Balancing Security and Opportunity:

The Challenge of Disability Income Policy

Report of the Disability Policy Panel

NATIONAL
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INSURANCE

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Jerry L. Mashaw
and
Virginia P. Reno
Editors

Report of the Disability Policy Panel
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Preface

Disability policy covers a broad and diverse set of objectives, serves a highly heterogenous population, and often is politically controversial. It is no surprise, therefore, that America's programs for persons with disabilities are multiple, complex, and in a constant state of flux.

In this context the Disability Policy Panel's first job was simply to understand the structure and dynamics of existing programs, the size and attributes of the population with disabilities, the history that has brought us to today's juncture in disability income policy, and the rapid changes in the broader social and economic environment that influence opportunities and constraints faced by workers with disabilities in contemporary society. The Panel's interim report presented our review of this broader environment after our first year of work. That report, *The Environment of Disability Income Policy: Programs, People, History and Context,* is being reissued as a companion to the final report. Only after gaining this common understanding of the environment could the Panel begin to propose, evaluate and, finally, recommend changes that might prove to be useful, responsible and realistic.

Responding to the challenge of the task that was put before it, this has been an extremely hard-working Panel. Its diverse group of experts has met a total of 31 days between March 1993 and January 1996. Subcommittees of the Panel have held additional meetings and have engaged in countless conference calls. We have commissioned several special studies, convened focus groups with beneficiaries and participated in a number of public fora for the discussion of disability policy issues. Our work on issues in childhood disability, led by our Committee on Childhood Disability, is contained in a companion report, *Restructuring the SSI Disability Program for Children and Adolescents.*

Our Panel has been assisted by the cooperation of various components of the Social Security Administration, the Department of Health and Human Services, the Department of the Treasury, the General Accounting Office, the Rehabilitation Services Administration and the National Institute on Disability and Rehabilitation Research, among others. This sustained effort has been structured, facilitated and informed by the extraordinary work of a talented staff at the National Academy of Social Insurance under the superb direction of Virginia Reno.

United in the view that disability policy's overarching purpose is the integration of persons with disabilities into the social, economic and political life of the nation, Panel members have not always all agreed completely on which policies, or mixes of policies, best promote that purpose. Nevertheless, this report represents a strong consensus among a Panel of scholars, administrators, analysts, practitioners and advocates who began with very different initial perspectives, but who have now had the common experience of studying and reasoning together over many months.

Because of the breadth of the Panel's expertise and the care and deliberation that has gone into its work, I feel confident that this report will serve two purposes. First, it provides a framework for understanding the nature of work disability and for drawing meaningful distinctions to clarify the purpose of various interventions — such as health care, rehabilitation, training and accommodations — that might prevent or remedy work disability, and the purposes of cash benefits to alleviate its economic consequences for workers and their families when earnings have been lost. Second, the report recommends reforms that should improve work outcomes for persons with disabilities while maintaining basic income security for those who cannot work. In the final analysis, the success of American disability income policy will be judged by the balance it maintains between these two goals.

It has been a great pleasure for me to serve as chair of this remarkable and dedicated group.

Jerry L. Mashaw, Chair
Disability Policy Panel
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Executive Summary

In response to a request from the Chairman of the Committee on Ways and Means of the U.S. House of Representatives and the Chairman of its Subcommittee on Social Security, the National Academy of Social Insurance in March 1993 convened a Disability Policy Panel of national experts to conduct a comprehensive review of the nation's Social Security disability benefit programs. The Academy secured funding for the Panel's work from The Pew Charitable Trusts, The Robert Wood Johnson Foundation and corporate members of the Health Insurance Association of America that offer long-term disability insurance.

The Panel was charged with determining whether the design of the programs strongly encouraged Americans with disabilities to emphasize their impairments as a means to securing and maintaining disability benefits; what changes could be made to encourage persons with disabilities to use their residual work capacity; and how rehabilitation could be incorporated into the benefit programs without greatly expanding costs or weakening the right to benefits for those who cannot work.

The Panel's findings and recommendations derive from its fundamental belief that the primary goal of national disability policy should be the integration of people with disabilities into American society.

The Nature and Scope of Work Disability

The Panel drew clear distinctions between *impairments,* such as heart disease, spinal cord injury, major depression or hearing loss, and *work disability.* Work disability occurs when an impairment reduces functional capacity and, in conjunction with the person's other abilities, the demands of work and the broader environment, makes the person unable to perform the tasks of work.

Disability policies can improve work outcomes by addressing any of the factors that together produce work disability. Potential remedies include: health care to prevent or ameliorate the disabling consequences of an impairment or chronic health condition; vocational rehabilitation, education and training to develop new work skills; job accommodations to change the tasks of work; and environmental changes to reduce other barriers to employment. These potential remedies typically are organized and financed locally, by employers, insurers, and local and state governments.

Income support ameliorates one of the consequences of work disability, loss of income from earnings. Earnings replacement benefits may be paid while remedies are tried or when they are not successful. Social Security disability insurance (DI) and Supplemental Security Income (SSI) are parts of a broader system of earnings replacement benefits for work disability that are financed largely by employers either through insurance they purchase or through self-insurance. These include workers' compensation for workers injured on the job, private short-term sickness and disability benefits, and private long-term disability benefits.

In 1994, DI spending for disabled workers and their families was $37.7 billion. Federally-administered SSI payments for blind or disabled working-age adults were $14.7 billion. Workers' compensation spending in 1993 included $23.5 billion for disability benefits, $2.0 billion for survivor benefits and $17.4 billion for medical care. Private short-term sickness and disability benefits totalled $14.6 billion in 1992; an additional $4.0 billion was paid through state mandatory temporary disability insurance. Private long-term disability insurance benefits were $3.1 billion in 1992.

Those who receive Social Security or SSI disability benefits are a subset of a much larger population who have any sort of impairment or work disability. Many in that larger population do work. About half the 30 million working-age persons with various kinds of functional limitations are employed. Further, about half the 34 million working-age adults who experience a spell of mental illness over the course of a year are employed. Indeed, about one-third of the 16.8 million persons with work disabilities are in the labor force, that is, either working or looking for work.

A smaller group, about 7.1 million working-age adults, were receiving Social Security or SSI benefits based on disability at the end of 1994. They include 4.0 million receiving DI disabled-worker benefits, nearly 0.8 million who receive Social Security as disabled widows or disabled adult children of insured workers who have died, retired or themselves become disabled, and nearly 2.4 million who receive only SSI benefits. The beneficiary population includes those with the most significant work disabilities.

The Relationships Between Disability Benefits and Work Incentives

The Panel reviewed the purposes of DI and SSI in light of its charge to determine whether disability benefit programs strongly encourage Americans with disabilities to emphasize their impairments as a means to secure benefits. It also reviewed the adequacy of the benefits, eligibility criteria and work incentive provisions.

The Panel's basic finding is that the Social Security and SSI disability benefit programs do not pose strong incentives for Americans with disabilities to seek benefits in lieu of working. Rather, the strict and frugal design of these programs makes remaining at work preferable to benefits for those who are able to work.

The purpose of DI is to protect workers against severe financial hardship when their ability to earn a living is interrupted by disabling illness or injury. As in any insurance program, applicants for benefits must show that the insured event has occurred before benefits are paid. DI uses a very strict test of work disability — inability to engage in any substantial gainful activity because of a medically determinable impairment expected to last 12 months or result in death. DI benefits are modest in relation to the worker's prior earnings. At most earnings levels, benefits amount to less than one-half of prior earnings. The average monthly benefit for disabled workers was $682 in December 1995.

The purpose of the needs-based SSI program is to provide a basic minimum income below which no American should have to live if he or she is elderly or has a severe work disability. The SSI federal benefit rate is modest — $470 per month for an individual in 1996 — and amounts to about 70 percent of the poverty threshold. The program uses the same strict test of disability used in the DI program.

Focus group discussions with DI and SSI beneficiaries revealed that they had left their jobs with great reluctance. They typically had remained on the job after the onset of their conditions and turned to disability benefits as a last resort when they could no longer function at work. Many were older workers. By the time they received benefits they had experienced the loss of their health, their livelihood and their hopes for ending their work lives with a comfortable retirement.

The strict and frugal design of the DI and SSI benefit programs is evident in cross-national comparisons. Compared with disability pension systems of other industrialized countries, U.S. public spending is relatively low. Social Security and SSI disability benefits combined amounted to 0.7 percent of gross domestic product in 1991. This is less than half the share spent on disability pensions by the United Kingdom (1.9 percent), or Germany (2.0 percent), a country that is often held up as a model for emphasizing work by requiring rehabilitation before pensions and that provides quotas, tax penalties and subsidies to encourage employers to hire persons with disabilities. Sweden, a mature welfare state that promotes public employment as a last resort for workers with disabilities, spends 3.3 percent of gross domestic product for long-term disability benefits. Other industrialized countries generally have universal systems of short-term disability benefits, while the United States does not, although many employers offer some type of short-term disability benefits. If public and private short-term benefits were included, the disparity in national spending for disability benefits would undoubtedly be larger.

Financing Rehabilitation for Social Security Beneficiaries Needs a Radical New Approach

The Panel proposes a radical new approach to paying for vocational rehabilitation and return-to-work services for Social Security disability beneficiaries. The plan would enlist private sector providers in helping beneficiaries return to work without greatly expanding costs or weakening the right to benefits for those who cannot work.

The Panel's return to work proposal builds on the principles of consumer choice and empowerment, encouraging competition and innovation among service providers, rewarding service providers for their results rather than for the cost of their inputs, and encouraging providers to have a continuing interest in their clients' long-term success in remaining employed.

Under the Panel's plan, disability beneficiaries would receive a return to work ticket, akin to a voucher, that they could use to shop among providers of rehabilitation or return-to-work services in either the public or private sector. Once a beneficiary deposits the ticket with a provider, the Social Security Administration would have an obligation to pay the provider after the beneficiary returned to work and left the benefit rolls. Providers whose clients successfully returned to work would, each year, receive in payment a fraction of the benefit savings that accrued to the Social Security trust funds because the former beneficiary is at work and not receiving benefits.

The Panel's plan differs from the traditional approach of relying on state vocational rehabilitation agencies to serve Social Security beneficiaries. It would expand the range of service providers who can be paid to assist beneficiaries to include both the private sector and public agencies, including vocational rehabilitation, mental health and developmental disability agencies.

A New Disabled Worker Tax Credit Is Designed to Encourage Work

As a way to encourage persons with disabilities to emphasize their residual work capacity, the Panel recommends a disabled worker tax credit (DWTC). The DWTC would provide a refundable federal income tax credit to workers with disabilities that rises as their work effort rises. It would gradually phase out at income levels above the poverty threshold. The credit would be paid to persons not because they are unable to work, but because they work, albeit at low wages, despite their impairments. As such, it rewards work for low earners with disabilities without increasing reliance on Social Security or SSI disability benefits that are designed primarily for persons who are unable to work.

The Panel recognizes that disability is a continuum and that Social Security and SSI beneficiaries are those who have the most significant work disabilities. A DWTC would encourage work for persons who have some residual capacity to do so. Eligibility could be based on disability findings by the Social Security Administration and state vocational rehabilitation agencies. Those eligible for the DWTC would include: DI and SSI disability beneficiaries; certain applicants denied DI or SSI benefits; and persons certified by vocational rehabilitation agencies to have impairments that are significant impediments to employment.

The DWTC is to designed to encourage work among low-income persons with impairments by:

- Encouraging older workers to remain at work even though their hours of work or wage rates decline due to progressive impairments. By subsidizing low wages, it encourages older workers to delay the point at which they turn to cash benefits.

- Easing the transition from school to work for young people with developmental disabilities whose earnings capacity is doubly limited by their youth and their impairments. By subsidizing their earnings, it encourages work even part-time or at low pay that over the long run can improve young workers' human capital through on-the-job experience.

- Easing the transition off the DI and SSI benefit rolls for beneficiaries who return to work. It would compensate for part of the loss of benefits that occurs when beneficiaries work.

The Panel believes that the DWTC is superior to other approaches that seek to encourage work by expanding eligibility for DI or SSI benefits. Proposals to pay partial disability benefits or to use a less strict test of work disability for Social Security would significantly increase benefit costs. A separate wage subsidy through the DWTC is a more targeted way to support and encourage low-income persons to work despite their impairments.

Lack of Access to Health Care Limits Employment Options

While neither DI nor SSI cash benefits pose strong incentives for Americans to seek these benefits in lieu of working, constraints on access to health care and related services can.

Many people with chronic health conditions or disabilities are at risk of very high health care costs. They often cannot gain coverage in the private insurance market, and even when they do have private coverage, it often does not cover the range of services and long-term supports that they need.

Current gaps in health care coverage for people with disabilities limit their labor market options in several ways. First, employers, despite the non-discrimination features of the Americans with Disabilities Act of 1990, may be reluctant to hire persons who are at risk of high health care costs if they would be covered under the employer's plan. Second, if persons with disabilities cannot obtain private insurance, work may not be an economically feasible option. Fear of losing Medicaid or Medicare coverage is often cited as a reason why some persons with disabilities work less than they would if secure health care coverage were available. Third, gaps in health care coverage can result in unnecessary losses in employment when uninsured people fail to get the care they need in order to treat, cure or ameliorate the disabling consequences of their conditions.

The Panel's interim report, *The Environment of Disability Income Policy: Programs, People, History and Context,* first issued in March 1994, emphasized that comprehensive health care coverage would be a major step forward for Americans with disabilities. Today universal health care is a more elusive goal than it appeared to be when those interim findings were issued. The Panel has three specific proposals that derive from its charge to improve incentives to return to work for persons who may now rely on cash benefit programs for support.

Improved Medicare Buy-In. The Panel recommends an improved Medicare buy-in for DI beneficiaries who return to work despite the continuation of their impairments.

Medicare coverage begins for DI beneficiaries 24 months after they enter the Social Security benefit rolls. If they return to work and leave the benefit rolls despite the continuation of their impairments, Medicare coverage continues for about four years. Then former DI beneficiaries have the option to purchase continued Medicare coverage. The coverage is expensive to purchase, the eligibility rules are extremely complex and few beneficiaries seem to know about it. By scaling Medicare premiums to the former beneficiary's earnings, the Panel's improved Medicare buy-in is more affordable, predictable and understandable for DI beneficiaries when they are contemplating a work attempt.

Medicaid Coverage. The Panel endorses the efforts of states to create affordable buy-ins to their Medicaid programs for persons with disabilities.

In most states, continued Medicaid coverage is available to former SSI recipients under the Section 1619 provisions of the Social Security Act. The provisions extend Medicaid to persons whose SSI benefits are totally offset because of their earnings, but who continue to have a disabling impairment. The Panel recommends that states, in revising their Medicaid programs, allocate both acute care coverage and on-going support services in ways that promote work and independence while maintaining coverage for vulnerable populations who rely on SSI benefits.

Personal Assistance Tax Credit. The Panel recommends a personal assistance tax credit to compensate working people with disabilities for part of the cost of personal assistance services they need in order to work.

Some persons with significant physical impairments require personal assistance services in order to live independently and, with those services, are able to work in the competitive labor market. Personal assistance services, however, can be very costly. They are financed by public programs in some states, but generally only for low-income persons. As such, those who need personal assistance face a dilemma when they go to work. If they work successfully, their income may disqualify them from receiving publicly-financed services, yet they may not earn enough to pay for the services on their own. The Panel is recommending a nonrefundable tax credit under the federal income tax to compensate working people for part of the cost of personal assistance services they need and pay for in order to work.

Existing Work Incentives Need to Be Implemented Effectively

The Panel believes that the most important way to improve work incentives in the Social Security and SSI disability benefit programs is to implement them effectively. Such improvements would involve service providers who assist beneficiaries and the Social Security Administration.

After in-depth analysis of existing work incentive provisions and extensive field research on how they are being implemented, the Panel concluded that:

- Work incentive provisions are inherently complex. Efforts to simplify them by redesigning them are not promising. Therefore, beneficiaries need assistance to understand and comply with the provisions when they work.
- Some kinds of assistance can offered by service providers who assist beneficiaries to return to work — such as those who accept the return-to-work tickets the Panel is recommending. Service providers need to recognize that part of their job is to understand the program rules and help their clients comply with them.
- Some tasks necessary to make work incentives work can only be performed by the Social Security Administration. They include prompt action on earnings reports from beneficiaries so that benefits can be adjusted as beneficiaries' circumstances change. Delays cause beneficiaries to be charged with overpayments or to be underpaid.

Both undermine a smooth transition to work. Actions to implement work incentives now have low priority. If return to work is to be a priority, Social Security Administration personnel and systems support for these functions are essential.

The Panel is proposing particular changes to make Social Security and SSI disability benefit provisions more "work friendly." They include: updating and indexing the level of earnings that is considered to be substantial gainful activity for the purpose of determining initial and continuing eligibility for benefits; and an unlimited extended period of eligibility to provide a safety net for former DI beneficiaries to return to the rolls if their work attempt fails. In addition, the Panel majority recommends: revising the deduction of impairment-related work expenses to strengthen the financial gain from working for SSI recipients who incur significant impairment-related expenses, such as job coaches or supported employment services; changing the treatment of scholarship income for SSI recipients to enable college students to remain eligible for Medicaid and publicly-financed personal assistance services in states that use SSI Section 1619 eligibility criteria for those services; and a Social Security/SSI transition proposal, that would allow resource-eligible DI beneficiaries who work to qualify for Medicaid or other support services in those states that use SSI Section 1619 eligibility criteria for those services.

Understanding Recent Program Growth

After a period of stability in the last half of the 1980s, the DI and SSI programs grew rapidly in the early 1990s. The rapid rate of growth in new benefit awards appears to have been a temporary phenomenon tied to the economic recession of 1990-91. The DI incidence rate (new benefit awards as a percent of the eligible population) declined and flattened out after 1992. The benefit rolls continue to grow, however, because fewer people are leaving than are entering. Death and shifting to retirement benefits at age 65 are the main reasons why people leave the DI rolls. The proportion who medically recover or return to work has always been small, but is at an all-time low.

Trends in the broader environment have contributed to the growth in the rolls. They include:

- The eligible population is larger. The working-age population is growing and the baby boom is entering the 35-to-50 age range where the risk of work disability rises. In addition, more women have enough work experience to be insured for benefits. Consequently, when they become severely disabled, they qualify for DI benefits.
- The eligible population is younger. While the baby boom makes a bulge in the disability rolls in the 35-to-50 age range, the birth dearth during the Great Depression 60 years ago means relatively fewer disability beneficiaries are entering their 60s. Consequently, fewer people are leaving the DI rolls because of retirement. Although the DI population is younger, their death rate remains high. The proportion who have life-threatening conditions has not declined.
- The economic recession of 1990-91 caused a rapid, but temporary, increase in benefit applications and awards. When jobs are scarce and firms are downsizing, workers with disabilities who lose their jobs, particularly at older ages, have few prospects for regaining employment or shifting to new careers.
- Cutbacks in state general assistance programs and active referral of former recipients to the SSI program contributed to growth in applications. While most did not meet the strict test of disability, some did.
- Increased recognition and diagnosis of disabling conditions may be a factor. Depression, a common form of disabling mental illness, has increasingly been recognized and diagnosed following a public information campaign by the National Institute of Mental Health to improve its diagnosis and treatment.
- Structural changes in the labor market affect the kinds of impairments that result in work disabil-

ity. The value placed on intellect, advanced education and adaptability mean fewer employment prospects for people with the double disadvantages of impairments combined with limited education and skills. Further, individuals whose social and adaptive functioning is impaired by mental disorders are particularly disadvantaged in a highly competitive job market.

Explicit changes in Social Security policy also contributed to growth in applications and awards. New medical and functional criteria to decide claims based on mental impairments were required by Congress in 1984 after retrenchment policies adopted in the early 1980s were challenged in the courts and lost public support. In addition, outreach to enroll eligible persons in the SSI program became a priority in 1989 when Congress earmarked funds for those efforts.

What Should Be Done

Many causes of the recent growth in the benefit programs lie in the broader environment. Some were temporary, such as the economic recession. Nonetheless, the Panel recommends specific policies to promote work for those who can, as well as administrative actions to ensure the continued integrity of the benefit determination process.

The Panel's Policy Proposals Promote Work. All of the Panel's recommendations are designed to promote work and reduce reliance on cash benefit programs, both by facilitating return to work for beneficiaries and by offering alternative supports to low-income workers with impairments who do not receive benefits.

Adequate Administrative Resources Are Essential. Based on its review of the last 25 years of DI policy, the Panel concludes that attempts to administer a complex and expensive benefit program without adequate administrative resources ill serves both beneficiaries and the public fisc. In relation to the importance and size of the DI program, investment in administrative resources is very small, at 2.7 percent of DI program outgo in 1994.

Administrative resources including technology must be set at a level that ensures stable, effective management of the disability programs. Resources must be adequate to provide: (1) fair, accurate and prompt decisions on disability claims, (2) individualized service to beneficiaries that is contemplated under the law, including accurate information and prompt action to implement benefit adjustments when beneficiaries work, and (3) timely and predictable review of the continuing disability of those on the rolls.

Medical and Vocational Criteria Should Be Kept Up-to-Date. The Panel believes that renewed emphasis should be placed on periodic updates of the medical and vocational criteria for assessing work disability. Updates are needed to ensure that past experience, new research and state-of-the-art knowledge are systematically incorporated into the programs' assessment of work disability. Categories of impairments that account for a significant portion of the disability rolls, or where rapid growth has prompted concern, are good candidates for expert review. They include the criteria for evaluating mental impairments and for assessing the role of pain in the disability determination.

Overview

In the summer of 1991, the Chairman of the Committee on Ways and Means of the U.S. House of Representatives and the Chairman of its Subcommittee on Social Security asked the National Academy of Social Insurance to undertake a comprehensive review of the Social Security disability benefit programs. In particular, the Academy was asked to explore the following questions:

- Is it correct that Americans with disabilities now confront strong incentives to emphasize their impairments as a means to securing and maintaining disability benefits?
- Can an emphasis on rehabilitation and work be incorporated into the program without greatly expanding costs or weakening the right to benefits for those who cannot work?
- Are there changes that would encourage beneficiaries to use their residual work capacity rather than emphasize their incapacity?
- How might we increase protection for the large numbers of claimants who are denied benefits but who still do not find employment?

The Academy was also encouraged to review other relevant issues and to take into account experience in the private sector and in foreign disability income systems.

To fulfill the request, the Academy secured private funding for the study from The Pew Charitable Trusts, The Robert Wood Johnson Foundation and corporate members of the Health Insurance Association of America that offer long-term disability insurance. In March 1993, the Academy convened a Disability Policy Panel drawn from the nation's leading experts to conduct the review. The Panel issued its interim report in March 1994. That report, *The Environment of Disability Income Policy: Programs, People, History and Context,* is being reissued as a companion to the final report. Because of the congressional timetable for considering legislative changes in the Supplemental Security Income (SSI) childhood disability program, the Committee on Childhood Disability of the Panel issued a report, *Restructuring the SSI Disability Program for Children and Adolescents*, in May 1995 which is also being reissued.[1] This overview of the Panel's full report presents the Panel's perspective on disability income policy and work, it responds directly to the questions posed to the Academy, and it highlights the Panel's findings and recommendations.

THE PANEL'S PERSPECTIVE ON DISABILITY POLICY

The Panel believes that the primary purpose of national disability policy should be the integration

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[1] The report of the Committee was not voted on by the full Panel and does not necessarily reflect the views of all Panel members.

of people with disabilities into American society. To that end, we endorse the disability policy goals set forth in the Americans with Disabilities Act of 1990 (ADA): equality of opportunity, full participation, independent living, and economic self-sufficiency. In pursuing these goals, disability policy should provide resources to promote functioning and work for people with disabilities as well as income support for those who cannot work or whose ability to work is very limited. For some individuals with disabilities there is a need for both income and other support to enable them to return to or enter the work force.

In assessing the current state of disability policy and in proposing reforms affecting income and work, the Panel has been guided by the following findings:

First, work in the marketplace is the principal source of income and social stability in all modern societies. While income security programs are essential for those who are severely limited in their ability to work, disability policy should strive wherever possible to maintain and integrate people with disabilities into mainstream employment.

Second, "disability" is not just a characteristic of individuals. Instead, it results from the interaction between individuals who have physical or mental impairments with resulting loss of function and the broader environment; and it is a limitation in performing a social role, such as work.[2] *Work disability* involves the interaction among four elements:

- a person's *chronic health condition or impairment*;
- the *tasks* that constitute work he or she can reasonably be expected to do;
- his or her offsetting *abilities* or compounding limitations in performing those tasks; and
- the physical, social, and economic *environment* in which he or she is expected to live and work.

Disability policies may seek to improve work outcomes for persons with disabilities by addressing any or all of the factors that together produce work disability.

Third, the population of persons with any sort of impairment is large and diverse. Physical and mental impairments are widespread in the population, they are a natural part of the life process, and people with impairments have extremely varied abilities, capacities, needs and limitations. Many people with impairments and/or functional limitations do work. About half of the nearly 30 million working-age persons who have various kinds of functional limitations are employed.[3] Further, about half of the 34 million working-age adults who experience a spell of mental illness over the course of a year are employed.[4] Indeed, one-third of the 16.8 million persons with work disabilities are in the work force, that is, either employed or seeking work.[5] Obviously, a wide range exists in the severity of disabling conditions within the population. Further, there is wide variation in the effects of the same condition on different individuals in different circumstances.

A smaller group, about 7.1 million working-age adults, were receiving Social Security or SSI benefits based on disability at the end of 1994.[6] The beneficiary population includes those with the most significant work disabilities. They include 4.0 million who receive Social Security disabled-worker benefits, nearly 2.4 million who receive only SSI and nearly 0.8 million who receive Social Security as disabled widows or disabled adult children of insured workers who have died, retired or themselves become disabled.

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[2] A.M. Pope and A.R. Tarlov (eds.), *Disability in America: Toward a National Agenda for Prevention* (Washington, DC: National Academy Press, 1991).

[3] U.S. Bureau of the Census, *American with Disabilities: 1991-1992, Data from the Survey of Income and Program Participation* P70-33 (Washington, DC: U.S. Government Printing Office, December 1993).

[4] National Institute of Mental Health, Diagnostic Interview Schedule, Epidemiological Catchment Area Project.

[5] U.S. Bureau of the Census, Current Population Survey, March 1994.

[6] Social Security Administration, *Annual Statistical Supplement to the Social Security Bulletin* (Washington, DC: U.S. Government Printing Office, August 1995), table 3.C6.1, p. 160.

Fourth, disability policy, broadly construed, should match the diversity of the population with remedies that are appropriate for different subsets of the population. Social Security and SSI typically are programs of last resort for persons with significant work disabilities. Many of the most promising remedies for increasing employment among persons with disabilities lie beyond the Social Security disability insurance (DI) and SSI benefit programs. These remedies include: access to health care and related services including wellness and prevention programs; access to appropriate rehabilitation; civil rights protections and employer accommodations; wage subsidies for low-income workers with disabilities; early intervention services, family support, special education and transition-to-work planning for children and adolescents with disabilities; and general education and training for the whole populace.

Fifth, social insurance and social assistance remain critical elements of disability policy. The income security goals of Social Security and SSI are thoroughly consistent with the ADA goals the Panel has endorsed. The benefits they provide offer an essential form of economic self-sufficiency for people who have lost their capacity to earn. Virtually all industrialized countries have some type of social insurance system for this purpose and most provide social assistance for those who do not achieve a basic minimum income from either work or social insurance benefits. The challenge is to design, administer and coordinate support for people with disabilities in ways that protect those unable to work, while both minimizing the disincentives to work inherent in any income security system and avoiding unrealistic expectations about the capacities of people to return to work without other supports.

Social Security and SSI are parts of a broader system of earnings replacement benefits for work disability that are financed largely by employers either through private insurance they purchase or through self-insurance. These include workers' compensation (WC) for workers injured on the job, short-term sickness and disability benefits, and private long-term disability benefits. In 1994, DI spending for disabled-worker benefits was $37.7 billion.[7] SSI payments for blind or disabled working-age adults were $14.7 billion.[8] Private short-term sickness and disability benefits amounted to $14.6 billion in 1992; an additional $4.0 billion was paid through state mandatory disability programs.[9] Workers' compensation spending in 1993 included $23.5 billion for disability benefits, $2.0 billion for survivor benefits and $17.5 billion for medical care.[10] Private long-term disability insurance benefits were $3.1 billion in 1992.[11]

Employer costs for disability can be substantial. One study of the full cost of disability for employers in selected firms estimated costs to be about 8 percent of payroll when all costs are considered, including: direct costs such as DI contributions and other disability benefits; hidden costs associated with lost productivity and the expense of replacement workers; and disability management activities that include claims management, return-to-work programs, wellness and employee assistance plans, on-site clinics and safety programs.[12]

Sixth, it is clear that in addition to the federal role, private and non-profit sectors as well as state and local governments have crucial roles in designing and funding services to help persons with disabilities integrate themselves into society. For example, improving access to health care for working-age adults and children — whether or not they have disabilities — is a challenge that involves all levels of

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[7] Ibid., table 4.A6, p. 179. This figure includes $4.0 billion for benefits for dependent children and spouses of disabled-worker beneficiaries.

[8] Social Security Administration, Office of Research and Statistics. This figure includes $13.0 billion in federal SSI benefits and $1.7 billion in federally-administered state supplementation benefits.

