cannot afford to purchase this type of expertise.

The trend toward enactment of strong equal opportunity employment provisions for disabled workers by states may provide a basis for increased state rehabilitation agency activity in disability management. Virginia, for example, enacted a comprehensive state law guaranteeing equal employment opportunity for disabled citizens whcih is resulting in a more active role for the state rehabilitation agency providing consultation to employers on worksite modification and job accommodation.

3. Employer attitudes. A number of attitudes on the part of employers may contribute to their reluctance to establish disability management programs.

a. Some employers may have little understanding of the effectiveness of these programs, what they consist of, or the expertise required to establish them (Davidson, 1985).

b. Employers with low numbers of accidents may feel that it is not worth the trouble. In the case of small employers, a serious industrial accident may be a rare event.

c. Employers, who for years have expected workers' compensation to provide needed disability protection, may not be inclined to institute programs that involve redesigning jobs, making job accommodations, providing new production equipment, and hiring disability management and rehabilitation personnel.

d. In some cases, firms may be reluctant to intervene in matters considered personal and hence they may be reluctant to establish programs to deal with drug abuse, stress, and other problems (Davidson, 1985).

e. Many employers still are dubious about the capabilities of severely handicapped workers to satisfactorily perform on a job. In consequence, they may not be convinced that the benefits are worth the amount that would need to be invested to instituted disability management programs.

In a 1984 survey of key experts in the area of providing vocational services to disabled adults, 63 percent reported that employer perceptions and attitudes were significant barriers to employment for disabled Americans (Kiernan, 1985).

4. Lack of Information. Part of the reason for adverse employer attitudes is a serious deficiency of meaningful information with which to demonstrate to employers the financial and humanitarian benefits of instituting disability management and rehabilitation programs. Although a number of case studies have been prepared, some of which report a substantial beneft-cost ratio arising out of employer disability management programs, it would be unwise to generalize from these cases to all firms.

Also, employers and insurers do not collect information on worker disability in a uniform manner. In some cases, proprietory concerns have been an obstacle to collection of data and analysis of personnel records on disability claims and return to work experiences.

There is a significant need for analysis of the early stages in the development of disability among workers and associated dependency behavior.

5. Financial Disincentives. Despite the economic advantages of establishing disability management programs that have been noted, there remain many powerful financial disincentives for firms to provide these services to injured and ill workers. These disincentives apply primarily to the provision of vocational services and the re-employment of injured or ill workers, and not to prevention strategies that firms may employ to prevent accidents or illnesses or to programs to manage stress, avert substance abuse problems, or

in some way prevent disability from becoming more serious.

Although we have indicated that the strongest financial incentives to develop disability management programs may arise out the the requirement to pay workers' compensation benefits, the operating procedures of the workers' compensation program also give rise to major financial disincentives to establishing disability management programs.

Worker's compensation is a state-mandated program that requires employers to provide prescribed benefits to workers who suffer a job related injury or illness. In general, employers must pay all medical expenses, pay indemnity benefits which are sometimes based on an assumed wage loss, and sometimes based on the degree of disability, and provide rehabilitation services if indicated and desired by workers. Employers may cover their workers' compensation obligations in several ways. In most states, they may either self insure or purchase insurance from a private carrier. In some states, they may either self-insure or purchase coverage from either a state fund or a private carrier. And in a few states, the options are limited to self-insurance or coverage only by the state fund. Firms that are self-insured are usually large firms that can meet state financial requirements and that can predict, with reasonable accuracy, the number and costs of workers' compensation claims.

Most firms that have established disability management programs are large firms. This is usually thought to be a consequence of the ability of large firms to spread the fixed costs of disability management programs over large numbers of workers.

Another reason why large firms are more likely to establish disability management programs is that the financial incentives to do so are much stronger. If they are self-insured for workers' compensation, then they must directly pay all workers' compensation benefts. Firms that are insured through private carriers or State funds, in contrast, have transferred their workers' compensation to third parties. Of course, many firms are experience rated so that above average workers' compensation costs will be reflected in higher insurance premiums. However, in most cases, the increase in premium does not fully reflect the above average cost of workers' compensation claims. Moreover, about 85 percent of American firms are not experience rated (Worral and Butler, 1985) and would not receive a reduction in their workers' compensation premium even if they established a successful disability management program.

Sometimes the fringe benefits offered by firms in the case of disability, particularly large firms, are more generous than

workers' compensation benefits and, in effect, these fringe benefits supplement workers' compensation benefits providing additional financial incentives for large firms to establish disability management programs.

How do the operating procedures of most workers' compensation programs create strong disincentives for employers to establish disability management programs, particularly re-employment and vocational rehabilitation programs, and strong disincentives for employees to accept these services? Workers' compensation originated as a no-fault system in which workers with a job-related injury or illness would receive limited, but assured benefits. The trade-off for accepting limited benefits was that workers would be entitled to these benefits regardless of how the injury was caused, e.g., by the worker's carelessness, or a co-worker's carelessness, or the employer's negligence.