[9] Social Security Administration, op. cit., footnote 6, table 3.A4, p. 153. Benefits for public sector employees are included in the totals for state mandatory disability insurance. They are not included in the total for private short-term sickness and disability benefits.

[10] J. Schmulowitz, "Workers' Compensation: Coverage, Benefits, and Costs, 1992-93," *Social Security Bulletin*, Summer 1995, table 1, p. 52.

[11] Social Security Administration, op. cit., footnote 6, table 3.A4, p. 153.

[12] M. Berkowitz, et al., *Full Costs of Disability Final Report*, September 1991, unpublished report for UNUM Corporation, Portland, ME.

government and the private sector including employers and insurers. Employers typically are the source of financing for short-term sickness benefits that may provide the best avenues for early intervention to prevent long-term disability. Rehabilitation is sometimes financed by workers' compensation systems or by employers or insurers who offer long-term disability insurance. Federal/state vocational rehabilitation agencies provide rehabilitation services to some Social Security beneficiaries, but largely serve persons unconnected to federal disability income programs. Education and training is largely the purview of local and state government, state-financed community colleges and universities. And, training in the use of new technology that usually occurs on the job is financed in large part by employers. Hence, recommendations for improving disability income policies must build on the existing roles of multiple nonfederal sectors.

Disability policy is of the utmost importance to the welfare of the community as a whole. We need the fullest possible participation of all persons in the civic, economic and social life of the country. Particularly in times of constrained resources we need to assure that the supports provided to persons with disabilities are consistent both with the nation's current ability to pay and with wise investment in its long-term social and economic well-being.

In our review of foreign experience, we find that by cross-national standards, U.S. spending on public disability benefits is relatively low. Spending on federal Social Security and SSI disability benefits combined amounted to about 0.7 percent of gross domestic product (GDP) in 1991. This is less than half the share (1.9 percent) spent by the United Kingdom, a country that also has fairly strict disability benefit systems. It is also less than half of the share spent by Germany (2.0 percent of GDP), a country that emphasizes rehabilitation before pensions and provides quotas, tax penalties and subsidies to encourage employers to hire persons with disabilities. Sweden, a mature welfare state that emphasizes public employment as a last resort, spends more than four times as much (3.3 percent of GDP) on long-term disability benefits.[13]

The Panel concludes that new disability policy initiatives must strive for a balance between policies that facilitate work and those that ensure a fair and decent level of income support during periods of work incapacity. That balance currently must be found in a policy environment where new public spending is sharply constrained. The Panel's response to the four questions posed to the Academy are presented in the following sections.

INCENTIVES TO CLAIM BENEFITS IN LIEU OF WORKING

Question 1: *Is it correct that Americans with disabilities now confront strong incentives to emphasize their impairments as a means of securing and maintaining disability benefits?*

Any income support system presents some level of work disincentive. The challenge is to design benefit policies that cost-effectively target reasonably adequate support to those who are unable to work, while minimizing work disincentives. Our findings in response to this question are in three parts, beginning with an evaluation of the basic purposes and designs of the Social Security and SSI disability benefit programs. Our second finding relates to gaps in health care coverage that limit work choices for persons with disabilities. Our last set of findings present our analysis of the reasons for the recent growth in the Social Security and SSI disability benefit programs and what should be done about it.

The Panel's basic finding is that the Social Security and SSI disability benefit programs do not pose strong incentives for Americans with disabilities to seek benefits in lieu of working. Rather, the strict and frugal design of these programs makes remaining at work preferable to benefits for those who are able to work.

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[13] L.J.M. Aarts and P.R. de Jong, "European Experiences with Disability Policy," *Disability, Work and Cash Benefits,* J.L. Mashaw, et al., (eds.) (Kalamazoo, MI: W.E. Upjohn Institute for Employment Research, forthcoming).

Social Security Disability Insurance

The purpose of DI is to protect workers and their families against the severe financial hardship that would otherwise occur when workers sustain severe illnesses or disabling conditions that interrupt their capacity to work. DI is part of the nation's Social Security — or old-age, survivors and disability insurance — system.

DI shares with every other insurance system the requirement that applicants for benefits must show that the insured event has occurred before benefits are paid. In the case of DI, the insured event is long-term work incapacity. Although DI is sometimes criticized for making people "prove their disability," a requirement that work disability be shown is unavoidable and is thoroughly consistent with the fundamental purpose of insurance — which is to cushion the financial loss when the insured event occurs. Any insurance system also builds in safeguards to discourage unwarranted claims and to protect the insurance system against paying them. In this regard, Social Security disability insurance includes a number of provisions that, taken together, make remaining at work preferable to claiming benefits for those who have the capacity to do so. As such, the following features could be characterized either as incentives to remain at work or as deterrents to leaving work to claim disability benefits.

First, only those who have a record of fairly steady and recent work are insured for DI benefits.[14] Second, the medical and vocational test of disability for DI benefits is very stringent. Under the law, benefits are paid only if one has a medically determinable impairment of such severity that given one's age, education and work experience, one cannot perform substantial gainful activity in any job that exists in significant numbers in the national economy, regardless of whether or not the claimant would be hired for such a job. Benefits are payable only if that impairment is expected to last at least 12 months or result in prior death.

Third, there is a five-month waiting period after the onset of disability before DI benefits are paid. And, health care coverage through Medicare begins only after an additional 24-month waiting period after benefits begin. Both of these waiting periods provide incentives for persons to remain at work, if possible.

Finally, the level of DI benefits is modest in relation to a worker's prior earnings from work. The average monthly benefit for disabled-worker beneficiaries was $682 in December 1995.[15] In December 1994, those receiving as much as $1,000 a month accounted for 14 percent of beneficiaries, while 30 percent received less than $500 a month.[16] Hence, remaining at one's job is more financially rewarding than receiving benefits. DI benefits replace a worker's prior earnings under a sliding scale that provides higher levels of earnings replacement for low earners than for higher earners. This recognizes that low earners have a smaller margin for reducing their consumption. It also recognizes that higher earners have better prospects for having private insurance or pensions to supplement Social Security benefits. DI also pays supplemental benefits to dependent children or spouses of disabled-worker beneficiaries.

For workers whose earnings are average or above, DI replacement rates range from 43 percent for a person earning $25,000 per year to about 26 percent for a person earning $60,000 (table 1). At lower earnings levels, when benefits amount to as much as half of prior earnings, they provide a level of living that is below the poverty threshold, which is estimated to be $661 a month for a working-age person living alone in 1995.[17]

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[14] To qualify for disabled-worker benefits, an individual must have worked in employment subject to Social Security contributions for about one-fourth of the time elapsing after age 21 and up to the year of disability. In addition, he or she must have recent covered work — equivalent to five of the preceding 10 years (or, if between ages 24 and 31, half the time since age 21, or if under age 24, half of the preceding three years).

[15] Social Security Administration, op. cit., footnote 6, table 5.E2, p. 233, updated by data from the Office of Research and Statistics.

[16] Ibid., table 5.E1, p. 233.

[17] See chapter 2.

Table 1. Illustrative Social Security Disabled Worker Benefits, 1995

Prior annual earnings	Monthly benefit: Amount	Monthly benefit: Replacement rate (percent)
$10,000	$507	61
15,000	636	51
20,000	766	46
25,000	896	43
30,000	1,026	41
40,000	1,170	35
60,000	1,332	26

Source: Chapter 2, table 2-1.

The replacement rates for DI are considerably less than what would be needed to match the worker's standard of living while working. Studies generally find that replacement rates of between 70 and 80 percent are needed to match the worker's prior level of living. These studies take account of the difference in tax treatment of various sources of income and the absence of work-related expenses. The studies that have been done, however, generally presume that the Social Security beneficiary is a relatively healthy retiree.[18] These studies do not take account of the additional costs of disabled workers, which include the need to support themselves without earnings during a five-month waiting period, and other disability-related expenses, including health care during the first 29 months after the onset of disability.

In brief, disability insurance from Social Security helps to avert financial disaster when workers sustain periods of long-term work incapacity. But the benefits are designed to make remaining at work a more rational and economically rewarding choice for those who are able to do so.

Supplemental Security Income

The purpose of the needs-based SSI program is different from that of Social Security disability insurance. SSI is intended to provide a basic minimum income below which no American should have to live if he or she is elderly or has a severe work disability. Although SSI, unlike DI, does not require prior covered employment that is the hallmark of social insurance, it has a number of features that make work preferable to claiming benefits for those who have the capacity to work.

SSI provisions that discourage benefit claims among those who have the capacity to work include: very modest benefits; a strict test of means that takes account of other income and financial resources; and a strict test of disability that is essentially the same as that for DI.

The SSI federal benefit rate ($470 a month for an individual in 1996) is modest, amounting to about 70 percent of the official poverty threshold for an individual under age 65. When SSI was originally being developed, Congress intended that it would keep elderly and severely disabled individuals out of poverty.[19] Financing fell short of that goal. While some states supplement federal SSI benefits, the federal benefit rate remains well below the poverty threshold.

The SSI means test reduces SSI benefits dollar for dollar for all other countable income. To build in incentives to work, a portion of the recipient's earnings from work is excluded from countable income. The SSI resource test renders an individual ineligible for benefits if he or she has financial resources in excess of $2,000.

Finally, the SSI program uses the same strict test of medical and vocational work disability used in the DI program. For individuals to choose SSI over work at reasonably remunerative employment would often mean choosing a level of living below the

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[18] B.A. Palmer, "Retirement Income Replacement Ratios: An Update," *Benefits Quarterly*, Second Quarter, 1994, pp. 59-75.

[19] U.S. Senate, *Social Security Amendments of 1972, Report of the Committee on Finance, U.S. Senate to Accompany H.R.1*, S. Rpt. No. 92-1230 (Washington, DC: U.S. Government Printing Office, September 26, 1972), p. 384.

poverty threshold. Thus, the SSI benefits, themselves, are not a powerful incentive for individuals to emphasize their impairments rather than their capacities to work if they are able to earn a living wage.

Notwithstanding these basic findings, the Panel believes that there are reasonable concerns about potential work disincentives that need to be addressed. The first involves gaps in health care coverage that limit employment options for persons with disabilities. The second involves concerns about recent growth in federal disability benefit programs.

LACK OF ACCESS TO HEALTH CARE LIMITS EMPLOYMENT OPTIONS

While the Panel believes that neither DI nor SSI, in and of themselves, pose strong incentives for Americans to seek these benefits in lieu of working, constraints on access to health care and related services can.

Health care is important to all Americans. It is particularly important to people with chronic health conditions or disabilities because many are at risk of very high health care costs. They often cannot gain coverage in the private insurance market, and even when they do have private coverage, it often does not cover the range of services and long-term supports that they may need in order to live independently.

The current structure and gaps in health care coverage for people with disabilities can limit their labor market options in several ways. First, on the demand side of the labor market, employers, despite the ADA, may be reluctant to hire persons who are at risk of high health care costs if they would be covered under the employer's plan. Second, on the supply side of the labor market, if persons with disabilities cannot obtain private insurance, work may not be an economically feasible option. Fear of losing Medicaid or Medicare coverage is often cited as a reason why some persons with disabilities work less than they would if secure health care coverage were available. Finally, gaps in health care coverage can result in unnecessary losses in employment when uninsured people fail to get the care they need in order to treat, cure or ameliorate the disabling consequences of their conditions.

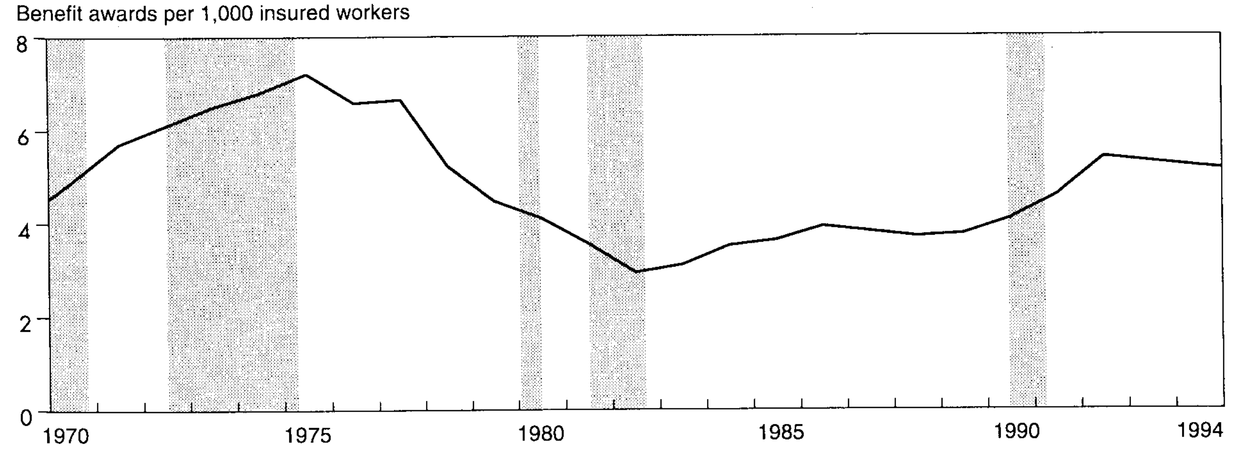
The Panel's interim report emphasized that comprehensive health care reform would be a major step forward for persons with disabilities. The Panel recognizes that today, universal health care is a more elusive goal than it appeared to be when we issued our interim findings in March 1994. The Panel has two specific recommendations for incremental reforms in Medicare and personal assistance services: an improved Medicare buy-in for former recipients of DI who return to work; and a tax credit for personal assistance services to compensate working people for part of the cost of the services they need in order to work. The Panel also endorses the efforts of states to create affordable buy-ins to their Medicaid programs for working people with disabilities.

The Panel recognizes these are piecemeal solutions to a much broader problem. Our proposals are limited in both scope and cost and derive from the Panel's charge to improve incentives to return to work for persons who may now rely on cash benefit programs for support. The broader challenge — to control the growth in health care costs and expand access to needed health care — is beyond our charge.

UNDERSTANDING RECENT GROWTH IN THE ROLLS

While the Panel believes that the designs of DI and SSI tend to discourage benefit claims, we recognize there is concern about the recent growth in the size and cost of the Social Security and SSI disability programs. Both the growth in benefit awards and the decline in benefit terminations have more complex causes than the potential work disincentive effects of cash benefits. While some of these causes lie in the broader economic and policy environment, others are amenable to policy prescriptions in the DI and SSI benefit programs.

Figure 1. DI Incidence Rates, 1970-94 (shaded areas are economic recessions)



Abbreviation: DI = Social Security disability insurance.
Source: Social Security Administration, Office of the Actuary.

Our analysis reviewed the causes of recent growth in the DI program in terms of the eligible population, the fluctuations in benefit awards, and the decline in benefit terminations. The review focuses largely on the DI program, drawing on research by others and data available from the Social Security Administration (SSA). Research and data on trends in the SSI program for working-age adults are more limited.

Growth in the Eligible Population

The number of persons who enter the benefit programs is influenced by the size of the eligible population. Those eligible for DI disabled-worker benefits are persons under age 65 who have enough covered work experience to be insured. The eligible population has grown for two reasons. First, the underlying working-age population has grown. Second, more women have enough paid employment to be insured for benefits. Consequently, they qualify for DI benefits when they become severely disabled. Had they remained housewives as many of their mothers were, their disabilities would not be recognized in federal benefit programs. Between 1988 and 1994 the insured population grew by 10 percent — 3 percent for men and 14 percent for women. This continues a longer term trend: between 1980 and 1994, the insured population grew by 27 percent, 15 percent for men and 45 percent for women.

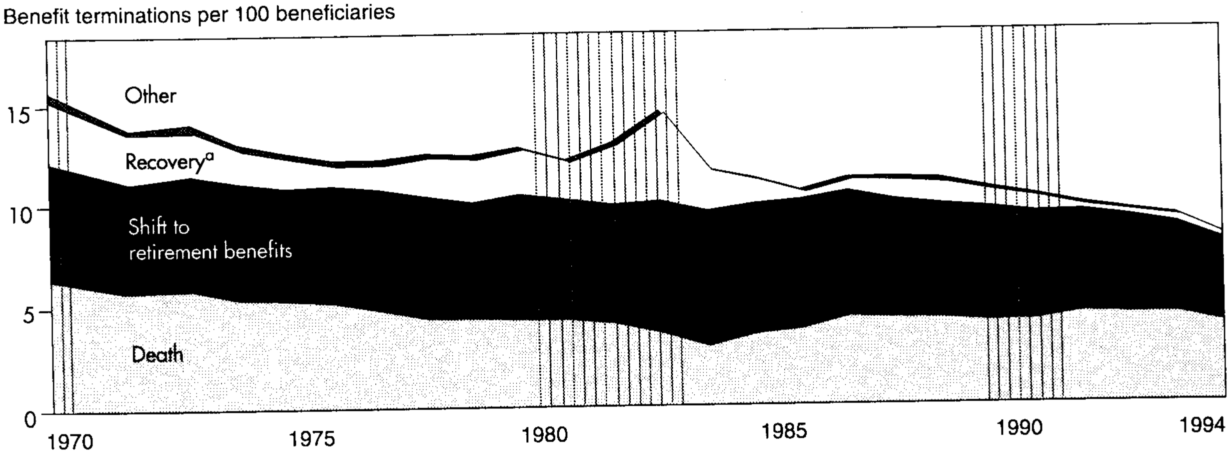
Growth in DI Benefit Awards in 1989-92

The DI incidence rate (new awards as a percent of the insured population) grew rapidly between 1989 and 1992. It then dropped in 1993 and again in 1994. While the incidence rate remains higher today than in the 1980s, it is lower than it was in the mid-1970s (figure 1).

Some of the factors that contribute to fluctuations in new benefit awards have been quantified in research studies. Others that are likely to contribute are more difficult to quantify.

First, the economic recession of 1990-91 clearly contributed to the number of benefit applications and awards, as did economic recessions during the 1970s. Economic recessions increase the likelihood that workers with serious physical or mental impairments will lose their jobs and apply for and qualify for disability benefits. This has occurred with the Social Security program, in private disability insurance and in foreign disability systems. When jobs are plentiful and employers are actively seeking qualified employees, they are much more inclined to

Figure 2. DI Termination Rates, by Cause 1970-94 (lined areas are economic recessions)



a. Includes terminations because of return to work or a finding that the beneficiary no longer has a disabling impairment.
Abbreviation: DI = Social Security disability insurance.
Sources: Social Security Administration, Office of the Actuary; and U.S. Department of Health and Human Services, *The Social Security Disability Insurance Program: An Analysis*, requested by the Board of Trustees of the Federal Old-Age and Survivors Insurance and Disability Insurance Trust Funds (Washington, DC: U.S. Department of Health and Human Services, December 1992), chart 2, p. 7.

accommodate workers who have impairments. When jobs are scarce and firms are downsizing, workers with disabilities who lose their jobs, particularly at older ages, have fewer prospects for regaining employment or shifting to new careers.

The early 1980s were an exception to the trend of increasing disability incidence rates during economic downturns. Retrenchment policies adopted then sought to reduce the size and cost of disability benefit programs by applying increasingly restrictive interpretations of the disability eligibility criteria both for new applicants and in the review of the continuing disability of persons on the rolls (figure 2). Disability incidence rates reached an all-time low and benefit terminations based on a finding of "no longer disabled" reached an all-time high. Public support for the retrenchment eroded when its consequences became known. The policies were challenged in the courts, some states ultimately refused to implement them, and the administration placed a moratorium on benefit termination and on denial of certain categories of benefit claims until new policies were developed. Congress in 1984 enacted legislation to preclude the kinds of policies that had been adopted, challenged and halted in the early 1980s.

Second, mandated outreach activities to enroll eligible persons in the SSI program contribute to growth. During the 1980s Congress mandated a number of SSI outreach activities.[20] Beginning with earmarked appropriations in 1989, SSI outreach became a priority for SSA. These outreach activities were cited by SSA field office managers as a source of growth in disability applications.[21] Some who applied for SSI were found to have enough covered work experience to qualify for DI benefits concurrently with SSI. Outreach activities contributed to growth in the early- and mid-1970s as well, with a nationwide effort to enroll eligible persons in the new SSI program that was enacted in 1972 and implemented in 1974.

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[20] U.S. House of Representatives, Committee on Ways and Means, *Overview of Entitlement Programs (1994 Green Book)*, WMCP: 103-27 (Washington, DC: U.S. Government Printing Office, July 1994), pp. 254-257.

[21] L.S. Muller and P.M. Wheeler, "Disability Program Growth: Results From Social Security's Survey of Field Office Managers," unpublished paper presented at a conference sponsored by the Social Security Administration (SSA) and the Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation (DHHS/ASPE), Washington, DC, July 20-21, 1995.

Third, cutbacks in state general assistance programs, and active referral of former recipients of such benefits to the SSI program, contributed to recent growth in applications for SSI benefits in some jurisdictions.[22] While most did not meet the strict test of disability, some did. Similar effects could be expected from state initiatives to cut back on Aid to Families with Dependent Children (AFDC) programs.[23] One study found a high rate of disability among families receiving AFDC.[24]

Fourth, revised medical and functional criteria and new evidentiary requirements used to determine eligibility for Social Security disability benefits were required by Congress and the courts. The changes included new criteria for evaluating mental disorders that complied with a 1984 Congressional mandate that such applicants be evaluated with an emphasis on the individual's ability to engage in substantial gainful work in a competitive work place environment. These changes were prompted by widespread agreement that SSA's practices with respect to mental impairment claims had been overly restrictive in the late 1970s and early 1980s.[25]

Fifth, increased recognition and diagnosis of disabling conditions, particularly mental disorders, may have contributed to growth in claims and awards in the early 1990s as well as to a change in the composition of the beneficiary population. In recent years, depression, a common form of disabling mental illness, has increasingly been recognized and diagnosed, perhaps due in part to a public information campaign launched by the National Institute of Mental Health designed to improve the diagnosis and treatment of depression. Further, depression often coexists with other physical or mental impairments. Therefore, improved diagnosis would increase the chances that depression is identified as a beneficiary's primary diagnosis. In the case of multiple impairments, the one identified as primary is likely to be the one that can be most promptly and cost-effectively documented by SSA.

Finally, structural changes in the labor market influence the kinds of impairments that result in work disability. The growing premium placed on intellect, advanced education and public relations skills can mean fewer employment prospects for people who have the double disadvantage of physical or mental impairments combined with limited human capital (education, skills, and aptitude).[26] Advances in assistive technology and public accommodations called for by the ADA may bring new opportunities for workers with physical impairments who have high aptitude and advanced education. The changing demands of work, however, may limit employment prospects for individuals whose social and adaptive functioning is impaired by mental disorders.

DI Benefit Terminations Have Declined

People leave the DI benefit rolls for one of four reasons: they die, they shift to retirement benefits at age 65, they medically recover, or they return to work despite the continuation of their impairments. While benefit termination rates (the number of persons who leave the benefit rolls per 100 beneficiaries) have been more stable than incidence rates, they too have fluctuated to some degree. They have declined since the mid-1980s (figure 2).

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[22] J. Bound, et al., "The Ending of General Assistance and SSI Disability Growth in Michigan: A Case Study," unpublished paper presented at a conference sponsored by SSA and DHHS/ASPE, Washington, DC, July 20-21, 1995, p. 9; and D.C. Stapleton, et al., "Lessons from Case Studies of Recent Program Growth in Five States," unpublished paper presented at a conference sponsored by SSA and DHHS/ASPE, Washington, DC, July 20-21, 1995, p. 16.

[23] D.C. Stapleton, et al., op. cit., footnote 22, p. 17.

[24] U.S. Department of Health and Human Services, "Disability Among Women on AFDC: An Issue Revisited," as reported in *Family Matters*, Fall 1993.

[25] H. Goldman and A. Gattozzi, "Balance of Powers: Social Security and the Mentally Disabled," *Milbank Quarterly*, Number 66, 1988, pp. 531-551; and Disability Policy Panel, *The Environment of Disability Income Policy: Programs, People, History and Context*, J.L. Mashaw and V.P. Reno (eds.) (Washington, DC: National Academy of Social Insurance, 1996), see chapter 5.

[26] One study found that men who were doubly disadvantaged by disabilities and limited human capital did not recover from the program cuts and economic recession of the early 1980s. It further concluded that the doubly disadvantaged were not likely to benefit from new mandates for job accommodations. R.V. Burkhauser, et al., "How People with Disabilities Fare When Public Policies Change," *Journal of Policy Analysis and Management*, Spring 1993.

Death and retirement have always accounted for the vast majority of DI benefit terminations. These termination rates are influenced by the underlying health and age distribution of the beneficiary population.

Terminations Because of Death Are Stable. The proportion of DI beneficiaries who die each year is high — between 4.5 and 5.0 percent. One study found that over one-quarter of DI beneficiaries (27 percent) died within five years of entering the rolls.[27] The annual probability of death for DI beneficiaries is much higher than in the general working-age population, where the probability of death ranges from about 0.1 per 100 insured workers at age 30 to about 1.2 per 100 at age 60. The death rate for DI beneficiaries has been quite stable, suggesting that the proportion of beneficiaries with life-threatening conditions has not changed.

Terminations For Retirement Are Down. The benefit termination rate due to retirement gradually declined since the mid-1980s. This is because a smaller proportion of DI beneficiaries are age 60 or older. Those ages 60 to 64 accounted for one-quarter of DI beneficiaries in 1994, down from one-third of beneficiaries in 1985. There are two reasons why a smaller proportion of DI beneficiaries are in their 60s. First, the underlying insured population is more concentrated at younger ages. The baby boom is entering the 35-to-50 age range, where they produce a bulge in both the work force and in work-based disability programs. At the same time, the cohort of workers entering their 60s in the 1990s is relatively small, because relatively few babies were born in the birth dearth of the Great Depression 60 years ago. The second reason why the DI beneficiary population is younger is that insured workers under age 50 are somewhat more likely than in the past to be receiving DI benefits. While the likelihood of receiving DI benefits rises sharply after the age of 55, the prevalence of benefit receipt has increased for those under age 50 since the mid-1980s.

Terminations For Recovery or Return to Work Have Declined. Finally, while the DI benefit termination rate due to medical recovery or return to work has always been modest, it is at an all-time low. This rate is influenced by the number and target-effectiveness of continuing disability reviews (CDRs) that SSA conducts and by the level of investment in efforts to assist beneficiaries return to work despite the continuation of their impairments.

What Should Be Done

The recent rapid rate of growth in new benefit awards appears to have been a temporary phenomenon, tied to the economic recession of 1990-91. The rate of new benefit awards declined and flattened out after 1992. Nonetheless the benefit rolls continue to grow because fewer people are leaving the rolls than are entering. Some reasons for this growth lie in the broader environment — such as shifts in the size and age composition of the population, or in broader social and economic trends. Nevertheless, policy and administrative changes should be pursued to promote return to work among beneficiaries and to ensure the continued integrity of the benefit determination process and the disability income support system as a whole.

The Panel's Policy Proposals Promote Work. Most of the Panel's proposals are designed to promote work and therefore should increase the number of people who leave the benefit rolls for this reason. Those proposals, which are described in more detail later in this overview, include:

- Return-to-work tickets that beneficiaries can use to get the vocational services they need to return to work (chapter 6);
- A disabled worker tax credit which is designed to facilitate exit from the DI and SSI benefit programs, as well as to encourage individuals to work despite their impairments instead of turning to DI or SSI benefits (chapter 7);
- An affordable and understandable Medicare buy-in option for former DI beneficiaries who return

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[27] See table 6-4.

to work. To the extent that fear of losing Medicare coverage discourages beneficiaries from seeking work, a Medicare buy-in option that is understandable, predictable and affordable should eliminate this deterrent to work attempts (chapter 8).

- Enhanced implementation of existing work incentive provisions so that beneficiaries who seek to return to work can do so without unexpected consequences in their benefits (chapter 9).

Adequate Administrative Resources Are Essential. A review of the last 25 years finds a common theme in the three periods that produced major concern about the disability programs: the two periods of rapid growth, in the mid-1970s and in the early 1990s, and the period of sharp retrenchment in the early 1980s. All three periods coincided with economic recessions, which place increased demands on disability benefit systems. In each case, new administrative demands were placed on the system without commensurate investment in administrative resources. In all three cases, the under-investment in administrative resources was followed by concerns that the program was out of control.

In the mid-1970s, SSA was called upon to implement the new SSI program and was not provided sufficient additional resources to do it. In the early 1990s, after agency staffing had been "downsized" by nearly 25 percent, SSA did not have the resources to respond to the growth in new claims that accompanied an economic recession. When backlogs grow and claims are not decided promptly, Congress responds to constituent concerns by urging the agency to speed up its disability decisions.

Pressure to speed up decisions in spite of inadequate administrative resources can contribute to growth in the rolls in a number of subtle and interrelated ways.[28]

- New instructions may be issued to ease standards for documenting claims that are allowed.

- Personnel involved in quality review of disability decisions are likely to be reassigned to help process claims. Fewer allowed claims then are reviewed for accuracy.

- Greater reliance may be placed on third parties to assemble and submit claims for disability benefits. While SSA does not pay third parties, some have a financial interest in benefits being allowed.

- Personnel responsible for CDRs of those on the rolls are shifted to processing new claims.

- Personnel and systems supports for so-called "post-entitlement actions" that are essential to support beneficiaries' attempts to work get low priority.

In the retrenchment period of the early 1980s, new policies were initiated to vigorously review the disability rolls and terminate benefits to anyone not found to meet a very restrictive interpretation of the eligibility criteria. This was done without adequate staffing or training in the new review procedures. The 1980 legislation that had required stepped up review of those on the rolls had estimated modest savings from this initiative, recognizing that investment in administrative resources in the early years would outweigh any early benefit savings. The reviews were vigorously launched, however, without the investment in staff and training. They were abandoned after they lost public support, were successfully challenged in the courts and some states refused to implement them.[29]

Given this history, the Panel repeats the concern expressed in our interim report that attempts to administer a complex and expensive benefit program without adequate administrative resources ill serves both beneficiaries and the public fisc. In relation to the importance and size of the disability benefit program, investment in administrative resources is very modest, at 2.7 percent of DI program outgo in 1994. In particular:

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[28] Disability Policy Panel, op. cit., footnote 25, see chapter 5.

[29] Ibid.

Administrative resources including technology must be set at a level that ensures stable, effective management of the disability programs. Resources must be adequate to provide: (1) fair, accurate and prompt decisions on disability claims, (2) individualized service to beneficiaries that is contemplated under the law, including accurate information and prompt action to implement benefit adjustments when beneficiaries work, and (3) timely and predictable review of the continuing eligibility of those receiving disability benefits.

The Panel considered a proposal to further emphasize review of the continuing disability of those on the rolls by making benefit allowances time limited for beneficiaries with reasonable prospects for return to work. The basic reason for considering such an approach was a desire to set expectations of return to work at the time benefits are allowed. Several members of the Panel believe that such an approach is consistent with the goals of more fully integrating people with disabilities into the work force and would send a signal to both people with disabilities and to Social Security administrators that permanent disability-based transfers are a last resort. The majority of the Panel, however, believes that the financial and administrative problems with time-limited benefits make them unworkable.

Briefly stated, the objections to time-limited benefits include: (1) the very limited success to date in developing criteria at the time of benefit award that are good predictors of recovery or return to work, (2) the potential for the availability of "temporary" benefits to increase applications and awards, and (3) the use of extremely scarce administrative resources in redetermining large numbers of claims in which the prior determination of disability may be confirmed. Given these difficulties, the Panel recommends greater commitment to staffing and implementation of the existing CDR process combined with its proposal for return-to-work tickets. It believes these initiatives can produce outcomes similar to the positive expectations for time-limited benefits.

The effectiveness of a systematic CDR process is supported by historical trends in benefit terminations. Termination rates because of medical recovery or return to work were considerably higher during the 1970s than they are today. During much of that period, SSA used a medical improvement standard for review that is similar to the standard in place today. SSA has indicated its intention to resume continuing disability reviews and to develop procedures to cost-effectively target reviews on those with the best prospects for recovery. The Panel supports those efforts.

A more fundamental restructuring of disability benefits, built on the German or Swedish models, would make the transition onto long-term disability benefits a two-step process in which a period of provisional benefits and extensive rehabilitation and accommodation efforts preceded entry onto the long-term disability rolls. This approach was discussed briefly. It was not pursued in depth because it would require substantial new resources, in both new short-term benefits and in services, which are unlikely to become available.

Medical and Vocational Criteria Should Be Kept Up to Date. The Panel believes that renewed emphasis should be placed on periodic updates of the medical and vocational criteria for assessing work disability. The Panel fully supports the use of medical criteria along with vocational criteria in the disability determination process. We did not review particular medical criteria, nor was that our job. Experts agree on the need for periodic reviews and updates of the criteria to ensure that past experience, new research and state-of-the-art knowledge are systematically incorporated into the programs' assessment of work disability. Categories of impairments that account for a significant portion of the disability rolls, or where rapid growth has prompted concern, are good candidates for expert review. For example:

- *Mental impairments.* Standards have now been in place for 10 years. It is time to undertake a comprehensive, expert examination of the mental impairment listings in light of experience and current thinking in the professional mental health community.

- *Pain.* As required by Congress in 1984, SSA convened a Commission on the Evaluation of Pain and a Committee on Pain and Disability of the Institute of Medicine, which reported in 1986 and 1987, respectively. Both recommended research to develop pain assessment instruments, which has now been completed.[30] SSA should convene an expert group to determine how to apply what has been learned to the Social Security disability determination process.

SSA has been engaged in reengineering its disability claims process. One of the premises of this redesign is a new, simplified assessment of disability. Such a fundamental realignment of the medical and functional assessment criteria would appear to require many years to develop and test before it is ready to be put into regulations as a substitute for existing criteria. In the meantime, existing criteria should be updated and those associated with rapid growth in allowances should be given high priority in order to maintain public confidence in the integrity of the program. Because the reengineering effort is ongoing and incomplete, the Panel is unable to evaluate it.

Experts on SSA's medical criteria report that there is considerable variation among the criteria used for different body systems in terms of the severity of impairments that are presumed to constitute work disability. To date no systematic research has been done to evaluate the consistency of the presumptions underlying the medical criteria for different body systems. Research of this kind should have high priority. The Panel supports investment in SSA's research program for this purpose.

REHABILITATION AND CASH BENEFITS POLICY

Question 2: *Can an emphasis on rehabilitation and work be incorporated into the disability benefit programs without greatly expanding costs or weakening the right to benefits for those who cannot work?*

Yes, and the Panel has a proposal to do so.

Return-to-Work Tickets

The Panel is proposing a new approach to financing vocational rehabilitation and return-to-work services for beneficiaries. The plan would promote consumer choice and enlist private sector providers in helping beneficiaries return to work, without greatly expanding costs or weakening the right to benefits for those who cannot work.

The Panel's return-to-work (RTW) proposal builds on the principles of consumer choice and empowerment, encouraging competition and innovation among service providers, rewarding service providers for their results rather than for the cost of their inputs, and encouraging providers to have a continuing interest in their clients' long-term success in remaining employed.

Under this plan, new beneficiaries would receive an RTW ticket, akin to a voucher, that they could use to shop among providers of rehabilitation or RTW services in either the public or private sector. Once a beneficiary deposits the ticket with a provider, the Social Security Administration would have an obligation to pay the provider only after the beneficiary returns to work and leaves the benefit rolls. Providers whose clients successfully return to work would, each year, receive in payment a fraction of the benefit savings that accrue to the Social Security trust funds because the former beneficiary is at work and not receiving benefits.

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[30] U.S. Department of Health and Human Services, *Report of the Commission on the Evaluation of Pain,* (Washington, DC: U.S. Government Printing Office, 1986); M. Osterweis, A. Kleinman, and D. Mechanic, (eds.), *Pain and Disability: Clinical, Behavioral and Public Policy Perspectives* (Washington, DC: National Academy Press, 1987); K.S. Rucker, et al., "Final Report on All Aspects of the Pain Assessment Instruments Development Project," unpublished paper, Virginia Commonwealth University, Richmond, VA, 1994.

The Panel recognizes that disability benefits are paid to a very impaired population, only a fraction of whom have prospects for returning to work. As long as DI continues to have very strict eligibility rules, it is reasonable to expect that only a small percentage of beneficiaries will be able to return to work, even with rehabilitation services. Nonetheless, we believe this incentive-based system of financing rehabilitation and return to work services could bring a substantial increase in the very low rate at which beneficiaries leave the benefit rolls because they have successfully returned to work.

The Panel considered several illustrative plans, including one in which RTW tickets would be given to newly-awarded DI beneficiaries (other than those expected to medically recover in the near term), and providers of RTW services would be paid 50 percent of the benefits savings that would accrue over five years after a beneficiary returned to work and left the rolls. If effective in October 1996, such a plan is estimated to save a total of $440 million through the year 2005.[31] The SSI savings over the same 10-year period are estimated total $235 million.[32]

Paying for Rehabilitation: Distinguishing Purposes

The Panel recognizes that there are different purposes for financing rehabilitation services. One purpose is to improve the quality of life, independent living and community integration of persons who receive services. This is the purpose of publicly-financed rehabilitation provided by the federal/state vocational rehabilitation (VR) program. It is required by law to give first priority to persons with the most significant impediments to employment. Success is defined in terms of placement for 60 days in settings which include unpaid homemaking or family work, sheltered employment and competitive employment.

A different rationale is used to justify paying for rehabilitation services out of funds earmarked for cash benefit programs. While services should improve the quality of life of persons served, the unique rationale for using benefit funds to pay for rehabilitation is to reduce long-run benefit expenditures. This is the rationale used by private insurers when they decide to invest in rehabilitation services. It has long been the legislative rationale for using Social Security funds to pay for rehabilitation. The Panel's RTW proposal is based on this rationale.

Cash Benefits and Rehabilitation: Distinguishing Assessments

The Panel also recognizes that an assessment of rehabilitation potential is different from an assessment of eligibility for disability insurance benefits. This is true in both private and public cash benefit programs.

In the private sector, long-term disability insurers sometimes pay for rehabilitation services for recipients of their cash benefits. But the decision to do so is made after the determination of benefit eligibility and it is based on a different set of criteria. Insured employees have a contractual entitlement to cash benefits if they meet the eligibility criteria in the insurance contract. Employees do not have a contractual entitlement to rehabilitation services.

The decision to pay for rehabilitation services is a discretionary choice for the insurer. It is based on cost-benefit considerations analyzed on a case by case basis and takes into account the insurers' future benefit liability as well as the employee's return-to-work prospects. Preferred candidates tend to be employees who are younger, have stable medical conditions, are well-educated white collar employees and who are highly motivated to return to work. Insurers often use rehabilitation professionals to screen and select candidates for rehabilitation and to develop service plans.

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[31] Social Security Administration, Office of the Actuary, memoranda, July 21, 1995, September 25, 1995 and December 15, 1995. The savings estimate is based on the assumption that new cases of beneficiaries returning to work would gradually rise to about 6,000 by the year 2003, nearly doubling the number of beneficiaries who leave the rolls to return to work under current law. (Although the number of beneficiaries who return to work as a result of the proposal rises, the savings are somewhat reduced because the trust funds would pay for RTW in some cases for which it does not now pay.)

[32] Social Security Administration, Office of the Actuary, memorandum, December 1, 1995.

The Panel's proposal for linking Social Security beneficiaries with rehabilitation services also provides for an assessment of rehabilitation potential that is distinct from the determination of benefit eligibility and, as in the private sector, is made after a finding of benefit eligibility. The Panel recognizes that SSA does not have the personnel or expertise to make case by case assessments of rehabilitation potential and it is not likely to get the additional resources necessary to do so. Consequently, the Panel's proposal enlists the expertise of service providers to identify candidates for return-to-work services. Providers would be paid based on their success in assisting those beneficiaries to return to work.

Early Intervention: Getting Rehabilitation First

It is an article of faith in the rehabilitation community that early intervention after the onset of illness or injury is the best time to offer rehabilitation services. In an ideal world, rehabilitation services would be offered *first*, before an application is made for long-term disability benefits. This is done in some foreign countries that have national systems of short-term disability benefits that are coordinated with long-term disability benefits. In Germany, for example, employers pay an ill or disabled worker full salary for the first 6 weeks of absence from work, after which sickness funds pay for up to 18 months of temporary disability, during which publicly-financed rehabilitation services are provided before a determination of long-term disability is made.[33]

The Panel considered a plan for universal short-term disability benefits in the United States. The purpose of such a plan would be to fill gaps in short-term disability income protection; to promote early intervention through a case management system to link employees with rehabilitation and RTW services; and to reduce reliance on long-term disability benefits from Social Security. Many consider the lack of short-term disability benefits to be a major gap in beneficiary protection and to inhibit early intervention to prevent long-term disability. Fully 30 percent of private sector employees have no formal sick leave or short-term disability insurance. Another 26 percent have only sick leave, which typically provides wage replacement for a few days or weeks, far less than the duration needed to cover the five-month waiting period for DI.[34]

The main drawback of such a plan is its cost. If financed equally by employees and employers, short-term disability protection has been estimated to cost roughly 1 percent of earnings that are subject to Social Security taxes (0.5 percent each for employees and employers).[35] Given today's very tight constraints on public budgets and lack of interest in new employer mandates, the Panel concluded such a proposal is not feasible. Further, if the United States were to expand social protection for American workers, in the Panel's view, comprehensive health care coverage should be the first priority.

If rehabilitation is to be provided *before* a determination of eligibility for DI or SSI benefits, the federal/state VR program is the main source of public financing for such services. Its availability is not limited to Social Security beneficiaries and most people it successfully serves are not beneficiaries. In FY 1992, Social Security or SSI beneficiaries accounted for about 20 percent of all those considered successfully rehabilitated. They included 15 percent of those placed in competitive employment; 70 percent of those placed in sheltered employment; and 40 percent of those placed in unpaid homemaking or family work.[36]

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[33] L.J.M. Aarts and P.R. de Jong, op. cit., footnote 13.

[34] Disability Policy Panel, op. cit., footnote 25, p. 47.

[35] A plan for national short-term sickness and disability benefits was developed in 1974 for the Department of Health, Education and Welfare. L.J. Haber, "Sickness and Injury Cash Benefits (SICB): Recommendations for a Temporary Incapacity Program," unpublished paper prepared for the Assistant Secretary of Planning and Evaluation, Department of Health, Education and Welfare, June 1994. At that time, it was estimated to cost about 1 percent of Social Security covered wages. The Panel did not update the plan. Rough estimates indicated the cost, as a percent of Social Security covered wages, would be no less today.

[36] U.S. Department of Education, Rehabilitation Services Administration. Those "successfully rehabilitated" were placed for 60 days in the chosen outcome. Beneficiary status is from Rehabilitation Services Administration data.

Whether the state VR program has the capacity to serve a much larger number of DI and SSI applicants is an open question. If state VR agencies are willing and able to serve a larger share of applicants before cash benefit claims are decided, SSA and state agencies could promote early intervention by setting up administrative arrangements to more actively promote VR services sooner by:

- Training local Social Security staff to actively inform benefit applicants about state VR agencies in their area, what those agencies offer and where and how to apply for such services. The main impediment to this approach appears to be a limitation on SSA field office staff; and

- Locating VR counselors in or near local Social Security offices to seek out benefit applicants, as was tested with reported success in SSA's Project NetWork demonstration in Virginia and New Hampshire.[37]

Encouraging Work Among Beneficiaries

Question 3: *Are there changes that would encourage beneficiaries to use their residual work capacity?*

Yes. The Panel recommends several initiatives to facilitate remaining at work or going to work among persons with disabilities, including a wage subsidy, better access to health care coverage and personal assistance services, and improvements in the implementation of work incentives.

A Wage Subsidy for Low-Income Workers with Disabilities

The Panel recommends a disabled worker tax credit (DWTC) that would be separate from disability benefit programs. The wage subsidy would be paid to low-income persons not because they are unable to work, but because they work despite their impairments.

As a way to encourage and subsidize work among low-income workers with disabilities, the Panel is proposing a wage subsidy that is separate from the DI and SSI programs. It is proposing a DWTC that would be paid to persons not because they are unable to work, but because they work, albeit at low wages, despite their impairments. As such, it rewards work for low earners with disabilities without increasing reliance on disability benefit programs that are designed primarily for persons who are unable to work.

The Panel recognizes that disability is a continuum and that Social Security and SSI beneficiaries are those who have the most significant work disabilities. A DWTC would encourage work for persons who have some residual capacity to do so. Eligibility could be based on disability findings by SSA and state VR agencies. In the illustrative plan developed by the Panel, those eligible for the DWTC would include: DI and SSI disability beneficiaries; certain applicants denied DI or SSI benefits;[38] and persons certified by VR agencies to have impairments that are significant impediments to employment. Thus the DWTC would be available to low-income workers with significant disabilities who work and do not receive DI or SSI benefits. As such it is designed to:

- Encourage older workers to remain at work even though they experience a decline in hours of work or wage rates due to progressive impairments. By subsidizing low wages, it encourages older workers to delay the point at which they turn to cash benefits.

- Ease the transition from school to work for young people with developmental disabilities whose earnings capacity is doubly limited by their youth and their impairments. By subsidizing their earnings, it encourages even part-time or low-paid work that over the long run can improve young workers' human capital through on-the-job experience.

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[37] Social Security Administration, Office of Disability.

[38] In the Panel's illustrative proposal, the DWTC would be available to applicants denied at the last step of the Social Security determination process. They are individuals who have severe impairments and are found unable to do their past work, but are considered able to do other work.

- Ease the transition off the DI and SSI benefit rolls for those who return to work. The wage subsidy would compensate for some of the loss of benefits that occurs when beneficiaries return to work.

The exact parameters for a DWTC will determine its cost and impact. The illustrative proposal the Panel developed would provide a refundable credit to low-income persons with disabilities who work, including those who do not receive DI or SSI benefits. Under the proposal, about 3.1 million low-income working people with disabilities are estimated to receive the credit, at a total cost of about $3 billion in 1996. The average subsidy would be about $1,000 per year, over any subsidy the individual might receive from the existing earned income tax credit. The credit targets low-income people who work despite their impairments. It is estimated that about 1 in 3 recipients of the DWTC would be persons with tax-unit incomes below the poverty threshold, and 3 in 4 would have incomes below twice the poverty threshold.[39]

Access to Health Care for Persons with Disabilities Who Work

Concerns about loss of health care coverage are reported to be a major impediment to leaving the disability benefit rolls.

The Panel recommends an improved Medicare buy-in for DI beneficiaries who return to work. It also recommends that states design their Medicaid programs in ways that promote work and independence while maintaining coverage for vulnerable populations who rely on SSI benefits.

Medicare Buy-In. Under current law, DI beneficiaries who leave the benefits rolls because they have returned to work despite the continuation of their impairments are eligible to purchase Medicare coverage. The eligibility criteria are complex, the coverage is expensive to purchase, beneficiaries appear not to know that this option would be available if they returned to work, and very few former beneficiaries purchase Medicare coverage. The Panel is proposing a simplified Medicare buy-in with premiums charged on a sliding scale related to the former beneficiary's earnings. If former beneficiaries paid a premium equal to 7 percent of earnings in excess of $15,000, capped by the full amount of the premium under current law, the buy-in is estimated to cost $230 million over FY 1996-2000.[40]

Medicaid. In most states, continued Medicaid coverage is available to former SSI recipients under the Section 1619 provisions of the Social Security Act. Under these provisions, Medicaid is available to persons whose SSI benefits are totally offset because of their earnings, but who continue to have a disabling impairment. Medicaid coverage continues until the former SSI recipient's earnings are sufficient to compensate for federal SSI benefits, any state supplements, the value of Medicaid, and any publicly-financed personal assistance services.

The Panel endorses the efforts of states to create affordable buy-ins to their Medicaid programs for persons with disabilities. It recommends that states, in revising their Medicaid programs, allocate both acute care coverage and on-going support services in ways that promote work and independence while maintaining coverage for vulnerable populations who rely on SSI benefits.

Personal Assistance Tax Credit

The Panel recommends a personal assistance tax credit to compensate working people for part of the cost of personal assistance services they need in order to work.

Some persons with significant physical impairments require personal assistance services in order to live independently and, with those services, are able to

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[39] Estimates were prepared by Richard Burkhauser and David Wittenburg of Syracuse University. Data from the 1990 Current Population Survey were used to estimate the size of the eligible population with disabilities and the impact of different credit options upon incomes. The estimate is based on 1996 earned income tax credit (EITC) parameters established by the Omnibus Budget Reconciliation Act of 1993. At the time this report was being prepared, changes in the EITC were under consideration in Congress.

[40] Health Care Financing Administration, Office of the Actuary.

work in the competitive labor market. Personal assistance services, however, can be very costly. They are financed by public programs in some states, but generally only for low-income persons. As such, those who need personal assistance services face a dilemma when they go to work. If they work successfully, their income may disqualify them from receiving publicly-financed services, yet they may not earn enough to pay for the services on their own. The Panel is recommending a tax credit to compensate working people for part of the cost of personal assistance services they need and pay for in order to work.

The credit would be available to persons who have a medically determinable impairment that is expected to last at least 12 months and who need personal assistance in order to engage in substantial gainful activity. The credit would be equal to one-half of personal assistance services expenses up to $15,000 (for a maximum credit of $7,500) and would phase out for persons with annual income between $50,000 and $70,000. The 5-year cost is estimated to total $537 million for FY 1996-2000.[41]

Administering DI and SSI Work Incentives

The Panel believes that the most important enhancement needed in existing work incentives in DI and SSI is to improve the way in which they are implemented. Such improvements would involve both service providers who assist beneficiaries and SSA.

After in-depth analysis of existing work incentive provisions and extensive field research on how they are being implemented, the Panel has concluded that:

- Work incentive provisions are inherently complex. Efforts to simplify them by redesigning them are not particularly promising. Therefore, beneficiaries are likely to need assistance with understanding and complying with the work incentives when they work. This is particularly true for SSI recipients because their benefits are subject to a monthly means test, where changes in other income or assets affect their benefit amounts.

- Some kinds of assistance could be offered by service providers who assist beneficiaries in returning to work — such as those who accept the RTW tickets the Panel is recommending, or state VR counselors, state or local mental health or developmental disabilities agencies, independent living centers, job coaches, providers of supported employment services or those who work with recipients of private disability benefits. Such service providers would, themselves, need to understand the rules and reporting requirements of the work incentive provisions and consider it part of their job to assist their clients in complying with them.

- Some tasks necessary to make work incentives work can only be performed by SSA or an entity employed by SSA. These tasks include prompt processing of earnings and other reports from beneficiaries so that benefits can be adjusted promptly as their circumstances change. If return to work is to be a priority, SSA personnel and systems support for these functions are essential.

Additional Work Incentive Proposals

The Panel is proposing several changes in DI and SSI to make them more "work friendly."

Updating and indexing the level of earnings that is considered to be substantial gainful activity (SGA) would keep it current with economy-wide wages, as is done for other earnings-based parameters of the Social Security program. The concept of SGA is used in determining initial and continuing eligibility for disability benefits. The SGA threshold is set by regulation at earnings of more than $500 per month. It has not been raised since 1990. The proposal would raise the SGA threshold to what it would have been if it had kept pace with growth in economy-wide wages since the beginning of the DI

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[41] U.S. Department of the Treasury, Office of Tax Analysis.

program — about $720 per month in 1996 — and would adjust it to keep pace with future wage growth. The change is estimated to increase DI expenditures by $700 million over 5 years (FY 1996-2000), and to increase SSI expenditures by $265 million over 5 years (FY 1997-2001).[42] It is projected to increase Medicare costs by $70 million over 5 years (FY 1996-2000) and to increase federal Medicaid costs by $1.2 billion over 5 years (FY 1997-2001).[43]

An unlimited extended period of eligibility would provide a "safe period" for former DI beneficiaries who work despite their impairments to return to the rolls if their work attempt fails. It particularly targets individuals with episodic mental or physical conditions who are able to work during "good spells," but need an earnings replacement benefit during "bad spells" of their conditions. (The extended period of eligibility under current law is 36 months.) The DI cost is estimated at $1.0 billion over 5 years (FY 1996-2000).[44]

In addition, the majority of the Panel supports the following changes.

Revising the deduction of impairment-related work expenses for SSI recipients would strengthen work incentives and the financial gain from working for SSI recipients who incur significant impairment-related expenses, such as job coaches, supported employment services, or other goods and services needed to accommodate their impairments so they can work.[45] The SSI cost of this change is estimated to be $26.1 million over 5 years (FY 1996-2000).[46]

Changing the treatment of scholarships for SSI purposes, such that any portion not already excluded from countable income would be treated as earned, rather than unearned, income, would enable college students to remain eligible for Medicaid and publicly-financed personal assistance services in states that use SSI Section 1619 eligibility criteria for those services. The cost of this proposal is estimated to be negligible.[47]

A Social Security-SSI transition proposal would enable resource-eligible Social Security disability beneficiaries who work to qualify for Medicaid or other support services in those states that use SSI Section 1619 eligibility criteria for those services.[48] This proposal is estimated to increase SSI expenditures by $25 million per year by 2005 and to increase federal Medicaid spending by $235 million over 5 years (FY 1997-2001).[49]

Proposals Not Recommended

The Panel considered a variety of proposals that would increase employment among beneficiaries by using a less strict test of eligibility for benefits. We are not recommending them because of their cost. Further, we believe that our recommendation for a DWTC — a wage subsidy for low-income workers with disabilities — is a more target effective and equitable way to encourage work for low-income persons whose impairments limit, but do not preclude, work.

Proposals that on their face sound appealing because they would increase the "work friendliness" of disability benefit programs by expanding eligibility for benefits are discussed in chapter 4 and include:

- Paying benefits based on impairment irrespective of its impact on ability to work, as is done in the Veterans' Compensation program, which pays veterans for impairments ranging from 10% to 100%.

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[42] Social Security Administration, Office of the Actuary, memoranda, January 25, 1995 and December 7, 1995.

[43] Health Care Financing Administration, Office of the Actuary.

[44] Social Security Administration, Office of the Actuary, memorandum, June 15, 1994.

[45] The proposal would change the order in which impairment-related work expenses are deducted from earnings so that they are excluded after, not before, the exclusion of half of earned income under the SSI earned income exclusion.

[46] Social Security Administration, Office of the Actuary, memorandum, June 19, 1995.

[47] Social Security Administration, Office of the Actuary, memorandum, June 16, 1995.

[48] SSI Modernization Project, *Final Report of the Experts* (Baltimore, MD: Social Security Administration, August 1992), p. 103.

[49] Social Security Administration, Office of the Actuary, memorandum, December 7, 1995; and Health Care Financing Administration, Office of the Actuary.

The obvious appeal of such an approach is that benefits are not affected by the recipient's work effort. But, to pay benefits to working-age persons with impairments comparable to a 50% or higher rating on the scale used for Veterans' Compensation could mean paying benefits to a population roughly twice the size of the current disability beneficiary population. Furthermore, the rationale for Veterans' Compensation is based on the government's liability, as employer, to compensate veterans (or their survivors) for harm sustained or lives lost while in military service in the government's employ. That rationale does not extend to income support for all members of society.

- Paying benefits based on an occupational test of disability.

  Many long-term disability insurance contracts use an occupational test — inability to perform one's own occupation — which pays benefits to those who are unable to do the kind of work they have done before. This approach could be viewed as more "work friendly" because it would allow benefits to individuals who are able to do other work. The increased cost of an occupational disability program would depend on the specifics of its design, but the increases are likely to be substantial. One proposal for using an occupational test in Social Security was estimated to increase the cost of the DI program by about $20 billion per year (in 1994 dollars) after 10 years.

- Paying partial benefits for partial loss of earnings capacity as is done is some foreign disability systems.

  The obvious appeal of such systems is that they recognize that work disability is a continuum. Some individuals sustain reduced earnings capacity, but nonetheless are able to work fewer hours or at reduced wage rates. The benefits help to compensate for partial disability. Foreign systems that pay partial disability benefits, such as in Sweden or The Netherlands, spend several times more on disability benefits as a share of GDP that does the United States on DI and SSI benefits. Further, payments for permanent partial disability in workers' compensation systems in the United States have been found to be the most contentious and costly part of cash compensation payments.

- Providing a partial benefit offset for DI beneficiaries, as is currently provided to SSI beneficiaries, by reducing DI benefits by $1 for each $2 of earnings as beneficiaries return to work.

  As discussed in chapter 9, the appeal of this approach is that by easing the transition off the DI benefit rolls, it could encourage more DI beneficiaries to return to work. Such a proposal, however, would also result in many more people receiving benefits. Benefit savings from more beneficiaries returning to work would be more than offset by increased benefit payments where none would now be paid. The net cost over a 5-year period is estimated to be $5.1 billion. Furthermore, such a proposal would pay partial DI benefits to some individuals who have quite high incomes from work.

In brief, the Panel recognizes that the current DI and SSI programs employ a very strict test of work disability. Easing the strictness of the test would result in more people receiving benefits. As such it would increase the size and cost of disability benefit programs. We believe our proposal for a tax credit that is a wage subsidy for low-income workers with disabilities is a more effective and equitable way to encourage work when impairments limit, but do not preclude, work.

THE POSITION OF DENIED APPLICANTS

Question 4: *How might we improve protection for the large numbers of claimants who are denied benefits but still do not find work?*

The problem of income support for those who are denied benefits but do not find work is a particularly challenging one in the United States. The difficulty is not a shortage of models to choose from, but of the willingness to implement and pay for them.

Most other industrialized countries have much more comprehensive protections for those with partial disabilities who cannot find work. They include universal health care coverage, universal short-term sickness benefits, extended unemployment benefits, family allowances, public employment programs, subsidies for employer accommodations and more widespread general assistance for the poor.

Applicants who are denied benefits at the last step of the Social Security determination process would be eligible for the Panel's DWTC. They are individuals who have severe impairments and are found unable to do their past work, but are considered able to do other work. If they succeed in gaining employment, they would be eligible for the DWTC.

If SGA is indexed as proposed, then some persons with very limited earning ability would no longer be denied benefits. And if states create affordable buy-ins to their Medicaid programs for working people with disabilities, as endorsed by the Panel, this could be of significant assistance to denied claimants. Further, the federal/state VR program remains available to provide publicly-financed rehabilitation services to individuals who do not receive Social Security benefits, including denied applicants. In general, however, the Panel's recommendations are directed at promoting work opportunities for existing beneficiaries or for nonbeneficiaries who are able to work some despite their impairments. The federal Social Security disability insurance program rightly targets earnings-replacement support to persons with very severe work disabilities. Broader social and economic policies for job creation, job training, employment assistance and generalized income support for those disadvantaged in the labor market remain critically important. These remedies lie beyond the scope of disability income policy.