If workers' compensation had worked as envisioned, one would expect little litigation, prompt and adequate benefits, and no financial disincentive to return to work since the indemnity benefit would be a prompt lump sum payment in the case of permanent disability. Although the workers' compensation program has probably met these expectations in the case of temporary disability claims reasonably well, it has not worked as intended in the case of most permanent disability cases, largely because of the problem that bedevils most systems that pay disability benefits, that of determining the extent of disability. About one-third of the permanent disability cases in workers' compensation are settled by use of a schedule which establishes a predetermined indemnity benefit for a specific type of injury - e.g., loss of an eye, loss of a hand, etc. In these cases, the workers' compensation system often does work as intended. However, in about two-thirds of the permanent disability cases, the injury cannot be related to a schedule. It is these "nonscheduled" cases that create disincentives for employers to establish disability management programs. In these cases, the claimant has an incentive to maximize the extent of the disability in order to maximize the size of his or her disability award, and the employer or carrier has the opposite incentive. Given this fundamental conflict, it should come as no surprise that the workers' compensation system is characterized by extensive litigation among permanent disability cases. It has been estimated that two-thirds of the permanent disability cases involve a controversy between the employee and the carrier/employer, and that about three-fifths of these cases are litigated over the amount of the award (Conley and Noble, 1979).

Resolution of these litigated cases may be prolonged, during which time the employee is gathering evidence to prove the maximum level of disability and inability to work and often

has little interest in work or rehabilitation. Although about three-fourths of the states require that workers' compensation claimants accept vocational rehabilitation services, the enforcement of this requirment is weak. Even if workers are compelled to accept vocational rehabilitation services, they can accept them in such a way as to render them largely ineffectual (Worrall and Butler, 1985).

In effect, not only may employers see little financial benefits in terms of workers' compensation costs to establishing disability management programs, they may also be confronted by recalcitrant disabled employees who may be further angered if benefits are delayed because of litigation. This climate is hardly conducive to establishing disability management programs.

Although disability managment programs are sometimes justified because of the high costs of lifetime support of disabled workers, about one-half of permanent disability cases in workers' compensation are settled by a formal compromise agreement (Conley and Noble, 1979). In principle, these formal compromise agreements should occur only if a fundamental disagreement exists between a carrier and a claimant about eligibility for benefits or their amount. In general, these agreements have the effect of ending any future liability on the part of the carrier or the employer for the workers' compensation claim. It also eliminates financial incentives on the part of the employer to provide disability services. It has been alleged that workers' compensation carriers will sometimes litigate in order to be able to settle by a formal compromise agreement in order to set limits to their liability for a case rather than leave it open.

If persons with permanent disability do not return to work promptly, and the case is litigated causing a suspension of benefit payments, there there will usually be enormous financial pressure on the worker to settle the case.

How do fringe benefits for workers who incur non-job related injuries or illnesses affect the financial incentives to establish disability managment programs. For the most part, the same factors are relevant here as are relevant in the case of workers' compensation. Is the employer self-insured? Are indemnity benefits paid in a lump sum or are they paid as income support for the period of disability? In addition, fringe benefit levels vary among firms ranging from lifetime income and medical protection to no benefits. Obviously, the more generous the benefits, the greater the financial incentive to establish disability management programs.

Most companies that replace income lost because of disability do so by supplementing, whenever possible, social

security payments for disability (Schwartz, 1980). In consequence,, firms paying disability benefits have a strong incentive to help those beneficiaries become entitled to social security benefits. In fact, Galvin (1985) reports that "...risk management consultants routinely advise their employer-clients to engage in 'cost shifting' by requiring that all employees receiving long term disability are to apply for SSDI benefits and are to routinely file for reconsideration if the application is initially denied." In addition, "...employers are advised to provide legal and medical council to their LTD-employees to bolster their case..." This creates strong disincentives to provide rehabilitation services.

What about disabled applicants who apply for jobs? One long-standing fear is that if the worker suffers another work-related injury or illness, the combination of the pre-existing condition and the new condition may create a disability far more severe than would the additional injury by itself. In order to fully compensate workers and not unfairly cause liability for employers, states have enacted second injury funds. In principle, employers are only held liable for the amount of damages that would have occurred had the work-related injury or illness been the only condition. Any additional award paid to the worker should be charged to the second injury fund.

Unfortunately, most second injury funds appear to be ineffectual, largely because of restrictions on the types of conditions for which claims can be made. During 1976, fewer than 10 claims were paid from the second injury funds by most states that bothered to collect this information (Conley and Noble, 1979).

The willingness of employers to employ disabled job applicants may be strongly influenced by existing fringe benefits. If the disabled applicant is perceived as one who would make extensive use of benefits such as sick leave and medical care, or whose condition would lead to an early disability retirement, and if the person would be eligible for these fringe benefits if hired, then the employer would have a strong financial disincentive to employ the applicant. And some severely disabled workers will certainly fall into a high usage category.

In the 1985 survey cited above (Kiernan, 1985), the most frequently reported barrier to employment for disabled persons were economic and benefit disincentives. Seventy-five percent of the respondents regarded these disincentives as a major barrier to employment.

Of course, this disincentive to hire can be avoided if employees with pre-existing conditions are excluded from

company-paid fringe benefits. Many employers do, in fact, exclude workers with pre-existing conditions from company-paid benefits which, while it may resolve the bias against hiring, creates major problems for the worker (including a disincentive to return to work if currently receiving Medicaid or Medicare) and diminishes the financial interest of the company in providing disability management sxervices.

6. Lack of rehabilitation services. Levitan and Taggart state, "The key to continued labor force participation is the ability to remain in the same job after the onset of the disability condition." The evidence suggests that once the attachment to the labor force is broken, and the individual settles into the income transfer system, complications arise which act as powerful barriers to the return to the individual to the labor force. Although almost every state requires that workers' compensation benefits include vocational rehabilitation benefits (Worrall and Butler, 1985), a recent report of the International Association of Accident Boards and Commissions (1984) states:

"In general, workmens' compensation is not doing an effective job of assuring that workers with work-related disabilities are helped to recover lost abilities and to return to their previous jobs, or where this is impossible, to learn substitute skills." There would generally be even fewer rehabilitation services available to workers whose disabilities are not work related.

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