Chapter 1

The Nature of Work Disability: What Do We Mean by Disability?

In common parlance "disability" is used to cover a wide range of circumstances. For the purpose of clarifying the nature of *work disability*, the Disability Policy Panel drew on a conceptual model from the disability research literature. The model defines disability as a limitation in performing a social role, such as work. Viewed in this way, a physical or mental impairment that poses a limitation in functioning is a necessary element of any disability. But neither the impairment nor the functional limitation it causes necessarily results in disability. Rather, disability in the work role involves the interaction of the following four elements:

- a person's chronic health condition or impairment;
- the tasks that constitute work the person can reasonably be expected to do;
- the person's offsetting capacities or compounding limitations in performing those tasks; and
- the environment in which the person is expected to live and work.

In common usage, "disability" is defined more loosely. Dictionary definitions tend to use *incapacity*, *impairment* or *disadvantage* as synonyms for disability.[1] The phrase *persons with disabilities* is sometimes used more expansively than in the conceptual model to encompass persons with impairments, whether or not those impairments limit participation in roles such as work.[2]

A distinction between illness and impairment is also important in considering the nature of work disability. It is sometimes said, for example, that persons with disabilities are not sick, and should not be treated as such. That is, of course, true for some people with medically stable impairments who are in reasonably good health and without pain. Whether their impairment or functional limitation — such as in seeing, hearing or walking — results in work disability depends on the other elements of work disability — their other abilities, the tasks of work and the broader environment. At the same time, some persons with work disabilities are very ill and the illness is the overriding reason why they are unable to work.

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[1] *Webster's College Dictionary 1995* defines disability as: (1) lack of adequate strength or physical or mental ability; incapacity; (2) a physical or mental handicap, especially one that prevents one from living a normal life or holding a specific job; and (3) anything that disables or puts one at a disadvantage. *The American Heritage Dictionary 1992* defines disability as: (1) the condition of being disabled: incapacity; the period of such condition; (2) a disadvantage or deficiency, especially a physical or mental impairment that prevents or restricts normal achievement; and (3) something that hinders or incapacitates.

[2] In this report, the term "people with disabilities" is sometimes used to describe the broader population of persons with chronic health conditions or impairments. Often an individualized assessment is needed to distinguish between impairment and work disability. The distinction is important in developing policies to remedy the consequences of work disability.

"Disability" is also defined in various public laws or private contractual arrangements. These legal definitions are part of systems meant to provide remedies — such as services or civil rights protections — or cash support to individuals who meet a particular definition of disability. Here, the definition of disability is used as an eligibility criterion and is directly related to the kinds of remedies or benefits the system offers. Chapter 4 discusses these legal definitions of disability.

This chapter lays out the Panel's conceptual model of work disability and how work disability can in some cases be remedied by addressing any of the four elements of work disability. It also reviews the landscape of programs that offer these various remedies for work disability and those that provide earnings-replacement income for disabled workers.

The chapter then describes the size and attributes of the population with chronic health conditions, functional limitations or work disabilities. Chronic health conditions are highly prevalent in the population; persons with work disabilities are only a subset of them. Those who receive Social Security disability insurance (DI) or Supplemental Security Income (SSI) are the subset who have the most significant work disabilities.

Finally, the chapter draws on focus group interviews with DI and SSI beneficiaries to convey their experience with other remedies before they turned to cash benefits. Interviews with mature adult beneficiaries included persons with serious illnesses that cut short their work lives and their remaining life expectancy; others with painful injuries that impede a broad range of the tasks of the work they used to do — such as lifting, standing, stooping, walking or sitting; and others with mental impairments that significantly limit their ability to function in a competitive labor market. Interviews with young adult beneficiaries, ages 18 to 25, included college students with visual impairments; persons with mental retardation who, with the aid of supportive families or case workers, were working part-time; and others who had not found work they could do with their disabilities. Parent interviews included some whose young adult sons or daughters have very significant cognitive or multiple impairments that preclude competitive work or participation in a focus group. Excerpts from the focus group interviews are in the appendix.

A CONCEPTUAL MODEL OF WORK DISABILITY

To clarify the nature of work disability and the various policy responses to it, the Panel adopted a conceptual model of disability developed by the Institute of Medicine Committee on Disability Prevention. This model draws heavily on work developed over the years by Saad Nagi and the World Health Organization[3] and is similar to models used by other prominent disability researchers.[4] In this model, disability is defined as a limitation in performing a social role, such as work, and is evidenced by the following findings with respect to an individual:

- a *medical condition* or pathology, which is manifest at the level of cells or tissues;
- an *impairment*, which is evident at the level of organs or organ systems, and represents a loss or abnormality of mental, emotional, physiological, or anatomical structure or function (including pain);
- a *functional limitation*, which is evident at the level of the person, and represents, as a result of an impairment, a restriction or lack of ability to perform particular tasks or activities.

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[3] A.M. Pope and A.R. Tarlov, (eds.), *Disability Prevention in America: Toward a National Agenda for Prevention* (Washington, DC: National Academy of Sciences, 1991), pp. 78-83.

[4] Similar four-stage models are described in other studies, for example: *Report and Plan for Medical Rehabilitation Research*, National Advisory Board, Lex Frieden, Chair, NIH, 1992; *Public Health Service Task Force on Improving Medical Criteria for Disability Determinations*, Raymond Seltzer, Chair, April 1992; M. A. Hill, *Disability Counts: The New Jersey Disability Survey*, Disability and Health Economics Research, Bureau of Economic Research, Rutgers University, July 1992; World Health Organization *International Classification of Impairments, Disabilities and Handicaps: A Manual of Classification Relation to the Consequences of Disease* (Geneva, Switzerland: World Health Organization, 1980).

Figure 1-1. Conceptual Model of Disability

Medical condition	Impairment	Functional limitation	Disability
Interruption or interference of normal bodily processes or structures	Loss and/or abnormality of mental, emotional, physiological, or anatomical structure or function; includes all losses or abnormalities, not just those attributable to active pathology; also includes pain	Restriction or lack of ability to perform an action or activity in the manner or within the range considered normal that results from impairment	Inability or limitation in performing socially defined activities and roles expected of individuals within a social and physical environment
Level of reference			
Cells and tissues	Organs and organ systems	Organism—action or activity performance (consistent with the purpose or function of the organ or organ system)	Society—task performance within the social and cultural context
Examples of levels			
Denervated muscle in arm due to trauma	Atrophy of muscle	Cannot pull with arm	Unable to do past job; can no longer swim recreationally

Source: A.M. Pope and A.R. Tarlov, (eds.), *Disability Prevention in America: Toward a National Agenda for Prevention* (Washington, DC: National Academy of Sciences, 1991), p. 79.

- a *disability*, when performance of a social role (such as work) is precluded or limited as a result of the interaction among the person's impairment, the tasks that constitute that role, the individual's skills and abilities, and the broader environment.

Figure 1-1 illustrates the four stages of the model, including examples of the distinctions among them.

The conceptual model draws important distinctions among disability-related concepts: chronic health conditions, which vary widely in their severity and duration; impairments, which may or may not limit functioning; functional limitations in performing particular tasks; and work disability. It makes clear that work disability is not just an impairment. Rather it involves the interaction among the following four elements:

- a person's physical or mental impairment;
- tasks that constitute work he or she can reasonably be expected to do;
- his or her offsetting abilities or compounding limitations in performing those tasks; and

- the broader social, economic and architectural environment.

The model suggests that the range of remedies for work disability may address any of the elements that cause it by changing:

- the *impairment* itself through health care, medications, or medical restoration;
- the *tasks* of work through job accommodation or the use of assistive equipment;
- the person's *abilities* and skills through education, training, or vocational rehabilitation; and
- the *environment* through physical accommodations or public access improvements.

Income support — from insurance benefits or DI or SSI — is not a remedy for work disability. Instead, it ameliorates one of the major consequences of work disability — loss of income from earnings — when work disabilities are not amenable to remedies. It also is used during periods of work incapacity while remedies are being tried.

THE LANDSCAPE OF REMEDIES FOR WORK DISABILITY

The following section surveys the landscape of policies that may prevent or remedy the consequences of work disability. They are broad and diverse and are financed by employers, individuals, and all levels of government. Potential remedies include: health care, environmental accommodations, rehabilitation, education and training, and social services. The sources of financing these remedies, and the level of national spending, when available, are noted.

Access to Health Care

Appropriate health care before or after the onset of an illness or injury can prevent, delay, cure or control the disabling consequences of some types of impairments. National spending for health care is significant — estimated to be just over $1,000 billion in 1994.[5] That spending is for all age groups in society and is shared by all sectors of the economy — private businesses, households and all levels of government. A recent analysis found the following shares of total national health care spending contributed by various sectors of the economy:[6]

- 29 percent was paid by private businesses for health care coverage for their employees. This expenditure covers private insurance premiums, workers' compensation health care and Medicare contributions.
- 35 percent was paid by individuals and families in households. This expenditure includes 20 percent that was paid out of pocket. The other spending was for private insurance premiums, Medicare contributions paid by workers and Medicare premiums paid by elderly and disabled persons.
- 17 percent was paid by state and local governments. This expenditure includes 5 percent for private insurance and Medicare contributions for their employees, about 6 percent for Medicaid, and 6 percent for other state or local health care programs.
- 19 percent was paid from general revenues of the federal government, including about 5 percent for coverage of current or former employees (civilians, the armed services and veterans). The other spending was for Medicaid (8 percent), the general revenue contribution to Medicare (5 percent) and other federal health programs (1 percent).

In spite of the sum spent on health care and the varied sources of financing, about 1 in 5 nonelderly Americans are without health care coverage. They include 20 percent of working adults, 23 percent of nonworking adults, and 16 percent of children. As

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[5] S.T. Burner and D.R. Waldo, "National Health Expenditure Projections, 1994-2005," *Health Care Financing Review,* Summer 1995, p. 221.

[6] C.A. Cowan and P.A. McDonnell. "Business, Households, and Governments: Health Spending, 1991," *Health Care Financing Review,* Spring 1993, pp. 227-48.

discussed in chapter 8, gaps in health care coverage can result in unnecessary work disability when uninsured Americans fail to get the care they need to prevent, treat, cure or ameliorate the disabling consequences of their conditions. Lack of health care coverage can also result in under employment of people with impairments who might be able to work if they could obtain health care coverage.

Civil Rights Protection

The Americans with Disabilities Act of 1990 (ADA) addresses the environment of work disability in several ways. First, provisions for making public buildings and transportation accessible for persons with mobility impairments will gradually remove those barriers to getting to work. Second, the Act bans discrimination against persons with disabilities who can perform the essential functions of the jobs they seek to hold or retain. By challenging negative stereotypes, the ADA encourages employers to reach out to qualified persons with disabilities in their recruitment activities. Some now actively do so.[7] Finally, it requires employers to make reasonable accommodations for workers with disabilities when the accommodations do not place an undue hardship on the employer. All these provisions hold promise for improving employment prospects for persons with impairments who are, in fact, able to work, but in the past have been prevented from doing so by architectural barriers or unwarranted discrimination.

Job accommodations are financed largely by employers, both private and governmental. Job accommodations have been found to be successful in enabling ill or injured workers to remain on their jobs, even before the ADA was enacted. A study based on data from the Social Security Administration's (SSA's) 1978 Survey of Disability and Work found that about 30 percent of men with work disabilities had been accommodated by their employers at the onset of their work-limiting health condition, and those accommodations increased the period of time they remained at work.[8] An analysis of the 1991 Health and Retirement Study also found that about 27 percent of men who had work limitations received job accommodations that increased their likelihood of remaining on the job.[9]

Vocational Rehabilitation Services

Vocational rehabilitation (VR) addresses work disability by enhancing workers' skills in relation to the tasks of work they could do. VR includes provision of assistive devices so that workers can perform tasks of work despite particular functional limitations. It also includes vocational training to enable workers with impairments to do work they have not done before. Workers' compensation and long-term disability insurers in some cases finance rehabilitation for their claimants. The federal/state VR program finances rehabilitation services for others.

Spending for the federal/state VR program in FY 1994 was about $2.7 billion, with about 80 percent from federal funds and the rest financed by states.[10]

In FY 1994, state VR agencies processed a total of about 675,000 applications for publicly-financed VR services, found 480,000 persons eligible for services and successfully placed about 200,000 persons in competitive employment, self-employment or other agreed-upon outcomes, which include unpaid homemaking, family work and sheltered employment.[11] A placement is counted as a success if the individual remains in the position for 60 days.[12]

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[7] "The New Competitive Advantage: Expanding the Participation of People with Disabilities in the American Work Force," *Business Week,* May 30, 1994.

[8] R.V. Burkhauser, et al., "The importance of Employer Accommodation on the Job Duration of Workers with Disabilities: A Hazard Model Approach," *Labor Economics,* June 1995, pp. 1-22.

[9] K.K. Charles, "Employer Accommodation and the Early Post-Onset Separation of Disabled Workers," unpublished paper, Cornell University, June 1995.

[10] U.S. Department of Education, Rehabilitation Services Administration.

[11] Ibid.

[12] U.S. Department of Education, Rehabilitation Services Administration, *Annual Report to the President and to the Congress on Federal Activities Related to the Rehabilitation Act of 1973, as Amended, Fiscal Year 1992,* (Washington, DC: U.S. Department of Education, 1992), p. A-2.

Most people that VR agencies successfully serve are not Social Security or SSI recipients. In 1992, about 20 percent of all those considered successfully rehabilitated were Social Security or SSI beneficiaries: they include 15 percent of those placed in competitive employment, 70 percent of those placed in sheltered employment and 40 percent of those placed in unpaid homemaking or family work.[13]

Education and Training

General investments in education for the whole populace also can, in some cases, remedy or prevent work disability by developing workers' aptitude and skills. The statistical profile later in this chapter shows that advanced education reduces the risk of work disability. This may occur in two ways. First, advanced education greatly improves employment prospects for youths who enter adulthood with physical or sensory impairments. Second, for nondisabled workers, having the skills to do mind work reduces the prospects that the future onset of physical impairments will impede their ability to remain at work.

Elementary and secondary education is financed largely by local and state governments. Post-secondary education is financed largely by states and by private individuals or philanthropy. Total U.S. spending on education in 1992 was $292 billion in local, state and federal funds, and $100 billion in private funds.[14]

Much learning of new technology, such as the use of computers, occurs on the job. This training is financed by employers through formal or informal arrangements and also can remedy or prevent work disability by enhancing workers' skills that are directly related to their work tasks. A recent study found that both advanced education and use of computers improved the employment and earnings prospects of spinal cord-injured workers. The same benefits are likely to accrue to individuals with other impairments. The study also found that most training in the use of computers occurred on the job, rather than in other training settings. Thus, computer literacy before the onset of disability improved prospects for post-injury employment.[15]

Supports for Children with Disabilities

Early intervention, special education, and transition planning services for youths with disabilities increase the prospects that children with disabilities will be able to engage in productive employments as adults. These services are financed by local, state and federal funds and are discussed further in the report to the Panel of its Committee on Childhood Disability, *Restructuring the SSI Disability Program for Children and Adolescents.*

Supports for Persons with Mental Disorders

Psychosocial rehabilitation, day treatment, case management and supported or sheltered employment serve the nation's most vulnerable citizens with cognitive impairments or severe mental illness. In some cases they enable clients to work, at least part time. These services are financed by local and state governments and by the federal/state Medicaid program.

In brief, the range of remedies for work disability focus on any of the four elements that cause it. They include: health care, to prevent or treat *illness or injury;* rehabilitation, which seeks to improve *abilities* in relation to job *tasks;* civil rights protections that address the broader *environment;* and education and training, which enhance workers' *skills* in relation to job demands.

These diverse remedies are often organized and financed locally, by employers or local or state governments. In some cases, however, work disability cannot be prevented or remedied. Income support systems ameliorate one of its major consequences — loss of income from earnings.

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[13] U.S. Department of Education, Rehabilitation Services Administration. See also table 6-2.

[14] Social Security Administration, *Annual Statistical Supplement to the Social Security Bulletin* (Washington, DC: U.S. Government Printing Office, August 1995), tables 3.A3 and 3.A4, pp. 152-53.

[15] D. Kruse and A. Krueger, *Disability, Employment and Earnings in the Dawn of the Computer Age,* unpublished report funded by the New Jersey Developmental Disabilities Council through the Disability Research Consortium, Bureau of Economic Research, Rutgers University, New Brunswick, NJ, October 1995.

EARNINGS-REPLACEMENT BENEFITS

Income support programs have a different purpose from the remedial programs discussed above. They ameliorate one of the consequences of work disability by replacing part of lost earnings while workers are unable to work. They help workers and their families meet day-to-day living expenses — housing, food and other living expenses — while other remedies are tried. And they provide ongoing support when returning to work is not feasible. They are not designed to be adequate to pay for the remedies discussed above. Those remedies — health care, rehabilitation, training and so forth — are financed and allocated separately. Earnings-replacement benefits include short-term benefits during temporary periods of work incapacity, although those benefits are not available to all workers. They also include workers' compensation, private long-term disability insurance, Social Security disability insurance and SSI assistance.

Short-Term Sickness and Disability Benefits

Short-term sickness benefits support workers while they recover from temporary illness, injury or disability (often including maternity leave) so that they can return to their jobs. Five states and the Railroad Retirement system have mandatory programs of short-term disability insurance that are financed by employees and, in some cases, by employers.[16] In other states, these benefits are offered at the discretion of the employer or are union-negotiated, and are generally financed by employers. Spending for private short-term disability benefits totalled $14.6 billion in 1992; an additional $4.0 billion was paid through state mandatory temporary disability insurance programs.[17]

About 44 percent of private sector employees are covered by some type of short-term disability insurance (including 24 percent who also have sick leave). Another 26 percent have formal sick leave policies only. About 30 percent of private sector workers, however, do not have any formal sick leave or short-term disability income protection.[18]

Workers' Compensation

About 87 percent of all American workers are covered by workers' compensation (WC), which pays for health care and cash benefits for workers injured on the job. Each state has its own program. Benefits are financed by insurance premiums paid by employers and are experience rated; that is, premiums are higher for employers who experience higher claims by workers injured on the job. Some states administer their WC programs through a state fund. Others require that employers purchase private insurance or self-insure for WC. WC pays temporary cash benefits while the injured worker is absent from work and long-term benefits (or lump-sum settlements) for permanent total or partial disability.

Total spending on WC benefits in 1993 was $42.9 billion. Of the total, $23.4 billion was for disability benefits, $2.0 billion for survivor benefits, and $17.5 billion for medical care. In 1992, annual growth in WC benefits was the lowest in more than a decade and in 1993 spending actually declined. The decline occurred mainly in plans that are administered by private insurers, where 1993 spending for WC benefits was 16 percent lower than in 1991 in inflation adjusted dollars. The change is attributed, in part, to efforts to control costs by implementing health care cost containment and stricter procedures for evaluating impairments.[19]

Long-Term Disability Insurance

Long-term disability insurance (LTDI) coverage is provided to workers at the employer's discretion or is negotiated by unions. Total spending for private

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[16] Mandatory temporary disability insurance programs are in California, Hawaii, New Jersey, New York and Rhode Island.

[17] Social Security Administration, op. cit., footnote 14, tables 3.A3 and 3.A4, pp. 152-53. Public sector employees are included in the totals for state mandatory temporary disability insurance. They are not included in the total for private short-term sickness and disability benefits.

[18] Disability Policy Panel, *The Environment of Disability Income Policy: Programs, People, History and Context,* Interim Report, J.L. Mashaw and V.P. Reno (eds.) see discussion in chapter 2, (Washington, DC: National Academy of Social Insurance, 1996).

[19] J.A. Schmulowitz, "Workers Compensation: Coverage, Benefits and Costs, 1992-93," *Social Security Bulletin,* Summer, 1995.

group LTDI benefits in 1992 was about $3.1 billion.[20] Private LTDI sometimes offers a bridge between temporary disability benefits and the return to work. Many LTDI contracts use an occupational test of disability — inability to perform the duties of one's own occupation — for the first two years, and then shift to a stricter test — inability to do any occupation. LTDI benefits for up to two years, therefore, are available to some workers who may be able to recover and return to their prior occupation or learn skills for a new line of work. In some cases, employers or insurers pay for rehabilitation services during the initial period of long-term disability benefits to help workers return to work if they can.

In other cases, LTDI benefits supplement the modest level of earnings replacement that Social Security provides to middle- and upper-income workers. Such plans often require or assist recipients of LTDI benefits to apply for Social Security. This is done because the LTDI benefits the insurer pays are generally reduced by the amount of Social Security benefits the worker receives. About 25 percent of private sector workers are covered by LTDI. Coverage rates are higher among professional, technical, and managerial workers (47 percent) and lower among production and service workers (13 percent).[21]

Social Security Disability Insurance

Social Security disability insurance provides income to partially replace earnings for insured workers who sustain severe, long-term work disabilities. Benefits are paid after a five-month waiting period after the onset of work disability and are subject to a strict test of work disability — inability to engage in any substantial gainful activity. Benefits are financed by Social Security contributions paid by employees and employers. In December 1994, benefits were paid to about 4.0 million disabled workers.[22] Total benefit payments to disabled workers and their dependents were $37.7 billion in 1994.[23]

Supplemental Security Income

Finally, the Supplemental Security Income program provides income support to persons with severe work disabilities whose countable income from all other sources falls below a federal standard ($470 for an individual in 1996). The benefits are financed from federal general revenues, and some states supplement the basic federal benefit. In December of 1994, about 3.3 million blind and disabled working-age adults received federally-administered SSI benefits.[24] About $14.7 billion was paid in SSI benefits for working-age adults in 1994.[25]

In brief, the DI and SSI programs are part of a broader system of earnings-replacement benefits for work disability that are financed by employers and employees. A fuller discussion of the purpose and design of the DI and SSI programs is in chapter 2.

Social Security disability and SSI are typically programs of last resort. As shown in the following section, persons who turn to DI or SSI are only a subset of the much larger population of persons with chronic health conditions, impairments or work disabilities.

THE POPULATION WITH DISABILITIES

The population of working-age persons with any sort of chronic health condition, functional limitation or disability is broad and diverse. The number who have work disabilities is only a subset of the population with any type of functional limitation (or the even larger population with any type of health condition). Those who receive DI or SSI benefits are a subset of those with work disabilities.

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[20] Social Security Administration, op. cit., footnote 14, table 3.A4, p. 153.

[21] Disability Policy Panel, op. cit., footnote 18, table 2-5.

[22] Social Security Administration, op. cit., footnote 14, table 3.C6.1, p. 160.

[23] Social Security Administration, op. cit., footnote 14, table 4.A6, p. 179.

[24] Social Security Administration, op. cit., footnote 14, table 3.C6.1, p. 160.

[25] In 1994, the $14.7 billion in SSI benefits for persons age 18-64 included $13.0 billion in federal benefits and $1.7 billion in federally-administered state benefits. Social Security Administration, Office of Research and Statistics.

Table 1-1. Prevalence of Mental Illness, Persons Ages 18 to 64, 1990[a]

	Prevalence rate			
Type of disorder	One month	New cases over the following year	Annual prevalence	Number of persons per year[b] (millions)
Mental disorders (other than addiction)	13.0	8.8	21.8	34.2
Schizophrenia	0.8	0.3	1.2	1.9
Affective disorders	5.6	4.4	10.0	15.7
Any bipolar	0.7	0.6	1.3	2.0
Unipolar major depression	2.0	3.3	5.3	8.3
Dysthymia	3.6	2.0	5.6	8.8
Anxiety disorders	7.7	5.2	12.9	20.3
Phobia	6.5	4.6	11.1	17.4
Panic disorder	0.6	0.8	1.4	2.2
Obsessive-compulsive disorder	1.4	0.8	2.2	3.5
Somatization disorder	0.1	0.1	0.2	0.3
Cognitive impairment (severe)	0.8	0.6	1.4	2.2

a. Table shows the combined community and institutionalized population of five Epidemiological Catchment Area sites.
b. Number of persons is based on 1990 U.S. Census.
Source: National Institute of Mental Health, unpublished data updating D.A. Regier, et al., "The de Facto U.S. Mental and Addictive Disorders Service System: Epidemiological Catchment Area Project 1-Year Prevalence Rates of Disorders and Services," *Archives of General Psychiatry*, February 1993, table 1, p. 88.

- About half the entire U.S. population, including children and elderly persons, is reported to have some type of chronic health condition or impairment.[26] About 34 million working-age Americans experienced a spell of mental illness over the course of a year.[27]

- Nearly 30 million working-age Americans have some type of functional impairment, which may or may not limit their ability to work.[28]

- Nearly 17 million Americans report having a work disability — they report having impairments that limit the kind or amount of work they can do.[29]

- Working-age adults who receive Social Security or SSI disability benefits — 7.1 million people[30] — are a subset of the 17 million who have a work disability. They are those with the most significant work disabilities.

Chronic Conditions or Impairments

A large proportion of the U.S. population reports having a chronic health condition or impairment. Frequently, these conditions do not present significant functional limitations, although some do. The National Health Interview Survey found that the most prevalent chronic condition reported is chronic sinusitis (about 34 million people), followed by arthritis (31 million), hypertension (28 million), and

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[26] M.P. LaPlante, "The Demographics of Disability," *The Americans with Disabilities Act: From Policy to Practice*, J. West (ed.) (New York, NY: Milbank Memorial Fund, 1991).
[27] National Institute of Mental Health, Diagnostic Interview Schedule, Epidemiological Catchment Area Project.
[28] Persons age 15-64. U.S. Bureau of the Census, *Americans with Disabilities: 1991-92, Data From the Survey of Income and Program Participation*, P70-33 (Washington, DC: U.S. Government Printing Office, December 1993), table 12, pp. 38-39
[29] U.S. Bureau of the Census, Current Population Survey, March 1994.
[30] Social Security Administration, op. cit., footnote 14, table 3.C6.1, p. 160.

Table 1-2. Prevalence of Limitations in Performing Tasks or Disabilities for Persons Ages 15 to 64, 1991-92

	Number (thousands)	Percent of population	Employment rate[a]
Total persons	**165,040**	**100.0**	75.1
With no limitation	135,558	82.1	80.5
With a functional limitation or disability	29,482	17.9	52.0
Difficulty Performing Tasks			
Has difficulty with:			
Seeing ordinary newsprint, with glasses if used	4,801	2.9	45.6
Hearing normal conversation with aid, if used	5,522	3.3	63.6
Having speech understood	1,517	0.9	34.9
Lifting and carrying 10 pounds	7,827	4.7	32.0
Climbing stairs without resting	8,068	4.9	30.0
Walking 3 city blocks	7,937	4.8	31.4
One or more tasks	18,948	11.5	48.6
Only one	9,826	6.0	63.8
Two	3,980	2.4	46.7
Three or more	5,143	3.1	21.9
Unable to perform tasks			
Unable to:			
See ordinary newsprint, with glasses if used	579	0.4	25.6
Hear normal conversations with aid, if used	364	0.2	58.2
Have speech understood	161	0.1	24.4
Lift and carry 10 pounds	3,121	1.9	22.3
Climb stairs without resting	3,595	2.2	20.5
Walk 3 city blocks	3,243	2.0	20.8
One or more tasks	6,552	4.0	27.6
Only one	3,642	2.2	36.1
Two	1,593	1.0	22.8
Three or more	1,361	0.8	10.6

a. Employment rate is for those ages 21 to 64.

Source: U.S. Bureau of the Census, *Americans with Disabilities: 1991-92, Data From the Survey of Income and Program Participation*, P70-33 (Washington, DC: U.S. Government Printing Office, December 1993), pp. 18-19 and 62-63.

Table 1-3. Prevalence of ADL Limitations, Use of Mobility Aids or Disabilities for Persons Ages 15 to 64, 1991-92

	Number (thousands)	Percent of population	Employment rate[a]
Total persons	165,040	100.0	75.1
With no limitation	135,558	82.1	80.5
With a functional limitation or disability	29,482	17.9	52.0
ADL limitations[b]			
Has difficulty with any ADL	3,442	2.1	25.2
Needs personal assistance with one or more ADLs	1,514	0.9	18.1
IADL limitations[c]			
Has difficulty with any IADLs	5,080	3.1	22.9
Needs assistance with one or more IADLs	3,585	2.2	19.5
Use of mobility aids			
Uses a wheelchair	529	0.3	18.4
Other aids only — cane, crutches or walker	1,115	0.7	17.6
Mental or emotional impairment[d]			
Any mental or emotional impairment	5,746	3.5	43.0
Mental retardation	1,151	0.7	30.8
Work disability			
With a work disability	18,017[e]	10.9	36.9
Unable to work	7,588	4.6	0.0
With a housework disability	9,641	5.8	30.9
Unable to do housework	1,235	0.7	11.6

a. Employment rates are for those ages 21 to 64.

b. ADLs are defined as: getting around inside the home; getting in or out of bed or a chair; taking a bath or shower; dressing; eating; and using the toilet (including getting to the toilet).

c. IADLs are defined as: getting around outside the home; keeping track of money and bills; preparing meals; doing light housework (such as washing dishes or sweeping the floor); and using the telephone.

d. The existence of specific conditions including: (1) dyslexia, (2) mental retardation, (3) developmental disabilities such as autism or cerebral palsy, (4) Alzheimer's disease, senility, or dementia, and (5) any other mental or emotional condition.

e. Those with work and housework disabilities are limited to those ages 16 to 64.

Abbreviations: ADL = activities of daily living, IADL = instrumental activities of daily living.

Source: U.S. Bureau of the Census, *Americans with Disabilities: 1991-92, Data From the Survey of Income and Program Participation,* P70-33 (Washington, DC: U.S. Government Printing Office, December 1993), pp. 18-19 and 62-63.

an orthopedic impairment (28 million). Together, the number of people with these health conditions or impairments constitute more than half the population.[31] Another survey some years earlier also found that nearly one-half of the working-age population has one or more chronic health conditions or impairments.[32]

Mental Disorders. General purpose household surveys have rather rudimentary data on the prevalence of mental or emotional disorders.[33] The National Institute of Mental Health (NIMH) has conducted special surveys to measure the prevalence of mental disorders in the U.S. population. Its Epidemiological Catchment Area program provides estimates of the prevalence of mental illness in the household and institutional populations combined. NIMH finds that about 34 million people ages 18 to 64, or 22 percent of the working-age population, experience some type of mental disorder during the course of a year (table 1-1). The two most common were affective disorders (bipolar disorder, major depression and dysthymia), that affected about 10 percent of the working-age population over the course of a year, and anxiety disorders (phobia, panic disorder and obsessive-compulsive disorder), that affected about 13 percent of working-age adults. Schizophrenia was reported to affect about 1.2 percent of the working-age population.

Mental illness varies widely in severity and duration. Overall, about half of working-age persons with various types of mental illness were employed at the time their illness was reported. And, as found in other surveys, employment rates are higher for men (64 percent) than for women (42 percent). While the employment rates for those with mental illnesses are high, the rates are lower than for the general population estimated in the same survey (77 percent for men and 49 percent for women).[34]

According to the Medical Outcomes Study, depression-related impairments can be particularly disabling. When compared to a range of other prevalent chronic conditions, such as arthritis, diabetes and cardiac conditions, depression-related impairment is exceeded only by cardiac impairment in terms of the limitation it poses on functioning, particularly with respect to days spent in bed.[35] The National Mental Health Advisory Committee estimates that about 12 percent of persons with affective disorders are considered to have severe mental disorders, based on functional criteria. This finding suggests that about 1.9 million of the 15.7 million working-age adults who experience affective disorders have disabling levels of the illness over the course of a year.

Functional Limitations

Nearly 30 million persons — or 18 percent of the working-age population — are reported to have some type of functional limitation or disability due to a physical or mental impairment, according to the 1991-92 Survey of Income and Program Participation (SIPP). This household survey counts persons with disabilities as those who have limitations in performing various activities that include: work; housework; tasks, such as seeing, hearing, speaking, walking, lifting or climbing stairs; activities of daily living (ADLs) that include bathing, eating, dressing, getting in or out of bed or getting around inside the home; and instrumental activities of daily living (IADLs) that include getting around outside the home, keeping track of money and bills, preparing meals, doing light housework and using the telephone. Also included among those with disabilities

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[31] M.P. LaPlante, op. cit., footnote 26, pp. 61 and 65.

[32] A. Krute and M.E. Burdette, "Prevalence of Chronic Disease, Injury and Work Disability," *Disability Survey 72: Disabled and Nondisabled Adults*, Research Report No. 56 (Baltimore, MD: Social Security Administration, Office of Research and Statistics, 1981).

[33] For example, the Survey of Income and Program Participation asked about whether those surveyed had any of the following: a learning disability such as dyslexia; mental retardation; a developmental disability such as autism or cerebral palsy; Alzheimer's disease, senility or dementia; or any other mental or emotional condition. About 3.5 percent of the working-age household population were reported to have one or more of these conditions.

[34] National Institute of Mental Health, unpublished data updating D.A. Regier, et al., "The de Facto U.S. Mental and Addictive Disorders Service System: Epidemiological Catchment Area Project 1-Year Prevalence Rates of Disorders and Services," *Archives of General Psychiatry*, February 1993, pp. 85-94.

[35] K. Wells, et al., "The Functioning and Well-being of Depressed Patients: Results from the Medical Outcomes Study," *Journal of the American Medical Association*, August 18, 1989, pp. 914-19.

are persons who use mobility aids, such as wheelchairs or canes, and persons who report particular kinds of mental or emotional disorders.

The most common activity limitation was a work disability, reported by 11 percent, or a limitation in ability to perform housework, reported by 6 percent of the working-age population. Among the various types of functions or tasks, the most common limitations involved strength or mobility. About 5 percent of the population each reported difficulty with one of the following: lifting and carrying 10 pounds; climbing stairs without resting; or walking three city blocks (table 1-2). Difficulty with seeing was reported by about 3 percent, and about 3 percent reported difficulty with hearing. About 2 percent of the population reported difficulty in performing at least one ADL; 3 percent reported difficulty with at least one IADL.

And in spite of the well-known disability symbol of a wheelchair, wheelchair users are a small proportion of the population. Those who have been using wheelchairs for six months or more accounted for about 0.3 percent of the working-age population in households. Another 0.7 percent have used other mobility aids, such as canes, crutches or walkers, for 6 months or more (table 1-3).

Employment Among Those with Functional Limitations. Among the working-age population, about half (52 percent) of those reported to have any functional limitations as measured by the SIPP are actually working — 58 percent of men and 44 percent of women. The employment rate for the total population without regard to functional limitations was 75 percent. Employment rates of those with functional limitations are higher among those ages 25 to 54, who rarely are students or retirees. In these age groups, about 2 in 3 men and 1 in 2 women with functional limitations were employed (table 1-4).

Employment rates also vary depending on the nature of the functional limitation being reported. Of those who report limitations in work, about 1 in 3 are working. Employment rates are higher among those who report difficulty in performing specific tasks such as seeing, hearing, speaking, lifting, walking, or climbing stairs. Of those who have difficulty performing at least one of these tasks, nearly half are working (49 percent). With a higher threshold of severity — inability to perform one or more of those tasks — the employment rate drops to just over one-fourth (28 percent). Employment rates also drop when people have combinations of these limitations — from 63 percent employed among those with a difficulty with only one of the six tasks to 10 percent employed among those who are unable to perform three or more of the tasks (table 1-2). Among the particular kinds of task limitations, employment rates are highest among those with hearing impairments. About 6 in 10 were employed among those who are unable to hear a normal conversation, even with a hearing aid, if normally used.

Table 1-4. Employment Rate for Persons with a Functional Disability, 1991-92 (percent)

Age	Total	Men	Women
Total (16-64)	51	58	45
16-24	44	44	44
25-54	59	66	53
25-34	57	64	51
35-44	62	69	56
45-54	58	66	51
55-64	35	43	26

Source: U.S. Bureau of the Census, Survey of Income and Program Participation, 1991-92.

Among those who use wheelchairs, nearly 1 in 5 are working; those who use other mobility aids, such as canes, crutches or walkers, are about as likely as wheelchair users to be employed. Similar employment rates (nearly 1 in 5) are found among working-age adults whose impairments are such that they need assistance with one or more ADLs or IADLs (table 1-3).

Table 1-5. Prevalence of Work Disability by Age and Educational Attainment, March 1994

		Educational attainment				
		Elementary only	High school		College	
Age	Total	0-8 years	1-3 years	4 years	1-3 years	4 years or more
		Percent reporting a work disability				
Total (16-64)	**10.1**	**15.8**	**20.2**	**34.4**	**21.1**	**8.5**
16-24	4.5	12.1	5.1	5.8	2.7	0.6
25-34	6.8	19.7	14.2	7.6	5.7	1.9
35-44	9.2	24.6	19.6	10.2	8.5	3.6
45-54	13.2	33.2	27.9	13.4	11.9	4.5
55-64	23.0	47.9	35.0	19.3	17.8	12.4
		Distribution of educational attainment of total population				
Ages 25-64	100.0	5.8	9.2	34.4	26.2	24.4

Source: U.S. Bureau of the Census, Current Population Survey, March 1994.

Work Disability

The Current Population Survey (CPS) uses a narrower measure of disability than the other surveys. It asks only about the prevalence of work disability — whether those surveyed have a physical or mental condition that limits the kind or amount of work they can do, or that prevents them from working. By this measure, about 16.8 million working-age adults (10 percent of the population age 16 to 64) had some type of work limitation.[36] This contrasts with the nearly 30 million (18 percent of the population) who had some type of functional limitation, as reported in the SIPP, or the 34 million (21 percent of the population) who experience mental illness over the course of a year.

Work Disability Rises with Age. The risk of work disability rises sharply with age, with persons ages 55 to 64 being four times as likely to have a work disability (22 percent) as persons ages 16 to 24 (fewer than 5 percent). The sharp increase in disability with age indicates that the onset of work disability usually occurs during the work life — often relatively late in the work life — rather than during childhood or adolescence (table 1-5).

Work Disability Declines with Advanced Education. Working-age Americans over the age of 25 who did not enter high school (6 percent) or have not completed it (9 percent) are at great risk of work disability, and that risk, too, rises with age. On the other hand, the advantages of post-secondary education in averting or compensating for the disabling consequences of chronic health conditions are evident among workers in all age categories.

- Among college graduates, the risk of work disability ranges from 2 percent of those age 25-34 to 11 percent of those age 55-64.
- For high school graduates, the risk of work disability ranges from 7 percent of those age 25-34 to 18 percent of those age 55-64.
- For high school dropouts, the risk of work disability ranges from 13 percent of those age 25-34 to 32 percent of those age 55-64.

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[36] U.S. Bureau of the Census, Housing and Household Economic Statistics Division.

Table 1-6. Percent Employed and Mean Earnings by Work Disability, 1994

	Percent employed in March 1994		Mean earnings in 1993	
	Persons with a work disability	Persons with no disability	Persons with a work disability	Persons with no disability
Total	27	75	**$15,618**	**$25,231**
Men	30	82	19,040	31,113
Women	24	69	11,093	18,434
		Age		
16-24	29	56	5,385	8,721
25-34	33	80	11,859	22,653
35-44	34	84	17,512	30,299
45-54	30	85	20,071	34,354
55-64	15	65	17,407	28,951
		Education[a]		
Less than 12 years	13	65	8,784	15,552
12 years	27	79	13,308	21,716
13-15 years	40	83	17,837	25,824
16 years or more	49	87	32,029	44,486

a. Educational attainment is for those ages 25 to 64.
Source: U.S. Bureau of the Census, Current Population Survey, March 1994.

Advanced education appears to reduce the risk of work disability in two ways. First, it greatly improves future employment prospects for youths who enter adulthood with physical impairments. Gaining the education needed to do mind work in lieu of physical work greatly improves chances they can work despite functional limitations such as in seeing, hearing or walking. Second, for the vast majority of young adults who begin their work lives without impairments, advanced education could be viewed as a form of protection against the risk of future work disability. This may occur for several reasons.

- By providing options to do less physically demanding white-collar jobs, advanced education may lower the risk of job-related injuries.
- If injuries do occur, they are more difficult to accommodate for a mechanic, meat packer or construction worker than for a white-collar worker who has the flexibility to accommodate such impairments by changing the physical environment in which work is performed.
- Finally, those with advanced education are likely to have a wider range of transferable skills to do other work if they are no longer able to do their past work. Those who do physical work may have fewer or no other work options as impairments associated with aging begin to limit movement, strength, and endurance.

Employment Among Those with a Work Disability. When they are compared with other working-age adults without work limitations, those with work disabilities not surprisingly have lower labor force participation rates and higher unemployment rates.

Table 1-7. Percent Employed Full-time and Year-Round Full-time Mean Earnings by Work Disability, 1994

	Percent employed full-time in March 1994		Mean earnings — year-round full-time in 1993	
	Persons with a work disability	Persons with no disability	Persons with a work disability	Persons with no disability
Total	**17**	**61**	**$28,449**	**$33,146**
Men	22	73	31,962	46,274
Women	13	49	21,760	31,732
		Age		
16-24	13	29	14,292	16,864
25-34	21	69	20,029	27,919
35-44	23	72	30,588	36,470
45-54	21	74	32,525	40,462
55-64	9	53	32,232	35,478
		Education[a]		
Less than 12 years	7	54	16,934	20,418
12 years	17	67	23,643	26,603
13-15 years	29	71	28,264	30,833
16 years or more	37	78	47,605	50,984

a. Educational attainment is for those ages 25 to 64.
Source: U.S. Bureau of the Census, Current Population Survey, March 1994.

- While 81 percent of working-age adults without work disabilities are in the labor force, just 32 percent of persons with work disabilities were in the labor force — that is, either employed or looking for work — in March 1994.

- The unemployment rate — those looking for work as a proportion of the labor force — was 6.7 percent for those without work disabilities, but it was 16.4 percent for those with work disabilities.

- In terms of actual numbers, job seekers who have work disabilities were outnumbered 9 to 1 by job seekers who were free of work limitations.

Thus, persons with disabilities who are looking for work must compete with large numbers of persons without limitations and who typically are younger.

The advantages of higher education are also evident in the employment and earnings of persons who have work disabilities. Within that population, one's chances of being employed and of working full-time throughout the year are improved by advanced education. Overall about 27 percent of persons with work disabilities are working; nearly half those with college degrees are working, including many who work full-time throughout the year (tables 1-6 and 1-7).

Earnings and Work Disability. In general, workers who report limitations in the kind or amount of work they can do have lower earnings than nondisabled workers. Average earnings were about $15,600 for those with work disabilities compared to about $25,200 for nondisabled workers. Among full-time workers, the earnings disparity was smaller — $28,500 compared to $33,100. The disparity in earnings is smaller still when full-time, full-year workers with similar educational attainment are compared (table 1-7).

The powerful role of education and job skills in preventing an impairment from resulting in work incapacity is highlighted in a recent study of persons with spinal-cord injuries (SCI). After taking account of other attributes of individuals with SCI, educational attainment was the most powerful predictor of post-injury employment. The predicted post-injury employment rate was 57 percent for those who had college degrees compared to 15 percent for those with only high school degrees and 10 percent for those who did not complete high school. Further, among those who did work, their earnings were strongly influenced by their technical skills — in this case, use of computers at work. Workers with SCI who used computers at work had weekly earnings comparable to a general population sample of noninjured workers who use computers. In contrast, workers with SCI who did not use computers had much lower weekly earnings than noncomputer users in the general population. In brief, for disabilities resulting from SCI, higher education vastly improved the individual's prospects of being employed after the injury; and use of computers at work appears to have eliminated any earnings differential between injured workers and other workers.[37]

Receipt of DI or SSI Benefits

Persons who receive Social Security or SSI benefits based on work disability are a subset of the larger population of persons with a work disability. In contrast with the high estimates of the prevalence of impairments, work limitations or mental illness in the general population, about 7.1 million working-age adults were receiving Social Security or SSI benefits based on disability at the end of 1994.

Unlike survey respondents, the beneficiaries have been found to meet the strict test of work disability in the Social Security Act — inability to engage in any substantial gainful activity because of a medically determinable impairment that is expected to last a year or result in death. This is a more strict definition of work disability than that used in surveys. And the finding of work disability for beneficiaries is based on medical and vocational evidence (see chapter 5). It is not simply a response to a survey question.

- About 4.0 million persons receive disabled-worker benefits from Social Security.[38] Many have impairments associated with aging, such as arthritis or other musculoskeletal disorders. Others have life-threatening diseases, such as AIDS, neoplasms or circulatory or respiratory diseases. Mental illness is also an important cause of disability for younger workers.[39]

  The ages of disabled-worker beneficiaries confirm that the risk of work disability rises with age: most disabled-worker beneficiaries (56 percent) are over the age of 50, while just 4 percent are under 30 and another 16 percent are under the age of 40.[40]

- About 161,000 persons ages 50-64 are not insured for disabled-worker benefits, but receive Social Security benefits as disabled widows or widowers on their deceased spouse's work record. Their impairments are similar to those of older disabled workers. About 618,000 persons age 18-64 receive Social Security benefits as adults disabled since childhood, as the dependent of a parent who is retired, disabled or deceased.[41] Mental retardation is by far their most common impairment, with nearly 2 in 3 having that as their primary diagnosis.[42]

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[37] D. Kruse and A. Krueger, op. cit. footnote 15, pp. iii and 67.

[38] Social Security Administration, op. cit., footnote 14, table 3.C6.1, p. 160.

[39] D.T. Ferron, "Diagnostic Trends of Disabled Social Security Beneficiaries, 1986-93," *Social Security Bulletin*, Fall 1995, pp. 15-31.

[40] Social Security Administration, op. cit., footnote 14, table 5.A1, pp. 197-98.

[41] Social Security Administration, op cit., footnote 14, table 3.C6.1, p. 160.

[42] D.T. Ferron, op. cit., footnote 39, table 7, p. 20.

- Some 2.4 million working-age adults who lack insured status for Social Security benefits receive SSI benefits. Another 1.0 million receive SSI that supplements their Social Security disability benefits.[43] Many SSI recipients have disabilities that began in childhood or early adulthood. Nearly a quarter (24 percent) have mental retardation as their primary diagnosis and another 34 percent have other mental disorders as their primary diagnosis. Others have sensory disorders such as blindness or neurological or musculoskeletal disorders.[44] Because they include individuals with childhood or early onset of disability, SSI recipients tend to be younger than DI beneficiaries. About 35 percent of SSI beneficiaries were over the age of 50, while about 40 percent were under the age of 40.[45]

The numbers alone — 7.1 million Social Security or SSI disability beneficiaries, in relation to 16.8 million people with work disabilities or nearly 30 million with various limitations in functioning — indicate that those receiving benefits are not representative of the broader population of persons who have work disabilities or functional impairments. Focus group interviews with beneficiaries show that they often are ill or have very significant work disabilities.

BENEFICIARY PROFILES

To get beneficiaries' perspectives on their work disabilities, benefits and prospects for work, focus group and telephone interviews with Social Security and SSI beneficiaries were conducted in four sites around the country. Excerpts from the focus group interviews are in the appendix and are summarized briefly here.

Focus groups were conducted with the following three age groups of beneficiaries: "young" beneficiaries ages 18 to 24 and parents of such beneficiaries; "middle" beneficiaries ages 25 to 49; and "older" beneficiaries ages 50 to 61. In each age group, participants were selected to include a mix by gender, ethnicity and the following three broad categories of impairments: musculoskeletal impairments, which are common among the "middle" and "older" groups; mental impairments, which are most common among young adult beneficiaries but are present in all age groups; and cardiovascular, respiratory and other impairments, which are also common among the "middle" and "older" groups.

The following is a summary of findings from adults ages 25 to 61, grouped in the three broad impairment categories, and the young adults ages 18 to 24 and their parents. Most participants in the ages 25 to 61 group, like beneficiaries generally, were in their 40s or 50s.

Adults with Cardiac, Respiratory and Other Impairments

Beneficiaries ages 25 to 61 whose impairments were other than mental or musculoskeletal disorders often were very ill or had life-threatening health conditions. They had conditions such as brain tumors, HIV, respiratory obstruction, cancer, lupus, multiple sclerosis and cardiac conditions. Many had remained on their jobs months or years after the onset of their conditions, determined to "beat the odds" of their diagnosis. By the time they turned to Social Security, they had experienced the loss of their health, their livelihood, and their hopes for ending their work lives with a comfortable retirement. Returning to work usually was not an option. Most had exhausted efforts to remain at work before turning to disability benefits. Their emphasis was on preserving their health, and often their lives, and finding meaning in activities without the psychological and monetary rewards of paid employment. Some were more serene about this than others, being grateful for their "good days" and finding meaning in family or other relationships. Many reported that their claims were processed promptly by Social

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[43] Social Security Administration, op. cit., footnote 14, table 3.C6.1, p. 160.

[44] Social Security Administration, op. cit., footnote 14, table 7.F1, p. 314.

[45] Social Security Administration, *Social Security Bulletin,* Fall 1995, table 2.A4, p. 79.

Security. They often had clearly diagnosed and documented medical conditions that probably met SSA's medical listings.[46] They came from a range of occupations — private school teacher, clerk, day care center worker, accountant, management secretary, nurse manager and financial services representative.

Adults with Musculoskeletal Impairments

Beneficiaries ages 25 to 61 with musculoskeletal impairments often had back injuries and chronic pain. They reported difficulty with a broad range of physical functions: walking, standing, stooping, lifting, sitting, even sleeping, and some had difficulty with concentration due to pain or the medications used to ease it. They shared a common experience that employers, insurers and doctors often were not sympathetic to their conditions, particularly when payment for their health care or income support was an issue.

Perhaps because pain is difficult to diagnose, measure and treat, many felt accused of malingering, being told, "You should be better by now" or "There's nothing wrong with you." They typically had remained on their jobs after the onset of their injuries. Some had aggressively sought training or other work and were still looking. Some found that both their age and medical history reduced their attractiveness to prospective employers. Both uncertainty about their ability to perform the tasks of work and the financial risk to employers for health care or workers' compensation coverage made them less attractive than younger, healthy job applicants. They typically qualified for Social Security disability benefits only after lengthy appeals. The long hiatus between earnings and benefits had often wiped out their savings. While they expressed frustrations with the Social Security claims process, their feelings about workers' compensation were even more negative. They came from a variety of occupations: custodian, construction contractor, hospital transcriber, meat packer, salesperson, restaurant manager and hospital information analyst.

Adults with Mental Disorders

Beneficiaries ages 25 to 61 with mental impairments included persons with cognitive impairments and mental illness, such as major depression or schizophrenia. Many of those with mental illness were taking concrete steps to get treatment. Some were working part-time, others looked forward to returning to work, although with some trepidation. Some were being treated with costly prescription medications, often financed by Medicaid. If they were able to earn enough to leave the benefit rolls, continued coverage of their medication would be essential. Like those with back injuries, they felt a stigma attached to their impairments. Having an advocate — whether a son, mother, therapist or community mental health clinic — was a key link in getting connected with supports in their communities. They had held jobs as a home shopping club worker, musician and piano teacher, graphic illustrator and a participant in sheltered employment.

Young Adults and Their Parents

Beneficiaries ages 18 to 25 were a highly diverse group. Some had high aptitude and strong support from their families and from public agencies, such as the state commission for the blind. They considered SSI benefits a temporary source of support while they attended college in preparation for professional careers. Some beneficiaries with mental retardation were working at low wages and were connected with social workers or skills trainers who helped them manage their affairs and their part-time work cleaning tables or bagging groceries. Some young beneficiaries had impairments with sudden onset, involving head injuries and physical trauma from automobile accidents, and were still recuperating. Others with physical or cognitive impairments were completing their high school general equivalency diploma. Many young beneficiaries hoped to work, but had not yet found a job they could do with their impairments. Parent interviews included some whose adult children had very significant cognitive or multiple impairments that precluded competitive work or participation in a focus group. They wanted their adult children to be treated with dignity and respect and to live with as much independence as possible.

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[46] The role of the medical listings is discussed in chapter 5.

Chapter 2

The Role of Social Insurance and Social Assistance

The Disability Policy Panel was asked whether the Social Security disability system poses strong incentives for Americans with disabilities to emphasize their impairments as a means to securing and maintaining disability benefits. To answer that question, the Panel reviewed the basic purpose of social insurance and social assistance programs, their particular provisions for persons with work disabilities, and how they balance incentives to work against other objectives that have to be considered in designing any income security program. This chapter presents the Panel's review of these programs and its findings about the question asked.

Income support systems are not, in themselves, remedies for work disability. Their purpose, instead, is to provide income necessary to meet day to day needs for people who are not presently able to work and support themselves. The largest income support systems in the United States, as well as in most other industrialized countries, derive from work. These *social insurance* systems build future income protection based on current work. *Social assistance*, which is means-tested, is available to those whose income from work-related support systems is inadequate or nonexistent. Social insurance and social assistance differ in important respects.

SOCIAL INSURANCE DERIVES FROM WORK

Social insurance is the chief way income support is provided to Americans who cannot work or are no longer expected to work. Benefits replace part of the earnings lost when an insured event occurs. In the United States, these insured events include death, severe work disability and retirement (Social Security benefits); involuntary unemployment (unemployment insurance); and injury on the job (workers' compensation). Benefit amounts are based on past earnings and may also be paid to dependent family members. Future benefit protection is earned while working. Benefits are generally financed from contributions from earnings.

Social Security Disability Insurance

Disability insurance (DI) is part of the nation's Social Security — or old-age, survivors, and disability insurance (OASDI) — system. DI benefits are financed through the OASDI contribution at a rate of 6.2 percent of earnings, which is paid by both employees and employers.[1] The DI portion is 0.94 percentage points.[2]

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[1] The limit for earnings subject to OASDI was $61,200 in 1995 and is $62,700 in 1996. This amount is indexed for wage growth and rises automatically each year. The self-employed pay both the employee and employer share, and may deduct one-half of their OASDI contributions as business expenses for income tax purposes.

[2] The DI portion of the tax is scheduled to be reduced to 0.85 percent for 1997-99, and to be increased to 0.90 percent for 2000 and later. The total OASDI tax rate remains unchanged. In addition to the DI share of the OASDI tax, any revenue derived from income taxation of DI benefits is deposited into the DI trust fund, as are interest earnings on its assets.

The funds are used to pay DI benefits, the cost of administering those benefits and payments to vocational rehabilitation (VR) agencies for successful rehabilitation of DI beneficiaries. DI administrative costs are 2.6 percent of trust fund expenditures, VR reimbursements are 0.1 percent. The rest is for benefit payments.

As with every other insurance system, DI requires that applicants show that the insured event has occurred before benefits are paid. For DI, the insured event is long-term work incapacity. Although DI is sometimes criticized for making people prove their disability, this requirement is unavoidable and is thoroughly consistent with the fundamental purpose of insurance, which is to protect workers and their families against the risk of financial disaster when the event insured against actually occurs. Insurance systems also build in safeguards to discourage unwarranted claims and to protect the insurance system against paying them. The following features contribute to the strict design of the DI program.

First, only those employees who have a record of fairly steady and recent work are insured for DI benefits.[3] Thus, only those individuals who have demonstrated a fairly strong attachment to the work force are eligible for benefits. Second, the medical and vocational test of disability to receive DI benefits is very stringent. The law requires that a worker have a medically determinable impairment of such severity that given one's age, education and work experience, one cannot perform substantial gainful activity in any job that exists in significant numbers in the national economy, regardless of whether or not the applicant would be hired for such a job. Benefits are payable only if the impairment is expected to last at least 12 months or result in death.

Third, DI benefits are paid following a five-month waiting period after the onset of the disability. Health care coverage through Medicare begins after an additional 24-month waiting period after cash benefits start.

The level of DI benefits is based on the worker's prior earnings from work. DI benefits replace a worker's prior earnings under a sliding scale that provides higher levels of benefits for low-wage earners than for higher-wage earners.[4] This recognizes that low earners have a smaller margin for reducing their consumption. It also recognizes that higher earners have better prospects for having private insurance or pensions to supplement Social Security benefits.

For workers whose earnings are average or above, DI replacement rates range from 43 percent for a person earning $25,000 per year to about 26 percent for a person earning $60,000 (table 2-1). At lower earnings levels, when benefits amount to as much as half of prior earnings, they provide a level of living that is below the poverty threshold.[5]

The replacement rates for DI are considerably less than what would be needed to match the worker's standard of living while working. Studies generally find that replacement rates of between 70 and 80 percent are needed to match the worker's prior level of living. These studies take account of the difference in tax treatment of various sources of income and the absence of work-related expenses. The studies that have been done, however, generally presume that the Social Security beneficiary is a relatively healthy retiree.[6] These studies do not take

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[3] To qualify for disabled-worker benefits, an individual must have worked in employment subject to Social Security contributions for about one-fourth of the time elapsing after age 21 and up to the year of disability. In addition, he or she must have recent covered work — equivalent to 5 of the preceding 10 years (or, if between ages 24 and 31, half the time since age 21, or if under age 24, half of the preceding three years).

[4] The benefit formula is based on the worker's average indexed monthly earnings (AIME). In 1995, the formula for workers becoming disabled in that year was the following: 90 percent of the first $426 of AIME plus 32 percent of the next $2,141 plus 15 percent above $2,567. Social Security Administration, *Annual Statistical Supplement to the Social Security Bulletin* (Washington, DC: U.S. Government Printing Office, August 1995), table 2.A11, p. 38.

[5] The poverty threshold for a nonelderly person living alone in 1995 is estimated to be $7,934, or $661 a month. (The estimate updates the 1994 poverty threshold by the increase in the Consumer Price Index for All Urban Consumers.) Social Security Administration, op. cit., footnote 4, table 3.E1, p. 162; and Social Security Administration, *Social Security Bulletin*, Fall 1995, p. 104, table 5.A2.

[6] B.A. Palmer, "Retirement Income Replacement Ratios: An Update," *Benefits Quarterly*, Second Quarter, 1994, pp. 59-75.

account of the additional costs of disabled workers, which include the need to support themselves without earnings during a five-month waiting period, and other disability-related expenses, including health care during the first 29 months after the onset of disability. In December 1995, the average monthly benefit for disabled-worker beneficiaries was $682.[7] In December 1994, those receiving as much as $1,000 a month accounted for 14 percent of beneficiaries, while 30 percent received less than $500 a month.[8]

Social Insurance, Private Insurance and Pensions

While social insurance benefits are paid based on loss of earnings, they are not reduced if the worker receives other income. Thus, workers and their employers are encouraged to make other provisions that can supplement social insurance benefits, such as pensions, private insurance or personal savings. In fact, such additional preparation is built into the design of the Social Security program. The U.S. Social Security system is part of a public-private system, where private pensions and disability insurance are designed to supplement Social Security, particularly for middle-wage and higher earners. Social insurance forms a foundation upon which a worker can build additional protection against the loss of earnings from work.

If Social Security were means-tested, it would undermine incentives for employers to offer pensions or insurance and incentives for workers to save on their own. This result would occur because those other sources of income would cause a reduction in the amount of Social Security the person received. For example, if Social Security benefits were reduced by $1 for each $1 retired or disabled workers received from their pensions, insurance or savings, these workers would have no net gain in income from deferred compensation from their employers or their own savings.[9] Without incentives for supplemental private sources of income, those sources would decline, and the public system would likely be called upon to fill an even larger role — in effect, the role of both social insurance and private supplements.

Table 2-1. Illustrative Social Security Disabled Worker Benefits, 1995

Prior annual earnings[a]	Monthly benefit	
	Amount	Replacement rate (percent)
$10,000	$507	61
15,000	636	51
20,000	766	46
25,000	896	43
30,000	1,026	41
40,000	1,170	35
60,000[b]	1,332	26

a. Estimates of Average Indexed Monthly Earnings (AIME) are based on the relationship between final earnings and AIME for an average earner becoming disabled in 1995. Social Security Administration, Office of the Actuary.

b. At earnings levels near the Social Security taxable maximum, replacement rates vary slightly by the worker's age at onset of disability, from 27 percent for an individual disabled at age 35 to 25 percent for an individual disabled at age 55. The amount shown here is for an individual disabled at age 45.

SOCIAL ASSISTANCE IS BASED ON PROVEN NEED

While work-based social insurance is the main system for income support in the United States, some people who need income support do not receive it because they have not worked before the insured event occurs. In other cases, the amount they receive from social insurance is inadequate. Social assistance fills in this gap. Social assistance benefits are paid on the basis of demonstrated need and form a level of income protection below which no eligible individual should have to live. In the United States, federal social assistance protection is available only to specific categories of individuals, such as elderly persons, children and persons with

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[7] Social Security Administration, op. cit., footnote 4, table 5.E2, p. 233, updated by data from the Office of Research and Statistics.

[8] Ibid, table 5.E1, p. 233.

[9] A net gain would only occur when income from pensions or insurance actually exceeded the amount of the Social Security benefit.

Figure 2-1. Income Support Objectives as met by DI and SSI

Objective	DI	SSI
Adequacy	Partial earnings replacement for those unable to work; weighted benefit formula with higher replacement for lower earners.	Minimum income guarantee for the poor.
Targeting	Strict test of work disability; five-month waiting period; insured status requires record of prior work the person can no longer do.	Strict test of work disability; strict test of means; very limited other income or assets.
Minimize cost	Modest levels of earnings replacement; insured status requires prior work record; strict test of work disability.	Modest federal benefit, about 70 percent of the poverty line; strict test of work disability.
	Minimizing administrative costs	
Disability determination	Determination of work disability, by its nature, is resource intensive. Requires medical and vocation assessment and evidence of inability to engage in SGA.	
Benefit determination	A predictable benefit amount, based on prior earnings; information needed to determine benefits is on hand at SSA; once determined, benefit amount does fluctuate depending on other income.	Benefit amount takes into account all other income; applicant must document other income; benefit amount requires periodic (if not constant) redetermination to take account of changes in all other income and resources.
	Incentives	
To plan ahead for supplemental income	Pensions, disability insurance or savings supplement benefits; modest levels of earnings replacement are an incentive to have supplemental protection, particularly for higher earners.	Modest asset exclusion.
To remain at work; deterrents to claiming benefits	Modest benefits in relation to prior earnings; strict test of work disability.	Modest income guarantee, subject to a test of low income and limited financial assests; strict test of work disability.
To return to work and leave the rolls	Earnings below SGA do not affect eligibility; beneficiaries can test ability to work for a period of time without loss of benefits (trial work period); benefits can then be reinstated if earnings fall below SGA during a three-year extended period of eligibility.	Part of earnings are disregarded in determining benefit amount (the first $20 of monthly income, plus the first $65 of earnings and half of remaining earnings are disregarded); special treatment of impairment-related work expenses.

Abbreviations: DI = Social Security disability insurance, SGA = substantial gainful activity, SSA = Social Security Administration, SSI = Supplemental Security Income.

significant work disabilities. Some states or localities provide general assistance to adults who are not disabled or caretakers of children. The amount of the social assistance payment is based on proven need (the amount by which the person's other income falls below the income standard) rather than on past earnings and contributions.

With the enactment of SSI in 1972, Congress established a basic income guarantee to underpin the economic security of the nation's most vulnerable citizens — those who are aged or severely disabled — who, under prior state assistance programs, were subject to very different treatment across the nation because of the wide disparity among states in their financial capacity and willingness to provide such support.

The SSI program uses the same strict test of medical and vocational work disability used by the DI program. There is no waiting period before cash benefits start, and in most states Medicaid eligibility accompanies receipt of SSI. The SSI federal benefit rate ($470 a month for an individual in 1996) amounts to about 70 percent of the official poverty threshold for an individual. When SSI was originally being developed, Congress intended that it would keep elderly persons and those individuals with severe work disabilities out of poverty.[10] Financing fell short of that goal and federal benefits today, as then, remain below the poverty threshold.

The SSI means test reduces SSI benefits by $1 for every $1 of other countable income; however, some income is not counted. The first $20 of income of any type (earned or unearned) is excluded from countable income, as is $65 of earnings. In addition, one-half of remaining earnings are excluded from countable income, as a work incentive. The SSI resource test renders an individual ineligible for benefits if he or she has financial resources in excess of $2,000. A home and automobile are not counted in the resource test.

BALANCING OBJECTIVES

All income security systems must balance several objectives. Each objective is important, but they cannot all be achieved perfectly at once. Trade-offs among these competing objectives are inherent in any income security system. If one objective is to be emphasized in particular, the other objectives will be somewhat compromised. These objectives include:

1. **maintaining income adequacy** — reasonably adequate benefits for those who receive them.

2. **targeting benefits** — benefits targeted to those who need them most.

3. **minimizing benefit costs** — limiting the cost of benefits, which must be met by earmarked contributions or general tax revenues.

4. **minimizing administrative costs** — limiting the administrative cost of providing accurate, prompt payments.

5. **providing incentives to work** — work incentives take two forms: (a) incentives to remain at work and not claim benefits (deterrents to claiming benefits), and (b) incentives to return to work while receiving income support (return to work).

6. **providing incentives for supplemental income** — to acquire savings or supplemental pensions or insurance.

Figure 2-1 summarizes how DI and SSI balance these objectives. *Adequacy* in DI is assessed in terms of the level at which benefits replace prior earnings. In SSI, it is the level of the benefit standard. Initiatives to improve the adequacy of either system require consideration of increased costs (compromising objective 3). It also may make claiming benefits more attractive relative to remaining at work (compromising objective 5a).

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[10] U.S. Senate, *Social Security Amendments of 1972, Report of the Committee on Finance, U.S. Senate to Accompany H.R.1*, S. Rpt. No. 92-1230 (Washington, DC: U.S. Government Printing Office, Sept. 26, 1972), p. 384.

Targeting is pursued in both DI and SSI by using a strict test of work disability. A less strict test of work disability would make more people eligible for benefits, thereby reducing targeting and increasing benefit costs (compromising objective 3).

The strict test of work disability by its nature is complex and requires individualized consideration of medical and vocational evidence. A less individualized assessment might decrease administrative costs, but would reduce the targeting of benefits to those with the most significant work disabilities. Limiting administrative costs in the disability determination is sought through a sequential process to assess medical and vocational evidence of work disability in ways that balance goals of validity, reliability and credibility as well as administrative efficiency (see chapter 5).

In determining benefit amounts, DI and SSI differ in the *administrative costs* of the benefit determination. Means-tested assistance is more labor intensive to administer because the correct benefit varies depending on the amount of other income the recipient has. The social insurance payment, in contrast, is based on replacing past earnings. Once determined, it does not need to be continuously updated to take account of changing circumstances.

Like other means-tested assistance, SSI generally does not provide *incentives to save or have private supplementation.* Instead, it is designed as the program of last resort. Therefore it targets those who are the neediest. Incentives to improve one's status by working or by saving can be incorporated into a means-tested system only by creating exceptions to the means-testing rules, that is, by making it less targeted on those who need it most (compromising objective 2) and increasing costs (compromising objective 3).

Work incentives for those receiving benefits are structured in several ways. Their basic purpose is to encourage earnings by limiting the loss of benefits as work increases. DI beneficiaries, for example, have an opportunity to test their ability to work before eligibility ends. In SSI, benefits are partially reduced as income from earnings rises. Expanding these work incentives generally increases benefit costs (compromising objective 3) and reduces targeting (compromising objective 2) by paying benefits to people with less severe work disabilities.

CONCLUSION

Any income support system presents some level of work disincentive. The Panel reviewed whether the Social Security disability system poses strong incentives for Americans with disabilities to emphasize their impairments as a means to securing and maintaining disability benefits.

The Panel's basic finding is that the Social Security and SSI disability benefit programs do not pose strong incentives for Americans with disabilities to seek benefits in lieu of working. Rather, the strict and frugal design of these programs makes remaining at work preferable to benefits for those who are able to work.

The challenge is to design benefit policies that cost-effectively target adequate support to those who are unable to work, while minimizing work disincentives. The U.S. system emphasizes strict eligibility criteria and relatively modest benefits to minimize incentives for workers to leave work and claim disability benefits. Systems that would significantly expand benefit eligibility to a larger portion of the population with impairments or partial work disabilities would significantly increase the cost of U.S. benefit programs.

By cross-national standards, U.S. spending on disability benefits is relatively low. Spending on Social Security disability insurance and SSI combined amounted to about 0.7 percent of gross domestic product (GDP) in the United States in 1991. This is less than one-half the share (1.9 percent) spent on similar disability benefits by the United Kingdom, a country that also has a fairly strict disability benefit system. It is about one-third of the share spent on similar benefits in Germany (2.0 percent of GDP), which has a disability system that places more emphasis on rehabilitation before pensions, and provides subsidies for private employment of persons with disabilities. In Germany, disability pensions generally replace 60 percent of the worker's predisability earnings, considerably more than the level provided in the United States' Social Security system.[11]

Other countries that provide partial benefits for partial work disabilities spend even larger shares of GDP on disability benefits. Sweden, a mature welfare state that emphasizes rehabilitation and offers public employment as a last resort for persons with disabilities, spends 3.3 percent of GDP on disability pensions. It offers partial disability pensions to workers whose earning capacity is reduced by 25 percent or more.[12] The Netherlands, which is now trying to control its disability benefit spending, spends 4.6 percent of GDP. It has offered disability pensions to workers whose earning capacity is reduced by as little as 15 percent.[13]

The United States spends considerably less on disability income than other relatively wealthy nations, which reflects the value placed on the goal of minimizing costs in the United States. While U.S. spending for these public disability benefits is a smaller share of GDP than in other countries, it is nonetheless significant. In 1994, $37.7 billion was allocated for DI benefits to disabled workers and their dependents[14] and $14.7 billion was for SSI-disability benefits for working-age adults.[15] Further, the U.S. disability benefit programs grew rapidly in the early 1990s, and that growth has prompted concern about their costs. The next chapter reviews causes of growth and the Panel's recommendations about what should be done.

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[11] L.J.M. Aarts and P.R. de Jong, "European Experiences with Disability Policy," *Disability, Work and Cash Benefits*, J.L. Mashaw, et al., (eds.) (Kalamazoo, MI: W.E. Upjohn Institute for Employment Research, forthcoming).

[12] F.S. Bloch, "Disability Benefit Claims Processing and Appeals in Six Industrialized Countries: Canada, Germany, Sweden, the Netherlands, Great Britain and the United States," *Occasional Papers on Social Security* (Geneva, Switzerland: International Social Security Association, 1994).

[13] Data for the Netherlands are not directly comparable to that of other countries because the Dutch system includes compensation for work injuries. It does not have a separate workers' compensation system. L.J.M. Aarts and P.R. de Jong, op. cit., footnote 11.

[14] Social Security Administration, op. cit., footnote 4, table 4.A6, p. 179.

[15] The $14.7 billion in federally-administered SSI benefits includes $13.0 billion in federal dollars and $1.7 billion in federally-administered state benefits. Social Security Administration, Office of Research Statistics.

Chapter 3

Why Have the Rolls Grown? What Should Be Done?

The Disability Policy Panel recognizes there is concern about the recent growth in the size and cost of the Social Security and Supplemental Security Income (SSI) disability benefit programs. The Panel's review of the history of these programs, the research literature, and the broader environment of disability policy suggests explanations for the recent growth as well as recommendations for what can be done.

DYNAMICS OF CHANGE

The size of the disability benefit program is influenced, first, by the size of the working-age population. Some growth would be expected as the eligible population grows. Beyond that, the size of disability programs is determined by the rate at which individuals enter them (the incidence rate) and the rate at which beneficiaries leave them (the termination rate). The Panel's review of trends in the eligible population and of incidence and termination rates focuses on the Social Security disability insurance (DI) program. Comparable data for the SSI program are more limited. Discussion of causes of growth include those that affect the SSI population because some who apply for SSI may be found to have enough covered work experience to qualify for DI.

Size of the DI Eligible Population

Those eligible for DI disabled-worker benefits are persons under age 65 who have enough covered work experience to be insured.[1] The insured population has grown, not only because of population growth, but because more working-age women are insured for benefits. More women are in the labor force and are supporting themselves and their families with their earnings. Consequently, when they sustain severe work disabilities, they qualify for disability benefits. Had they remained housewives as many of their mothers were, their disabilities would not have been recognized in the disability insurance program. Between 1988 and 1994, the insured population grew by 10 percent (3 percent for men and 14 percent for women). This increase continues a longer term trend: between 1980 and 1994, the total insured population grew by 27 percent (15 percent for men and 45 percent for women).

Persons Awarded DI Benefits

Incidence rates show the change in the number of people entering the benefit rolls after taking account of changes in the size of the insured population. The incidence rate — the number of persons awarded DI benefits per 1,000 insured workers —

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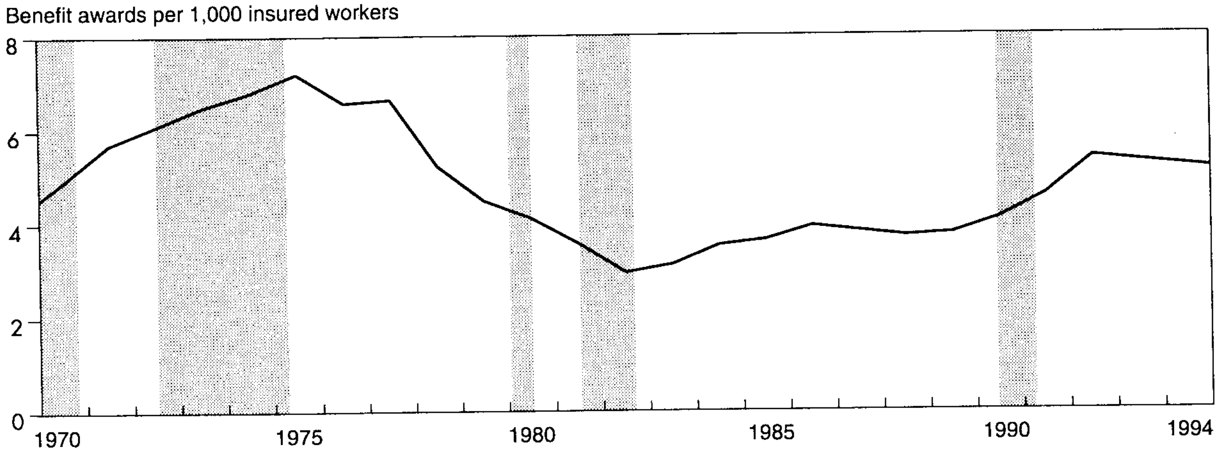
[1] To qualify for disabled-worker benefits, an individual must have worked in employment subject to Social Security contributions for about one-fourth of the time elapsing after age 21 and up to the year of disability. In addition, he or she must have recent covered work — equivalent to 5 of the preceding 10 years (or, if between ages 24 and 31, half the time since age 21, or if under age 24, half of the preceding 3 years).

Figure 3-1. DI Incidence Rates, 1970-94 (shaded areas are economic recessions)



Abbreviations: DI = Social Security disability insurance.
Source: Social Security Administration, Office of the Actuary.

has fluctuated widely over the last 25 years (figure 3-1). It ranged from an all-time high of 7.2 in 1975 to an all-time low of 2.9 in 1982. The incidence rate rose and leveled off between 3.5 and 4.0 in the last half of the 1980s. It rose again in the early 1990s, when it peaked at 5.4 in 1992, and then declined slightly and flattened out in 1993-95.[2]

The radical shifts in disability incidence rates reflect changes in legislative and administrative policy and in the external environment of work disability that are discussed later in this chapter.

Persons Leaving the DI Rolls

The size of the disability rolls is also affected by the number of persons leaving the benefit rolls, or termination rates. Persons leave the DI rolls for one of four reasons: they die; they shift to retirement benefits at age 65; they medically recover; or they return to work despite the continuation of their impairments. Termination rates (the number of persons who leave the DI rolls per 100 beneficiaries) have been more stable than incidence rates, but they too have fluctuated to some degree. They have declined since the mid-1980s (figure 3-2).

Death and retirement have always accounted for the vast majority of DI benefit terminations. These reasons for termination are influenced by the underlying health and age distribution of the beneficiary population.

Terminations Because of Death Are Stable. The benefit termination rate because of death has not declined. The proportion of DI beneficiaries who die each year is high, much higher than that for the working population in general. Each year between 4.5 and 5.0 percent of DI beneficiaries die (figure 3-2). One study found that over one-quarter (27 percent) died within 5 years of entering the rolls.[3] In the broader working population, in contrast, the annual probability of death is about 0.2 per 100 insured workers at age 40 or about 1.2 per 100 for those age 60.[4] The death rate for DI beneficiaries has been quite stable, suggesting that the proportion of beneficiaries with life-threatening conditions has not changed in recent years.

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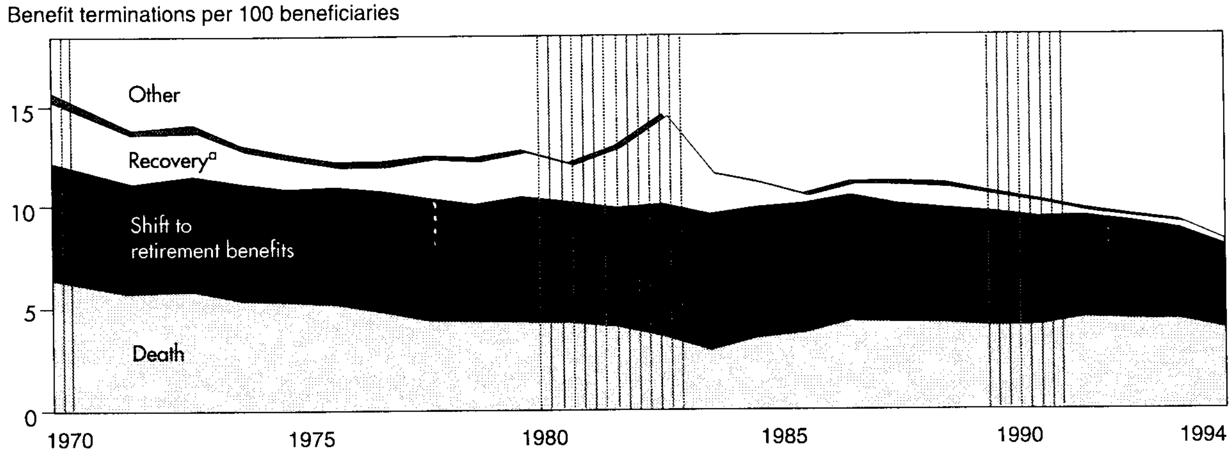
[2] Social Security Administration, Office of the Actuary.

[3] See table 6-4.

[4] Social Security Administration, *Annual Statistical Supplement to the Social Security Bulletin* (Washington, DC: U.S. Government Printing Office, August 1995), table 4.C6, p. 195.

Figure 3-2. DI Termination Rates, by Cause 1970-94 (shaded areas are economic recessions)



a. Includes terminations because of return to work or a finding that the beneficiary no longer has a disabling impairment.
Abbreviation: DI = Social Security disability insurance.
Sources: Social Security Administration, Office of the Actuary; and U.S. Department of Health and Human Services, *The Social Security Disability Insurance Program: An Analysis*, requested by the Board of Trustees of the Federal Old-Age and Survivors Insurance and Disability Insurance Trust Funds (Washington, DC: U.S. Department of Health and Human Services, December 1992), chart 2, p. 7.

Terminations for Retirement Are Down. The benefit termination rate due to retirement gradually declined since the mid-1980s. This is because a smaller proportion of DI beneficiaries are age 60 or older. Those ages 60 to 64 accounted for about one-fourth of all DI beneficiaries in 1994, compared to about one-third of all beneficiaries in 1975 (table 3-1).

Part of the reason why beneficiaries are younger is simply the age distribution of the underlying insured population. The baby boom generation is entering the 35-to-50 age range. Just as they swell the ranks of the labor force, they swell the ranks of the disability rolls when they reach disability-prone ages. At the same time, the cohort of workers age 60 and older is relatively small now because relatively few babies were born during the birth dearth of the Great Depression 60 years ago. These changes in the age distribution of the underlying insured population contribute to a decline in the benefit termination rate because of retirement.

The baby boom bulge and the Great Depression birth dearth, however, are not the whole explanation for younger DI recipients. Today, insured workers under age 50 are somewhat more likely than in the past to receive DI benefits. While the likelihood of receiving DI benefits rises sharply after the age of 55, the recent growth in prevalence of benefit receipt has been among younger insured workers.[5]

Terminations for Recovery or Return to Work are Low. The benefit termination rate due to medical recovery or return to work has always been modest, but is at an all-time low. Historical data from the Social Security Administration (SSA) do not distinguish between medical recovery and return to work as a cause of benefit termination, despite clear policy distinctions that date back to 1980. Under the law, DI beneficiaries who return to work despite the continuation of their impairments maintain Medicare coverage and benefit eligibility

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[5] Social Security Administration, Office of the Actuary.

Table 3-1. Age Distribution of DI Beneficiaries in Current Payment Status as of December, Selected Years

	1994	1990	1985	1980	1975
Total number (thousands)	3,967	3,011	2,657	2,859	2,489
Total percent	100	100	100	100	100
Under 30	4	4	4	4	4
30-39	16	15	12	9	7
40-44	11	10	7	6	6
45-49	13	11	9	9	10
50-54	15	13	13	14	16
55-59	18	19	22	24	24
60-64	23	28	33	34	33

Abbreviation: DI = Social Security disability insurance.
Source: Social Security Administration, *Annual Statistical Supplement to the Social Security Bulletin* (Washington, DC: U.S. Government Printing Office, August 1995), table 5.D4, p. 230.

while they test their ability to work;[6] persons who medically recover do not.

Terminations for recovery or return to work are influenced by two kinds of policy initiatives: policies that encourage and assist beneficiaries to return to work and ultimately leave the benefit rolls despite the continuation of their impairments (return to work), and policies that determine the number and target effectiveness of continuing disability reviews (CDRs) to identify individuals who have medically recovered.

Benefit terminations for medical recovery and return to work, combined, were considerably higher in the 1970s than they are today. Two policies of the 1970s might have contributed to higher termination rates then. First, there was greater investment in vocational rehabilitation for beneficiaries. In inflation-adjusted dollars, funds allocated to vocational rehabilitation agencies to serve DI beneficiaries in 1975-79 were about 5 to 6 times what is spent today.[7] And the number of beneficiaries whose benefits were terminated after receiving rehabilitation services was a larger share of the benefit rolls then than it is today.[8] Second, in the 1970s, systematic procedures were in place to "diary" and conduct follow-up reviews of beneficiaries whose conditions were thought likely to improve.

The spike in benefit terminations in the early 1980s reflects the energetic, but error-prone, CDR policies adopted then, but abandoned in 1983-84. The very low rate of terminations in the early 1990s reflects the virtual cessation of CDR activity in 1990-92 while administrative resources were diverted to processing initial claims.

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[6] In 1980, beneficiaries who work despite the continuation of their impairments were provided a 15-month extended period of eligibility (EPE) during which benefits would be reinstated in any month they did not engage in substantial gainful activity (SGA). The 15-month EPE was increased to 36 months in 1987. In 1980 beneficiaries also were provided a 36-month extended period of Medicare eligibility after their benefits ended. In 1989 beneficiaries were provided with the option to purchase Medicare coverage after their regular coverage ended.

[7] See chapter 6 for a legislative history of policies for financing VR services for Social Security beneficiaries.

[8] Disability Advisory Council, *Report of the Disability Advisory Council* (Washington, DC: U.S. Government Printing Office, 1988), table 4.3, p. 52.

Disabling Conditions of Persons Entering the DI Rolls

The nature of disabling impairments of those who enter the rolls has shifted over time. The data to measure this shift, however, are incomplete.[9] Despite this caveat, they show that mental disorders account for a larger share of disabling conditions now than in the past. Mental impairments were the primary diagnosis for nearly 25 percent of workers initially awarded DI benefits in 1994, compared to about 22 percent in 1990, 20 percent in 1985 and 10 percent in 1981 (table 3-2).

Over the same period, the proportion of persons entering the rolls with cardiovascular disease as the primary diagnosis declined. Important changes have occurred in cardiovascular treatment that make some cardiovascular conditions less disabling than they were in the past. In 1994, SSA revised its medical criteria for evaluating work disability caused by cardiovascular impairments. The changes were based on expert medical opinion and changes in treatment for these conditions. Impairments of the musculoskeletal system, which include arthritis and back disorders, remain an important cause of work disability, particularly among older workers. They are probably undercounted in the data on initial benefit awards. A better sense of the importance of musculoskeletal impairments is shown in the total population on the DI rolls, where musculoskeletal impairments were the primary diagnosis for 20 percent, compared to 13 percent of those initially allowed benefits before any appeal. Cancer, respiratory disease and infectious diseases also are important causes of work disability.

REASONS FOR FLUCTUATIONS IN BENEFIT AWARDS

Fluctuations in the number of persons awarded disability benefit are influenced by the broader economic and social environment, most notably economic recessions, changes in Social Security policy and changes in administrative resources to process applications. The discussion begins with the role of economic recessions and other aspects of the broader economic and social environment.

Economic Recessions

The economic recession of 1990-91 clearly contributed to the recent growth in applications for disability benefits, as economic recessions have in the past, particularly in the early and mid-1970s.[10] Economic recessions increase the likelihood that workers with physical or mental impairments will apply for disability benefits. While not all meet the strict test of disability, some do. This experience is common across the Social Security program, private disability insurance programs and foreign disability systems. When jobs are plentiful and employers are actively seeking qualified employees, they are much more inclined to accommodate workers who have impairments. When firms are downsizing and jobs are scarce, workers with disabilities who lose their jobs, particularly at older ages, have few prospects for regaining employment or shifting to new careers.

Recent empirical research found that the recession of 1990-91 had a significant impact on DI applications and awards. In-depth case studies in several states suggested that the recession's impact is greater than that indicated by empirical estimates because they fail to capture subtleties that vary greatly in local labor markets.[11]

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[9] The Social Security Administration's historical data on the primary diagnoses of new beneficiaries do not include those whose benefits were allowed on appeal. As such, it undercounts the more difficult cases to decide, many of which involve musculoskeletal impairments, often accompanied by pain. This omission is a growing problem as the share of new benefit awards that are allowed only after appeal has increased.

[10] M.E. Lando, et al., "Disability Benefit Applications and the Economy," *Social Security Bulletin*, October 1979, pp. 1-10; J.C. Hambor, "Unemployment and Disability: An Econometric Analysis with Time Series Data," SSA Staff Paper 20, 1975; and J.C. Hambor, *The Role of Economic Factors in the Decline of the DI Trust Fund*, SSA Working Paper 57, 1992.

[11] D.C. Stapleton, et al., "Lessons from Case Studies of Recent Program Growth in Five States," unpublished paper presented at a conference sponsored by the Social Security Administration (SSA) and the U.S. Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation (DHHS/ASPE), Washington, DC, July 20-21, 1995, p. 16; and Lewin-VHI, Inc., "Labor Market Conditions, Socioeconomic Factors, and the Growth of Applications and Awards for SSDI and SSI Disability Benefits," prepared for SSA and DHHS/ASPE, May 23, 1995, chapter 4.

Table 3-2. Impairments of DI Beneficiaries, Selected Years

		New awards				
Impairment codes	1994 Current pay	1994	1990	1985	1981	1975
Total number	**3,974,600**	**631,870**	**467,977**	**377,371**	**345,252**	**592,049**
Total percent	**100.0**	**100.0**	**100.0**	**100.0**	**100.0**	**100.0**
Infectious and parasitic diseases[a]	2.2	5.7	4.7	0.9	0.8	1.3
Neoplasms	3.0	14.1	14.1	15.9	16.3	10.1
Endocrine, nutritional and metabolic diseases	4.1	5.0	3.5	4.9	4.3	3.9
Mental retardation	5.4	—	—	—	—	—
Other mental disorders	25.5	24.8	22.5	19.9	10.5	11.4
Diseases of the:						
Blood	0.3	0.3	0.4	0.3	0.3	0.2
Nervous system and sense organs	10.0	7.6	8.1	8.3	8.3	6.7
Circulatory system	13.6	13.7	15.7	21.1	24.9	29.9
Respiratory system	3.9	4.9	4.7	5.8	6.2	6.7
Digestive system	1.4	1.7	1.6	1.6	2.1	3.0
Genitourinary system	1.5	2.5	2.2	1.0	1.8	1.0
Skin	0.2	0.2	0.2	0.3	0.4	0.4
Musculoskeletal system	20.9	13.4	15.9	14.2	17.0	18.7
Cogenital anomalies	0.4	0.1	0.1	0.7	0.9	1.1
Injuries	6.1	3.6	4.7	4.8	6.0	5.5
Other	1.5	2.5	1.6	0.3	0.2	0.2

a. Human immunodeficiency virus (HIV) was moved from the "other" category to the infectious disease category in 1990.

Abbreviation: DI = Social Security disability insurance.

Source: Social Security Administration, *Annual Statistical Supplement to the Social Security Bulletin* (Washington, DC: U.S. Government Printing Office, August 1995), table 5.D6, p. 232; Ibid., 1991, table 6.C4, p. 235; Ibid., 1987, table 58, p. 134; Ibid., 1983, table 49, p. 110.

The recession of the early 1980s was an exception to the usual experience of rising claims and awards. During this period, the administration engaged in successively more restrictive retrenchment policies that sharply limited new benefit awards and increased benefit terminations. As discussed in the section on Social Security policy changes, those policies were challenged by the courts, lost public support and were stopped by the administration and Congress.

Other Aspects of the Broader Environment

While difficult if not impossible to quantify, aspects of the social and economic environment beyond cyclical changes in the economy also affect demands placed on public disability benefit systems and the kinds of impairments that result in work disability. They include structural changes in the demands of work, changes in other public or private income support systems, and changes in the diagnosis and treatment of disabling conditions.

Structural Changes in the Demands of Work. Structural changes in the labor market influence the kinds of impairments that result in work disability. Because work disability involves the interaction between workers' impairments and their abilities in relation to the demands of work, changes in job requirements affect the kinds of impairments that result in work disability.

As the economy shifts from heavy industry to the information age — where the work place increasingly emphasizes streamlined organizations, high technology and rapid service delivery — the requirements of jobs are changing as well. Moreover, the work place is increasingly characterized by rapid turnover, frequent downsizing and task-oriented team effort. As a result, certain attributes of workers are more valued, such as technological sophistication, intelligence, adaptability, social ability and skill in delivering human services.

In this environment, people with physical impairments who have high aptitude and advanced education may have better employment prospects than 20 or 30 years ago. Recent policy changes such as those required by the Americans with Disabilities Act of 1990 (ADA) make the general environment more accessible to people with mobility limitations. Advances in assistive technology also expand employment opportunities for well-educated people with sensory or physical impairments that can be compensated by technology. However, people with cognitive impairments or emotional disorders may have fewer employment prospects than in the past. The premium placed on intellect, adaptability and public relations skills can mean fewer employment opportunities for people whose social and adaptive functioning is impaired by mental disorders.

Moreover, there has been a decline in the demand for workers without advanced education, whether or not they have impairments. The decline is evident in the growing disparity between earnings of high school graduates and college graduates. While earnings of college graduates have increased, those of high school graduates have not kept up with inflation. The fall in real weekly earnings is particularly evident for young workers.[12] And while workers with less formal education are at a disadvantage in the labor market, those who experience the onset of a disabling impairment in combination with limited education are doubly disadvantaged. One study found that men who were doubly disadvantaged by disabilities and limited human capital did not recover from the program cuts and economic recession of the early 1980s. It further concluded that the doubly disadvantaged were not likely to benefit from new mandates for job accommodations.[13]

Cutbacks in Other Public Support. In recent years, states and localities have cut back general assistance programs for the poor and actively referred former recipients of such benefits to the SSI program. Case studies show that these cutbacks caused significant growth in SSI applications and SSA workloads in some jurisdictions.[14] While most applicants did not meet the strict test of disability in the SSI program, some did. Similar effects can be expected from state initiatives to reduce Aid to Families with Dependent Children (AFDC). One study found that the disability rate is high among families receiving AFDC. In about 29 percent of families, either a child, a caretaking parent or both were reported to have some type of disability.[15] One study explained the dynamic as follows: "the intellectual and emotional investments required to successfully apply for SSI are a sufficient obstacle that many who are eligible will not apply when other sources of support, although lower, are more readily available. Thus, cuts in other support, or provision of intellectual and emotional support for application, can induce the filing of SSI claims" among eligible persons who had previously not done so.[16]

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[12] G. Burtless, *A Future of Lousy Jobs? The Changing Structure of U.S. Wages* (Washington, DC: The Brookings Institution, 1990), p. 74; and G. Burtless and L. Mishel, "Recent Wage Trends, the Implications for Low-Wage Workers," unpublished paper presented at a conference sponsored by the Social Security Research Council, Washington, DC, November 9-10, 1993.

[13] R.V. Burkhauser, et al., "How People with Disabilities Fare When Public Policies Change," *Journal of Policy Analysis and Management*, Spring 1993.

[14] J. Bound, et al., "The Ending of General Assistance and SSI Disability Growth in Michigan: A Case Study," unpublished paper presented at a conference sponsored by SSA and DHHS/ASPE, Washington, DC, July 20-21, 1995, p. 9; and D.C. Stapleton, et al., op. cit., footnote 11, p. 16.

[15] U.S. Department of Health and Human Services, "Disability Among Women on AFDC: An Issue Revisited," as reported in *Family Matters*, Fall 1993.

[16] D.C. Stapleton, et al., op. cit., footnote 11, p. 17.

Cost Controls in Other Work-Based Disability Benefits. Policies in other work-based disability benefits — workers' compensation and long-term disability insurance — can influence demands placed on the DI program. These two systems have different purposes and relate to DI in different ways.

Workers' compensation. Workers' compensation (WC) pays for medical care and cash benefits for workers injured on the job. It covers temporary or permanent disability, both partial and total. WC policies are set by state laws. In general, workers cannot receive both WC and Social Security disability benefits in full. Generally, DI benefits are reduced if the worker receives WC benefits, but in 14 states, WC payments may be reduced if the beneficiary receives DI.[17]

During the 1980s WC benefit payments grew very rapidly. The largest growth was in spending for medical care, but WC disability cash benefits also grew, from 0.66 percent of WC-covered payroll in 1980 to 0.72 percent in 1984 and 0.99 percent in 1991.[18] In contrast, DI spending as a share of its covered payroll declined in the early 1980s and was fairly stable for the remainder of the decade.[19] In the early 1990s states introduced a variety of measures to stem the rising costs of workers' compensation. Some states reduced their benefit levels. Others concentrated on more rigorous review of claims and various measures to promote safety and to control medical costs when accidents did occur.

In the early 1990s, when the DI rolls grew rapidly, WC payments leveled off and declined. Growth in WC cash disability payments in 1992 was the lowest in more than a decade, and in 1993 WC payments for both cash benefits and medical care actually declined.[20]

The interaction between WC and DI needs to be better understood. Only a small proportion of WC claims are for severe injuries of long duration that might meet the strict DI eligibility criteria. The recent decline in WC cash benefit payments may reflect more effective disability prevention or return to work policies for injured workers with temporary disabilities. At the same time, more restrictive interpretation of eligibility criteria for long-term disabilities, particularly on the question of whether the impairment is job-related, could increase demands placed on the DI program. Focus groups interviews with DI beneficiaries with musculoskeletal impairments, including some whose conditions appeared to have been caused or exacerbated on the job, provide anecdotal evidence of difficulties injured workers experienced with WC before they turned to DI (see the appendix). Research is needed to better understand the relationship, if any, between trends in WC and the DI program.

Long-term disability insurance. Private long-term disability insurance (LTDI) — for which employers purchase insurance or self-insure — interacts with the DI program more directly. Private LTDI disproportionately covers white-collar workers and generally is designed to supplement DI for middle and higher earning workers whose replacement rates from Social Security are relatively modest. (See chapter 2 for discussion of the complementary roles of Social Security and private supplemental insurance.)

The most common replacement rate in private LTDI is 60 percent, although replacement rates of 50 or 66 percent also are common. Plans typically reduce their benefits dollar for dollar by the amount of Social Security the claimant receives.[21] The rationale for this is to ensure that the target replace-

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[17] Social Security Administration, Office of Disability.

[18] Social Security Administration, op. cit., footnote 4, table 9.B1, p. 347.

[19] Social Security Administration, Office of the Actuary. The DI cost rate dropped from 1.39 percent of payroll in 1981 to 1.13 percent in 1985 and 1.09 percent in 1990.

[20] Social Security Administration, op. cit., footnote 4, table 9.B1, p. 347.

[21] Disability Policy Panel, *The Environment of Disability Income Policy: Programs, People, History and Context,* Interim Report, J.L. Mashaw and V.P. Reno (eds.) (Washington, DC: National Academy of Social Insurance, 1996), see table 2-6 and related discussion.

ment rate is achieved, while preserving financial incentives for the worker to return to work if he or she can by paying less than full replacement of prior earnings. The dollar-for-dollar offset means that LTDI plans have a financial incentive to help their claimants qualify for DI. The premiums they charge reflect an assumption that a portion of the private benefits over the long term will be offset by DI.

At the same time, private LTDI plans often use a less strict test of disability than does DI. Typically, they use an occupational test — inability to do one's own occupation — for the first year or two after disability onset, before shifting to a stricter test — inability to do any occupation — which is more similar to the DI test.[22]

In the early period of an insured worker's "occupational disability," some firms may use disability management techniques that are designed to help workers return to work at the same or a different job with the same employer.[23] These return-to-work initiatives are considered most likely to succeed when they are undertaken before the worker files for DI. When they are successful, they ultimately reduce costs for both LTDI and DI. When return to work is not successful, the claimant may be helped to qualify for DI. Establishing entitlement to DI in these cases has advantages for the individual as well as the payer for LTDI. While immediate benefits are no higher, other advantages to the beneficiary are: DI provides cost of living increases while private plans may not; establishing a "disability freeze" protects the worker's retirement benefits; and Medicare coverage becomes available through DI.

In other cases, firms may seek to control their costs by routinely requiring all their claimants to apply immediately for DI and to help them by paying for an attorney or other expert help to appeal a denial of DI, if needed. While this practice, in the absence of other investments in return-to-work assistance, may limit LTDI costs, it could increase demands on the DI system. More in-depth study is needed of how particular policies and practices in work-based disability programs affect claims for DI.

Increased Recognition of Mental Illness. Increased recognition and diagnosis of disabling conditions, particularly mental disorders, may have contributed to increased disability claims in recent years. Depression, the most common cause of disability based on mental illness, has been increasingly recognized and diagnosed in recent years.[24] It is a prevalent and often very disabling condition, but is amenable to effective treatment in some cases. Starting in 1985, the National Institute of Mental Health launched an ongoing public information campaign, "Depression: Awareness, Recognition and Treatment," to improve public and professional awareness of depression through a better informed lay public, primary care physicians, mental health organizations and employers.[25] The increased awareness and destigmatization of depression may have increased disability claims and allowances based on this diagnosis. Depression may coexist with other physical injuries or diseases or chronic pain. Whether depression or the physical impairment is the primary diagnosis in allowing a Social Security benefit award may depend on which condition can be more promptly and cost-effectively documented to meet SSA's medical and vocational criteria. As discussed in the next section, new criteria for evaluating mental disorders, which were issued in the mid-1980s, may also have contributed to growth.

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[22] M.W. Kita, "Morbidity and Disability," *Journal of Insurance Medicine,* Winter 1992, page 272.

[23] H.A. Hunt, et al., "Disability and Work: Lessons from the Private Sector," *Disability, Work and Cash Benefits,* J.L. Mashaw, et al., (eds.) (Kalamazoo, MI: W.E. Upjohn Institute for Employment Research, forthcoming).

[24] As noted in chapter 1, about 10 percent of the population, or 15.7 million working-age persons, is estimated to experience affective disorders over the course of a year. The National Mental Health Advisory Committee estimates that about 12 percent of persons with affective disorders are considered to have severe mental disorders, based on functional criteria. This estimate suggests that about 1.9 million of the 15.7 million working-age adults who experience affective disorders have disabling levels of the illness over the course of a year. The data do not indicate how many of those have disabling affective disorders that last at least 12 months, as specified in the test of disability for DI and SSI eligibility.

[25] National Institute of Mental Health, Depression: Awareness, Recognition and Treatment (D/ART) Campaign.

Community-Based Alternatives to Institutional Care. While very difficult to measure, changes in service patterns for people with severely disabling conditions may have contributed to the growth in the number of people who apply and qualify for SSI or DI benefits. In the past, persons with very severe mental illness, mental retardation or physical impairments were more likely than today to reside in state mental hospitals, intermediate care facilities for the mentally retarded (ICFs/MR) or in nursing homes. As states developed community-based alternatives to institutional care, community-based supports — SSI, food stamps and housing subsidies — become critical supports to meet day-to-day needs of those who are severely disabled. Anecdotal evidence suggests community-based service providers increasingly consider it part of their job to assist their clients to establish eligibility for these benefits. To the extent that persons with very significant disabilities are in the community and participate in sheltered or supported employment activities, they may gain sufficient work experience to qualify for DI benefits. Growth in the small number of disabled-worker beneficiaries with mental retardation may reflect this trend.[26]

The Health Care Squeeze. In the absence of comprehensive health care coverage, health care providers, particularly hospitals, have an incentive to assist uninsured patients to qualify for Medicaid, which in some jurisdictions involves establishing eligibility for SSI. Hospitals are not permitted to refuse emergency treatment to patients who are uninsured and cannot afford to pay for their care.[27] In the past, such uncompensated care was, in part, covered by fees charged to patients covered by private insurance or Medicare. However, recent cost control measures in Medicare and private insurance that limit payment rates to hospitals increase hospitals' incentive to help their low-income patients qualify for Medicaid. Hospital efforts include using benefits specialists to help their patients qualify. Some patients who are enrolled in SSI may have enough work history to qualify for DI. Focus group interviews provided anecdotal evidence that some beneficiaries were enrolled in SSI while they were hospitalized (see the appendix). It is unclear whether this is a source of increase in SSI claims, or simply a source of assistance for people who would have learned about SSI and applied anyway.

The broad social and economic environment — the state of the economy, the skill demands of jobs, the availability (or lack thereof) of other sources of income support and health care financing, and changes in the diagnosis and treatment of disabling conditions — all affect demands placed on the Social Security and SSI disability programs.

At the same time, legislative and administrative changes in the DI and SSI programs themselves contributed to the wide fluctuations in disability incidence rates and termination rates over the last 25 years.

Social Security Policy Changes Since 1970

Over the last 25 years, Social Security policy changes, juxtaposed with cyclical changes in the economy, help account for the wide fluctuations in new benefit awards. These changes are reviewed in greater detail in the Panel's interim report, and they are summarized briefly here.[28]

1970-75: Economic Recessions, Outreach, Rising Benefits. Rapid growth in DI incidence rates in the early 1970s coincided with economic recessions in 1969-70 and 1973-75, legislated benefit increases, outreach to enroll eligible persons in the SSI program and restrictions in staffing for disability-related activities.

The SSI program was enacted in 1972 and implemented in 1974 with a national outreach effort to notify and enroll eligible aged and disabled persons. Some who applied also qualified for DI. In addition, during this period Social Security benefit levels

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[26] The proportion of all disabled-worker beneficiaries on the rolls with mental retardation as their primary diagnosis rose from 4.3 percent to 5.4 percent between 1986 and 1994. Among the small number of disabled workers under age 30, the proportion with mental retardation rose from 13.3 percent to 17.8 percent between 1986 and 1994.

[27] Section 1867 of the Social Security Act.

[28] Disability Policy Panel, op. cit., footnote 21, chapter 4.

and replacement rates rose as a result of legislative increases, and Medicare was extended to DI beneficiaries who had been on the rolls for 24 months. At the same time, SSA staffing was reduced in the early 1970s as part of a government-wide effort to reduce the number of federal employees. To handle the rising workload, personnel were diverted from reviewing the accuracy of disability decisions and conducting CDRs to processing new claims.

1975-80: Tightening Rules, Lowering Benefits. Declining DI incidence rates in the last half of the 1970s accompanied administrative initiatives to tighten disability adjudication and legislative changes that lowered replacement rates for new disabled-worker beneficiaries.

Legislation in 1977 lowered replacement rates for new disabled-worker beneficiaries, as well as other Social Security beneficiaries. In 1980, new limits on family benefits for disabled workers were adopted. The higher benefit levels that had been in place were viewed as posing too great an incentive to claim benefits for some subsets of disabled workers.

In response to congressional concerns about growth in the rolls, SSA instituted administrative measures to tighten adjudication of DI and SSI initial disability claims and CDRs; it also stepped up the number of CDRs being done.

Initial claims. In 1979, after more than a decade of work, SSA published in regulations the "vocational grid," which was designed to introduce more objectivity and uniformity in assessment of applicants' residual functional capacity in relation to their vocational factors (age, education and work experience) in determining their ability to work. The grid was based largely on physical requirements of jobs — strength and endurance — and was not well suited to assessing ability to work for persons with mental impairments.

Terminations without medical improvement. Between 1969 and 1975 SSA had followed a policy of terminating benefits only when the beneficiary did not meet the current disability criteria and medical improvement was indicated. In 1976, the policy was changed to no longer require evidence of improvement before benefits were terminated. With the new policy in place benefit termination rates increased in the late 1970s and escalated in the early 1980s.

In some cases, benefits were terminated that had been allowed by an administrative law judge (ALJ), after being denied earlier. On close calls, beneficiaries found themselves buffeted between the ALJ decision, which had allowed benefits, and reviews by state disability determination agencies, which terminated them, without apparent change in the beneficiary's condition. As adjudication criteria were tightened at all levels, beneficiaries were subject to having their benefits terminated unexpectedly and without indication of a change in their condition.

In 1980, Congress set in law requirements for SSA to review initial allowances before benefits could be paid (called "pre-effectuation reviews"), and legislated a timetable for CDRs for those on the rolls.

1981-84: Retrenchment and Reaction. With the congressional mandate for pre-effectuation reviews and CDRs in place, the new Reagan administration sought to fulfill its promise to significantly reduce the size and cost of government by applying an increasingly restrictive interpretation to disability eligibility criteria. The administration aggressively reviewed the continuing disability of those on the rolls and terminated benefits for many. During this period — and in spite of the severe recession in 1980-82 — the disability incidence rate reached an all-time low and benefit terminations reached an all-time high (figures 3-1 and 3-2).

Public support for the sharp retrenchment eroded as its consequences became known. The policies were challenged in the courts and some states refused to implement them. Ultimately, the administration stopped doing CDRs and denying mental impairment claims until new guidelines were developed. In 1984, Congress enacted legislation to preclude the kinds of policies that had been adopted, challenged, and halted in the early 1980s.

New mental impairment criteria. Many of those whose benefits were denied or terminated during the retrenchment of the late 1970s and early 1980s were persons with mental impairments, and there was widespread agreement that SSA's practices with respect to mental impairment claims had become overly restrictive.[29] SSA's practices for deciding claims of persons with mental impairments were challenged in the courts and were criticized by Congress and congressional agencies for such deficiencies as: inadequate consideration of the functional consequences of mental impairments; inadequate consideration of claimants' residual functional capacity and vocational factors; inadequate use of existing medical evidence from treating sources and over-reliance on medical examinations purchased by SSA; and inadequate use of psychiatrists or psychologists in assessing disabling mental impairments.[30]

In 1983 the administration placed a moratorium on denial or termination of benefits for claimants with mental impairments and began work in collaboration with the professional mental health community to develop new regulations. In 1984 Congress mandated that new regulations be developed that focused on evaluating the person's ability "to engage in substantial gainful work in a competitive work place environment."[31] The new mental impairment criteria were published in the summer of 1985.

Medical improvement standard for CDRs. The policy of aggressively reviewing the rolls and terminating benefits without evidence of an improvement in the beneficiary's condition was also challenged by the courts and ultimately met resistance from states, as they experienced increased claims for state assistance from people whose disability benefits had been terminated. In April 1984, the administration placed a temporary moratorium on CDRs. At the time, nine states were operating under court-ordered medical improvement standards, and nine others had suspended reviews pending a court-ordered medical improvement standard or pending action by the circuit court.

Legislation passed in 1984 required SSA to establish and publish in regulations a medical improvement standard to use when evaluating the continuing disability of those on the rolls.

1985-89: Economic Expansion, Agency Downsizing. In the mid-1980s, disability incidence rates rose slightly from the all-time low in 1982 and then stabilized in the last half of the decade as the nation enjoyed a sustained period of economic growth and the policies to undo the sharp retrenchment of the early 1980s took effect. The main Social Security initiative during this period was to downsize agency staffing and streamline operations. Fewer administrative resources were available to perform tasks that required individualized attention such as implementing work incentives, assisting those who could not independently file an application for benefits, or assigning and monitoring representative payees for beneficiaries who were not capable of managing their benefits.

1989-92: Outreach, Economic Recession. In the early 1990s, DI incidence rates again rose as an economic recession coincided with renewed interest in outreach activities and administrative resources were sharply constrained.

Beginning in 1989, Congress appropriated earmarked funds over five years for outreach efforts to enroll eligible persons in SSI. With the new funding, SSI outreach became an SSA priority. Outreach activities were cited by SSA field office managers as a cause of growth in disability applications in the early 1990s.[32] Some who applied for SSI were found to have enough covered work experience to qualify for DI concurrently with SSI.

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[29] H. Goldman and A. Gattozzi, "Balance of Powers: Social Security and the Mentally Disabled," *Milbank Quarterly*, Number 66, 1988, pp. 531-551.

[30] U.S. Senate, Special Committee on Aging, *Social Security Reviews of the Mentally Disabled*, Hearing 98-170 (Washington, DC: U.S. Goverment Printing Office, 1983).

[31] Public Law 98-460, Section 5(e).

[32] L.S. Muller and P.M. Wheeler, "Disability Program Growth: Results from Social Security's Survey of Field Office Managers," unpublished paper presented at a conference sponsored by SSA and DHHS/ASPE, Washington, DC, July 20-21, 1995.

Also during this period, new criteria were issued to adjudicate childhood disability claims. These changes were required by the Supreme Court decision in *Sullivan* v. *Zebley.* National outreach to enroll eligible children, as required by Congress and the Court, contributed to SSA's new claims workload in the early 1990s and to increased disability awards in the SSI childhood disability program.[33]

The recession of the early 1990s contributed to the rapid increase in benefit applications. Coming on the heels of a 25-percent reduction in staff, SSA was not able to process the huge workload of new claims. As in similar circumstances in the past, pressure to adjudicate claims quickly, without adequate resources, coincided with higher levels of awards.

1993-95: Incidence Rates Flatten, Rolls Continue to Grow. The DI incidence rate declined slightly and flattened out after 1992. Thus, the rapid rate of growth in benefit awards appears to have been a temporary phenomenon due, in part, to the economic recession in 1990-91.[34] The number of people receiving benefits continues to grow, however, because fewer people are leaving the benefit rolls than are entering.

WHAT SHOULD BE DONE

Although the recent rapid rate of growth in new benefit awards appears to have been a temporary phenomenon tied to the economic recession of 1990-91, the benefit rolls continue to grow. Some reasons for this growth lie in the broader environment. The eligible population is larger; it is also younger, which reduces the rate at which disability beneficiaries leave the rolls due to retirement. Cutbacks in state public assistance and in other sources of disability income may have increased pressure on the DI and SSI programs. Increased recognition and diagnosis of disabling conditions may also be a contributor to growth. Finally, structural changes in the labor market and the demands of work can increase work disability. These factors are beyond the realm of DI and SSI benefit policy. Nevertheless, policy and administrative changes should be pursued to promote return to work where possible and to ensure the continued integrity of the benefit determination process and the disability income support system as a whole.

The Panel's Policy Proposals Promote Work

Most of the Panel's proposals are designed to promote work and therefore should increase the number of people who leave the benefit rolls for this reason. Those proposals include:

- Return-to-work (RTW) tickets that beneficiaries can use to get the vocational services they need to return to work (chapter 6);
- A disabled worker tax credit, which is designed to facilitate exit from the DI and SSI benefit programs, as well as to encourage individuals to work despite their impairments instead of turning to DI or SSI benefits (chapter 7);
- An affordable and understandable Medicare buy-in option for former DI beneficiaries who return to work. To the extent that fear of losing Medicare coverage discourages beneficiaries from seeking work, a Medicare buy-in option that is understandable, predictable and affordable should eliminate this deterrent to work attempts (chapter 8).
- Enhanced implementation of existing work incentive provisions so that beneficiaries who seek to return to work can do so without unexpected consequences in their benefits (chapter 9).

Adequate Administrative Resources Are Essential

A review of the last 25 years finds a common theme in the three periods that produced concern about the disability programs: the two periods of rapid growth in the mid-1970s and the early 1990s, and the

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[33] Committee on Childhood Disability of the Disability Policy Panel, *Restructuring the SSI Disability Program for Children and Adolescents* J.L. Mashaw, J.M. Perrin and V.P. Reno (eds.) (Washington, DC: National Academy of Social Insurance, 1996).

[34] D.C. Stapleton, et al., op. cit., footnote 11, p. 18.

period of sharp retrenchment in the early 1980s. All three periods coincided with economic recessions, which weaken employment prospects and accommodations for workers with disabilities. In each period new administrative demands were placed on the system without commensurate investment in administrative resources, including technology. In all three periods, the under-investment in administrative resources was followed by concerns that the program was out of control.

In the mid-1970s, SSA was called upon to implement the new SSI program and was not provided sufficient additional resources to do it. In the early 1990s, after the agency had been downsized by nearly 25 percent, SSA did not have the resources to respond to the huge growth in new claims that accompanied an economic recession. When backlogs grow and claims are not decided promptly, Congress responds to constituent concerns by urging the agency to speed up its disability decisions.

Pressure to speed up decisions in spite of inadequate administrative resources can contribute to growth in the rolls in a number of subtle and interrelated ways.

- New instructions may be issued to ease standards for documenting claims that are allowed.

- Personnel involved in quality review of disability decisions are likely to be reassigned to help process claims. Fewer allowed claims then are reviewed for accuracy.

- Greater reliance may be placed on third parties to assemble and submit claims for disability benefits. While SSA does not pay third parties, some have a financial interest in benefits being allowed.

- Personnel responsible for CDRs of those on the rolls are shifted to processing new claims.

- Personnel and systems supports for so-called "post-entitlement actions" that are essential to support beneficiaries' attempts to work get low priority.

In the retrenchment period of the early 1980s, new policies were initiated to vigorously review the disability rolls and terminate benefits to anyone not found to meet a very restrictive interpretation of the eligibility criteria. This was done without adequate staffing or training in the new review procedures. The 1980 legislation that had required stepped up review of those on the rolls had estimated modest savings from this initiative, recognizing that investment in administrative resources in the early years would outweigh any early benefit savings. The reviews were vigorously launched, however, without the investment in staff and training. They were abandoned after they lost public support, were challenged in the courts and some states refused to implement them.

Given this history, the Panel repeats the concern expressed in our interim report, that attempts to administer a complex and expensive benefit program without adequate administrative resources ill serves both beneficiaries and the public fisc. In relation to the importance and size of the disability benefit program, investment in administrative resources is very modest, at 2.7 percent of DI program outgo in 1994.

Moreover, because SSA has a large workload and limited resources, administering the work incentives for beneficiaries attempting a return to work is a low priority. Yet if beneficiaries are to be encouraged to return to work, effective implementation of the work incentives is essential so that beneficiaries can make a smooth transition off the benefit rolls when they do work. The Panel emphasizes that:

Administrative resources including technology must be set at a level that ensures stable, effective management of the disability programs. Resources must be adequate to provide: (1) fair, accurate and prompt decisions on disability claims, (2) individualized service to beneficiaries that is contemplated under the law, including accurate information and prompt action to implement benefit adjustments when beneficia-

ries work, and (3) timely and predictable review of the continuing eligibility of those receiving disability benefits.

The Panel considered a proposal to further emphasize review of the continuing disability of those on the rolls by making benefit allowances time limited for beneficiaries with reasonable prospects for return to work. The basic reason for considering such as approach was a desire to set expectations of return to work at the time benefits are allowed. Several members of the Panel believe that such an approach is consistent with the goals of more fully integrating people with disabilities into the work force and would send a signal to both people with disabilities and to Social Security administrators that permanent disability-based transfers are a last resort. The majority of the Panel, however, believes that the financial and administrative problems with time-limited benefits make them unworkable.

Briefly stated, the objections to time-limited benefits include: (1) the very limited success to date in developing criteria at the time of benefit award that are good predictors of recovery or return to work, (2) the potential for the availability of "temporary" benefits to increase applications and awards, and (3) the use of extremely scarce administrative resources in redetermining large numbers of claims in which the prior determination of disability may be confirmed. Given these difficulties, the Panel recommends greater commitment to staffing and implementation of the existing CDR process combined with its proposal for return-to-work tickets. It believes these initiatives can produce outcomes similar to the positive expectations for time-limited benefits.

The effectiveness of a systematic CDR process is supported by historical trends in benefit terminations. Termination rates because of medical recovery or return to work were considerably higher during the 1970s than they are today. During much of that period, SSA used a medical improvement standard for review that is similar to the standard in place today. SSA has indicated its intention to resume CDRs and to develop procedures to cost-effectively target reviews on those with the best prospects for recovery. The Panel supports those efforts.

A more fundamental restructuring of disability benefits, built on the German or Swedish models, would make the transition onto long-term disability benefits a two-step process in which a period of provisional benefits and extensive rehabilitation and accommodation efforts preceded entry onto the long-term disability rolls. This approach was discussed briefly. It was not pursued in depth because it would require substantial new resources, in both new short-term benefits and in services, which are unlikely to become available.

Medical and Vocational Criteria Should Be Kept Up to Date

The Panel believes that renewed emphasis should be placed on periodic updates of the medical and vocational criteria for assessing work disability. The Panel fully supports the use of medical listings along with vocational criteria in the disability determination process (see chapter 5). We did not review particular listings, nor was that our job. Experts agree on the need for periodic reviews and updates of the criteria to ensure that past experience, new research and state-of-the-art knowledge are systematically incorporated into the programs' assessment of work disability. Categories of impairments that account for a significant portion of the disability rolls, or where rapid growth has prompted concern, are good candidates for expert review. For example:

- *Mental impairments.* Standards have now been in place for 10 years. It is time to undertake a full, expert examination of the mental impairment listings in light of experience and current thinking of the professional mental health community.

- *Pain.* As required by Congress in 1984, SSA convened a Commission on the Evaluation of Pain and a Committee on Pain and Disability of the Institute of Medicine, which reported in 1986 and 1987, respectively. Both recommended research to develop pain assessment instruments, which has now been completed.[35] SSA should convene an expert group to determine how to apply what has been learned to the Social Security disability determination process.

SSA has been engaged in reengineering its disability claims process. One of the premises of this redesign is the creation of a new, simplified assessment of work disability. Such a fundamental realignment of the medical and functional assessment criteria would appear to require many years to develop and test before it is ready to be put into regulations as a substitute for existing criteria. In the meantime, existing criteria should be updated and those associated with rapid growth in allowances should be given high priority in order to maintain public confidence in the integrity of the program. Because the reengineering effort is ongoing and incomplete, the Panel is unable to evaluate it.

Experts on SSA's medical listings report that there is considerable variation among the medical listings for different body systems in terms of the severity of impairments that are presumed to constitute work disability. To date no systematic research has been done to evaluate the consistency of the presumptions underlying the medical listings for different body systems. Research of this kind should have high priority. The Panel supports investment in SSA's research program for this purpose.

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[35] U.S. Department of Health and Human Services, *Report of the Commission on the Evaluation of Pain*, (Washington, DC: U.S. Government Printing Office, 1986); M. Osterweis, A. Kleinman and D. Mechanic, (eds.), *Pain and Disability: Clinical, Behavioral and Public Policy Perspectives* (Washington, DC: National Academy Press, 1987); K.S. Rucker, et al., "Final Report on All Aspects of the Pain Assessment Instruments Development Project," unpublished paper, Virginia Commonwealth University, Richmond, VA, 1994.

Chapter 4

Defining Eligibility for Benefits and Services: Distinguishing Programs and Purposes

In chapter 1, the Disability Policy Panel presented a single conceptual definition of disability for purposes of clarifying the nature of work disability. This chapter presents the Panel's review of specialized definitions of disability that are used as *eligibility criteria* in public laws or private contracts that offer civil rights protection, rehabilitation, other services or income support to persons with impairments or work disabilities. In reviewing these definitions, the Panel concluded that:

- different definitions of disability are appropriate for programs that offer different kinds of services or benefits;
- work disability — based on loss of ability to earn — is an appropriate eligibility criteria for earnings-replacement insurance; and
- the Social Security Act definition of work disability is very strict. A less strict test would significantly increase the cost of Social Security disability benefits.

This chapter addresses concerns that these eligibility criteria differ in their definition of disability; reviews the definitions used for specific disability-related programs; and discusses various alternative definitions of disability that have been suggested for the Social Security program. It concludes by exploring whether programs with different, specific purposes and eligibility criteria — such as vocational rehabilitation and Social Security disability insurance (DI), or the Americans with Disabilities Act of 1990 (ADA) and DI — are in conflict.

DO WE NEED A SINGLE DEFINITION OF DISABILITY?

A single, broad definition of disability, as illustrated by the conceptual model of disability adopted by the Panel, is useful in drawing meaningful distinctions among such disability-related concepts as *medical condition, impairment, functional limitation* and *work disability.* The conceptual definition of *work disability* is useful in clarifying its four elements — impairments, skills and abilities, tasks of work, and the broader environment — and therefore in considering various possible remedies for work disability.

But a single legal definition of disability for purposes of defining eligibility for benefits and services is neither necessary nor desirable. A one-size-fits-all definition would be ill-suited to the diverse needs of persons with impairments or work disabilities. Rather, eligibility criteria should and do relate directly to the service or benefit being offered:

- A definition of disability based on need for assistance with activities of daily living (ADLs) is appropriate for determining eligibility for publicly-financed services that assist with ADLs.

- A definition of disability based on need for and likely benefit from vocational services is appropriate for determining eligibility for publicly-financed vocational rehabilitation (VR) services.
- A definition of disability that encompasses all who are at risk of discrimination in employment or public access is appropriate for determining who is covered by civil rights protection.
- A definition based on loss of earning capacity is appropriate for determining who is eligible for public or private cash benefits to replace part of lost earnings.

A mismatch between eligibility criteria and benefits that are offered creates inappropriate incentives and gaps in coverage for people seeking to gain access to the services they need. For example:

- Basing eligibility for personal assistance with ADLs on a definition of disability related to work incapacity fails to cover individuals who need such assistance whether or not they are working.
- Basing eligibility for health care on a definition of disability related to work incapacity is appropriate if, and only if, people who work are ensured access to health care through their jobs. If they cannot get health care coverage when they work, then basing eligibility for health care coverage on work disability leaves uncovered those who can and do work.

Consistency in disability policy is found instead in its overarching goals. The Panel believes the primary goal of a national disability policy should be the integration of people with disabilities into American society. That includes equality of opportunity, full participation, independent living and economic self-sufficiency. These goals are pursued through a broad landscape of systems that finance health care and education for the general population and various programs that provide disability-related goods and services, legal protections and earnings replacement benefits, as discussed in chapter 1. Legal definitions of disability that are used as eligibility criteria for these various services, legal protections and cash benefits rightly differ because they target particular remedies to a specific need among the varied needs that people with disabilities have.

DEFINING ELIGIBILITY FOR SERVICES OR BENEFITS

The Panel reviewed a number of different definitions of disability that are used in public laws or private contracts. These legal definitions of disability are not meant to be an all-purpose definition of the meaning of disability. Instead, they are used as eligibility criteria to specify who is eligible for particular protections, services or benefits provided by various public laws or private contracts.

Each of the programs the Panel reviewed offers a different kind of remedy or benefit to people who have impairments, functional limitations or work disabilities. As such, each employs a different legal definition of disability for determining who is eligible for what the program provides, whether that is civil rights protection, rehabilitation, long-term care services or earnings-replacement benefits. The programs are not in conflict with one another because they offer different remedies or because they define eligibility for different remedies in different ways. Rather, taken together, they reflect the extraordinary diversity of both abilities and needs among persons who have some sort of impairment, functional limitation or disability.

The variations among legal definitions and their match with the purposes of particular programs is illustrated by examining four different sets of disability policies: civil rights protection, vocational rehabilitation, long-term care services and earnings-replacement insurance.

Civil Rights Protection

The ADA defines disability for the purpose of providing legal remedies to those at risk of discrimination in employment or public access (figure 4-1). The ADA defines disability broadly for the purpose

Figure 4-1. Definitions of Disability for Civil Rights Protection and Eligibility for Services

Program or law	Purpose of definition	Definition
Civil rights protection		
Americans with Disabilities Act	To determine who is protected by the nondiscrimination and public accommodation provisions of the ADA.	Individual with a physical or mental impairment that substantially limits one or more major life activity; a record of such an impairment; or being regarded as having such an impairment.
Eligibility for rehabilitation services		
Vocational rehabilitation (public program)	To determine who is eligible to receive VR services.	An individual who (i) has a physical or mental disability that constitutes or results in a substantial impediment to employment and (ii) can benefit in terms of an employ ment outcome from VR services provided.
Vocational rehabilitation (private employment-based disability insurance)	To determine who might be offered employer-financed VR services	Cost/benefit analysis. Employer- or insurer-financed VR services are offered at the discretion of the employer/insurer and are provided based on their cost recovery potential from the employee returning to work.
Eligibility for long-term care services		
Medicaid (institutional care)	To determine who is eligible for Medicaid-financed institutional care, or community-based alternatives.	Needs assistance with ADLs or medical assessment of need for institutional care. Depends on the state plan.

Abbreviations: ADA = Americans with Disabilities Act, ADLs = activities of daily living, VR = vocational rehabilitation.

of identifying who is covered by the civil rights protection of the Act:

- "Disability" means with respect to an individual (1) a physical or mental impairment that substantially limits one or more major life activities of such individual, (2) a record of such an impairment, or (3) being regarded as having such an impairment.[1]
- "Major life activities" means functions such as caring for oneself, performing manual tasks, walking, seeing, hearing, speaking, breathing, learning, and working.[2]

Regarding discrimination in employment, the ADA states that no covered entity shall discriminate against a "qualified individual with a disability" because of disability in regard to job-application

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[1] 42 U.S.C. 12102(2).

[2] U.S. House of Representatives, *Americans with Disabilities Act of 1990: Report Together with Minority Views,* Rpt. No. 101-485, Part 2 (Washington, DC: U.S. Government Printing Office, 1990), p. 51.

procedures; the hiring, advancement or discharge of employees; employee compensation; job training; and other terms and conditions of employment.

- A qualified individual with a disability is an individual with a disability who, "with or without reasonable accommodation, can perform the essential functions of the employment position that such person holds or desires."[3]

Employers are required to provide reasonable accommodation, unless the accommodation would place an undue hardship on the operation of the business. Undue hardship is an action that would require significant difficulty or expense. It is determined on a case-by-case basis.[4]

The broad definition of who is covered by the ADA is appropriate for the purpose of the Act, which is to offer legal remedies to those who face discrimination in employment or public accommodation. For that purpose, it is appropriate to include not only those who have impairments, but also those who are believed to have impairments or in the past have had impairments because they too may be at risk of discrimination.

Vocational Rehabilitation

The federal/state program that provides VR services defines disability in terms of the need for and likely benefit from the rehabilitation services the program offers. The Vocational Rehabilitation Act, as amended in 1992, adopted the ADA definition for setting its research, training and independent-living center goals. The definition used for eligibility for VR services, however, remains related to the need for and likelihood of benefiting from the services the program offers. That is:

> An individual who (i) has a physical or mental disability that constitutes or results in a substantial impediment to employment and (ii) can benefit in terms of an employment outcome from vocational rehabilitation services provided.[5]

The 1992 amendments modified the eligibility criteria by adding:

> it shall be presumed that an individual can benefit in terms of an employment outcome from vocational rehabilitation services ... unless the designated state unit can demonstrate by clear and convincing evidence that such individual is incapable of benefiting from vocational rehabilitation services in terms of an employment outcome.[6]

The change shifts the burden of proof from the applicant to the VR agency in determining whether a person can benefit from VR services. The eligibility criteria, however, remain based on the need for, and prospect of benefiting from, services that VR agencies offer.

Private employers or disability insurers also offer vocational rehabilitation services. The services rarely, however, are an entitlement or contractual obligation to the individual worker from the employer or insurer. Instead, eligibility for insurer-financed rehabilitation services is based on the cost recovery potential to the employer or insurer of paying for those services, so the employee can return to work and leave the private disability insurance rolls.

Long-Term Care Services

Programs that provide long-term care services, while neither widely developed nor uniformly available in the United States, generally define disability in terms of limitations in performing ADLs. They provide institutional or community-based services to assist individuals with ADLs.

The Medicaid program is the main source of public financing to provide individuals with very significant disabilities with long-term care services, such as

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[3] 42 U.S.C. 12111.

[4] N.L. Jones, "Essential Requirements of the Act: A Short History and Review," in *The Americans with Disabilities Act: From Policy to Practice,* J. West (ed.) (New York, NY: Milbank Memorial Fund, 1991), pp. 36-37.

[5] Section 7(8)(A) of the Rehabilitation Act, as amended in 1992.

[6] Ibid., Section 102 (a)(4)(A).

institutional care in nursing homes for elderly persons or intermediate care facilities for persons with mental retardation (ICFs/MR). To encourage community-based alternatives to institutional care, Medicaid waivers have allowed states to arrange long-term care in the community for individuals who would otherwise meet the state's test of need for institutional care, if the community-based alternative costs no more than institutional care. The Medicaid program has also permitted states to fund user-directed, community-based personal assistance services.[7] To qualify for institutional or community-based services, individuals must meet the state's eligibility criteria, which are usually based on need for assistance with ADLs such as bathing, eating, toileting, getting around inside the home and getting in or out of bed or a chair.[8]

Earnings Replacement Insurance

Cash benefit programs that are designed to replace earnings from prior work all use a definition of disability based on loss of ability to work. In addition, they all have other eligibility rules that require a record of prior work from which contributions toward disability protection were paid (by the employee, the employer or both) and all, in one way or another, relate the amount of the benefit paid to the prior level of covered earnings that have been lost because of work disability. Various definitions used to determine eligibility for benefits to replace lost earnings are summarized in figure 4-2. They differ mainly in the range of jobs that must be considered in determining whether the insured individual is unable to work.

- **Private long-term disability insurance** (LTDI) contracts usually define disability in terms of inability to perform one's usual occupation, although after a period of time (often two years) the definition shifts to a stricter test of inability to perform the duties of any occupation for which one is qualified by training, education or experience.[9]

- **Private short-term disability insurance** contracts usually define disability in terms of inability to perform one's own job, which is a less strict test than the "own occupation" test used for long-term disability insurance. The job-specific test is used for short-term disability benefits because it is generally assumed that the employee will be able to return to his or her job after he or she recovers from temporary illness, injury or maternity.

- The **U.S. Civil Service Retirement System** definition of long-term disability for eligibility for disability retirement pensions is similar to an occupational test in private LTDI — inability to perform the employee's current position or another available position in the same agency at comparable pay for which the person is qualified.

- The **Railroad Retirement system** offers an occupational definition of disability (inability to perform their usual occupation) for workers with 20 years of service and a current connection to the railroad industry. Railroad workers with fewer years of service, or those who have left railroad employment, can receive disability benefits from the railroad retirement system if they meet a definition of disability that is essentially the same as the Social Security definition.

- The **Social Security Act** definition of long-term disability is clearly the most stringent. It defines disability as:

  "the inability to engage in any substantial gainful activity by reason of any medically determinable physical or mental impairment which can be expected to result in death or which has lasted or can be expected to last for a continuous period of

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[7] This is made possible by a regulation (42 CFR 440.170(f)) "that permits personal assistance services to be provided in a person's home by an individual, not a member of the family who is qualified to provide such services, where services are prescribed by a physician in accordance with a plan of treatment and are supervised by a nurse." Because this regulation does not specify the amount of nurse supervision required, it permits states to allow a great deal of consumer direction in the daily management of one's personal assistance needs. G. DeJong and T. Wenker, "Attendant Care as a Prototype Independent Living Service," *Caring*, November 1982, pp. 26-30.

[8] These need-for-service eligibility criteria are in addition to the Medicaid categorical criteria (SSI or AFDC receipt, or over age 65) and the Medicaid income and resource eligibility criteria.

[9] M.W. Kita, "Morbidity and Disability," *Journal of Insurance Medicine*, Winter 1992, p. 272.

Figure 4-2. Definition of Disability for Cash Benefits

Program or law	Purpose of definition	Definition
Replacement of prior earnings		
Disability insurance (OASDI)	Eligibility for benefits to partially replace past earnings.	INABILITY TO WORK. Inability to engage in SGA because of a medically determinable physical or mental impairment expected to last 12 months and of such severity that individuals cannot, after considering their age, education, and work experience, do their previous work or other work that exists in the national economy.
Private long-term disability insurance	Contractual entitlement to benefits to partially replace past earnings.	OWN OCCUPATION/ANY OCCUPATION. Often, for first 2 years, inability to do own occupation. Then inability to do any suitable occupation.
Private short-term disability insurance	Contractual entitlement to benefits to temporarily replace earnings.	OWN JOB. Inability to perform own job.
U.S. Civil Service disability	Federal employees' entitlement to disability pension.	OCCUPATIONAL. Because of disease or injury, unable to render useful and efficient service in the employee's current position or in a vacant position in the same agency at the same pay level for which the individual is qualified for reassignment.
Railroad retirement disability annuity	Railroad workers' entitlement to monthly benefits based on disability.	Regular disability: same as OASDI. Occupational disability (for workers with 20 years of service and a current railroad job): inability to perform the worker's regular railroad job.

Abbreviations: OASDI = Social Security old-age, survivors, and disability insurance, SGA = substantial gainful activity.

not less that 12 months ... An individual shall be determined to be under a disability only if his physical or mental impairment or impairments are of such severity that he is not only unable to do his previous work but cannot, considering his age, education, and work experience, engage in any other kind of substantial gainful work which exists in the national economy..."[10]

All of these systems have in common the purpose of providing income to replace part of lost earnings while the worker is unable to work as a result of illness, injury or work disability. Their definitions of disability all relate to the demands of work. They differ in terms of the range of jobs or job tasks that are considered in determining work disability. Short-term disability usually considers the worker's current job; insurance or pensions for long-term disability often consider the full range of jobs within

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[10] Section 223(d)(1)(A) and (2)(A) of the Social Security Act.

the worker's occupational group. Social Security disability insurance has the most demanding standard because it considers the person's ability to do *any* work that exists in significant numbers in the national economy. (The Social Security Act definition is discussed in greater detail in chapter 5.)

The Panel concludes that work disability is an appropriate legal definition — or eligibility criterion — in public laws or private contracts that are designed to pay benefits to replace part of lost earnings from work.

On the other hand, work disability is not necessarily a proper eligibility criterion for allocating publicly-financed services or benefits that people need whether or not they are working, particularly if these services or benefits are not available to people with impairments or chronic health conditions who do work. Examples of services people need whether or not they are working include health care coverage and, in some cases, personal assistance services or other ongoing impairment-related supports.

The Social Security Act definition, while very strict, is consistent with the Panel's conceptual model of work disability. Work disability involves the interaction among a person's medically determinable impairment; the environment in which he or she is expected to work; the tasks that constitute work the person can reasonably be expected to do; and his or her offsetting capacities or compounding limitations in performing those tasks.

ALTERNATIVE DEFINITIONS OF DISABILITY FOR SOCIAL SECURITY

Because the Social Security test of disability is very strict, it is often criticized for requiring that applicants be unable to do "any substantial gainful activity" in order to qualify for benefits. That is, of course, true. The Panel considered various less strict tests of work disability for Social Security. The appeal of such alternatives is that they would make Social Security more "work friendly" by paying benefits to more persons who can and do work. The drawback of such proposals is that they would increase the number of people who would qualify for Social Security disability benefits and, therefore, would increase the cost of the DI program.

Occupational Test of Disability

The occupational test of disability — inability to perform one's own occupation — that is used in many private long-term disability insurance plans is less strict than the Social Security test. This test would allow benefits to be paid to workers who are no longer able to do their usual occupation, but nonetheless are quite capable of doing other work, including work at relatively high pay.

The Panel reviewed a comprehensive reform proposal that involved an occupational test of disability for DI that would allow benefits if the applicant were unable to do his or her usual occupation.[11] This occupational test was estimated to increase the cost of the DI program by about $20 billion per year (in 1994 dollars) after 10 years, or by roughly 50 percent.[12]

Partial Disability

Some European social insurance programs pay partial disability benefits. In the Netherlands, for example, if workers have a loss of 15 to 80 percent of their working capacity, they may receive a partial disability pension. If such workers are employed, they are eligible for a fraction of the full disability pension. In Sweden, partial disability pensions may be paid at 25 percent, 50 percent or 75 percent of a full disability pension for either the universal disability pension or the earnings-related pension.[13]

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[11] A.I. Batavia and S.B. Parker, "From Disability Rolls to Payrolls: A Proposal for Social Security Program Reform," *Journal of Disability Policy Studies*, Vol. 6, No. 1, 1995.

[12] Social Security Administration, Office of the Actuary, memorandum, "Estimated Increase in OASDI Benefit Payments Under the 'Batavia-Parker' Proposal to Modify The DI Program," September 10, 1993.

[13] Social Security Administration, *Social Security Programs Throughout the World—1995* (Washington, DC: U.S. Government Printing Office, July 1995), pp. 316-17.

Both the Netherlands and Sweden spend significantly more on disability benefits than does the United States. The United States in 1991 spent 0.7 percent of its gross domestic product (GDP) on Social Security and SSI disability benefits. In contrast, the Netherlands and Sweden spent 4.6 and 3.3 percent of their GDP, respectively for their disability benefit systems that include partial disability benefits.[14]

In the United States, permanent partial disability benefits also are provided by state workers' compensation programs. Compensation for permanent partial disability is one of the most complicated and contentious aspects of workers' compensation. Broadly speaking, three different bases are used for determining compensation for permanent partial disability:

- Impairment-based methods provide compensation based on physical or mental loss of use of bodily function. This method pays a specified amount for such factors as loss of motion, loss of strength or loss of a part of the body.
- Wage-loss methods base the benefit on the actual partial loss of earnings as a result of the permanent partial impairment. The amount of the benefit is based on demonstrated loss of past earning capacity.
- Earnings-capacity-loss methods take into account the impact of the worker's age, education and work experience in combination with the permanent partial impairment to estimate the consequences of the injury for the worker's future stream of earnings.

A recent blue ribbon panel on workers' compensation concluded that each of these methods has certain advantages as well as significant flaws. *Impairment-based valuations* of loss can be measured with ease, but the benefit is not related to the economic consequences of the loss for the individual worker. *Wage-loss systems* come the closest to the traditional purpose of workers' compensation, but they provide disincentives for workers to return to full employment if the amount of the benefit is related to the demonstrated partial wage loss. In addition, it is difficult to determine whether the wage loss experienced long after the injury is due to the injury or to other factors, such as economic conditions. Finally, assessment of *earnings-capacity loss* takes account of both the impairment and its future economic consequences, but the assessment is highly subjective and often involves dispute and litigation about the valuation of future earnings lost due to the injury.[15]

In brief, experience in other countries and with workers' compensation in the United States suggests that partial disability benefits tend to be costly as well as difficult and contentious to implement. The Panel believes that the disabled worker tax credit it is recommending as a wage subsidy for low-income workers with disabilities is a far preferable way to provide partial support to low-income workers whose capacity to earn is reduced, but not eliminated, by a disabling impairment (see chapter 7).

Veterans' Compensation Impairment Test

The veterans' compensation (VC) system in the United States uses a wholly different concept for paying cash compensation. It pays monthly benefits to veterans whose impairments resulted from injury or disease incurred or aggravated while in active military service. The amount of compensation depends solely on the degree of impairment, rated as a percentage of normal function that is lost. One appeal of this approach is that receipt of benefits is not based on work incapacity. Veterans with service-connected impairments receive benefits for life, regardless of their future success in the labor market. Monthly payments range from $89 for an impair-

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[14] L.J.M. Aarts and P.R. de Jong, "European Experiences with Disability Policy," *Disability, Work and Cash Benefits*, J.L. Mashaw, et al., (eds.) (Kalamazoo, MI: W.E. Upjohn Institute for Employment Research, forthcoming).

[15] Blue Ribbon Panel on Workers' Compensation, *Policy Statement on Permanent Partial Disability* (Denver, CO: National Conference of State Legislatures, 1992).

ment with a 10-percent rating to $2,165 for a 100-percent impairment rating in 1995. Applying this concept to Social Security for all Americans is problematic for at least two reasons:

Cost versus Benefit Adequacy. The VC impairment test for paying compensation is much more expansive that the Social Security test based on "inability to engage in any substantial gainful activity." Of the 1.3 million people under age 65 receiving veterans' compensation, only about 9 percent are classified as "unemployable," a concept similar to the Social Security definition of work disability. About 22 percent have impairment ratings of 50 percent or more.[16] The rest have lesser impairments. If the distribution of impairments in the general population is comparable to that among veterans receiving compensation, then;

- To compensate all Americans who have an impairment equal to the VC rating scale from 10 to 100 percent would cover about 10 times the number of people who meet the Social Security test of work disability.
- To compensate only those Americans who had an impairment rating of 50 percent or more on the VC scale would cover a population more than twice the size of the Social Security beneficiary population.

To pay this much larger group would require either a tremendous increase in Social Security benefit outlays, or a significant reduction in the current level of support for those who are found unable to work, or both.

Problem of Rationale. Veterans' compensation is based on a unique employer-employee relationship where the federal government is the employer. It has the authority to draft people into military service and subject them to extremely hazardous duty. While the draft has not been used since 1974, the government has the authority to reinstate it when needed. Even with an all volunteer military, there is a special responsibility of the federal government to compensate people in the armed forces and their family members for lives lost or impairments sustained in order to attract a volunteer force that is subject to the rigors and dangers of military service.

This compensation concept is not based on the veteran's need for income support. Rather, it is based on the government's liability, as employer, to compensate the veteran for the harm sustained while in the government's employ. The amount of compensation is related to the degree of harm as determined by the veteran's impairment rating. It is not directly related to veterans' need for support either because of their lost earnings capacity or because of the cost of particular impairment-related services or supports they have to buy. In fact, the federal government generally pays for those other services for injured veterans — such as medical care, attendant allowances, prostheses, equipment and rehabilitation — in addition to cash compensation for their impairments.

In short, the rationale for the federal government to compensate veterans or their survivors for harm sustained or lives lost while on active duty in the armed forces does not apply to income support for all members of society.

On the other hand, the idea of compensating for some of the impediments or financial costs people face because of their impairments is an important element of U.S. disability policy. It is not based on government liability, but rather on the social value of leveling the playing field between people with and without impairments. Examples include: eliminating environmental barriers and providing job accommodations as called for in the ADA, providing publicly-financed rehabilitation services and compensating for some of the added costs that people face because of their impairments. This "leveling of the playing field" concept of compensation underlies the Panel's recommendation for a federal income tax

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[16] Disability Policy Panel, *The Environment of Disability Income Policy: Programs, People, History and Context,* Interim Report, J.L. Mashaw and V.P. Reno (eds.) (Washington, DC: National Academy of Social Insurance, 1996), table 2-4.

credit for expenditures for personal assistance by working taxpayers with disabilities (see chapter 8).

Such policies that compensate for impairments by leveling the playing field promote employment and full participation for people who have various kinds of impairments. But they are not a substitute for income support to replace earnings while workers are unable to work because of illness or disability.

ARE PROGRAMS WITH DIFFERENT PURPOSES IN CONFLICT?

Some observers are troubled by the multiplicity of program definitions of disability and are concerned that the programs involved have conflicting goals and work at cross-purposes. The Panel, however, finds that programs are not in conflict simply because they are designed to meet different needs of various subsets of the population who have impairments or work disabilities. Nor are they in conflict because they use different definitions of disability to target the different services, legal protections or earnings-replacement benefits that they offer.

Rehabilitation and Social Security

Cash benefits to replace earnings are not in conflict with vocational rehabilitation aimed at improving an individual's skills and abilities to perform the tasks of work. They complement each other: cash benefits can provide income to meet daily living expenses while rehabilitation and a job search take place. At the same time, not everyone who receives cash benefits is a good candidate for vocational rehabilitation. Some who receive Social Security disability benefits are too ill to work. In focus group interviews, many beneficiaries indicated they had exhausted other options for rehabilitation or return to work before they applied for Social Security benefits (see the appendix). DI beneficiaries tend to be older than rehabilitation clients. While about half those who enter the DI rolls are over the age of 50, about half those successfully rehabilitated by state VR agencies are younger than age 35.[17] Nonetheless, a subset of Social Security beneficiaries may be good candidates for rehabilitation and return-to-work services. Linking beneficiaries with return-to-work services and providing income support while return to work is tried are complementary elements of disability policy. The Panel's proposal for issuing return-to-work tickets to Social Security beneficiaries is designed to improve that linkage and to expand the supply of service providers who can be paid to assist beneficiaries to return to work (see chapter 6).

The Panel also recognizes that VR services can be beneficial to persons who are not Social Security beneficiaries. The large majority of persons that state VR agencies successfully place in competitive employment (85 percent) are not recipients of DI or SSI benefits.[18]

In brief, both Social Security and VR are important elements of disability policy. In many cases they serve different subsets of the population. In other cases, individuals with severe work disabilities receive earnings-replacement benefits from Social Security while they engage in vocational training to return to work.

Social Security and the ADA

The income support provided through the Social Security Act and the civil rights protection of the ADA are both essential pillars of disability policy, but one is not a substitute for the other. Some work disabilities are amenable to the solutions offered by the ADA. Others are not. The ADA provides legal remedies to workers who face discrimination in employment. Social Security provides income support to those who have lost their capacity to work. The two laws typically target different needs of the very diverse population of persons who have impairments or disabilities.

The ADA bans discrimination against workers who have impairments but who are nonetheless able to perform the essential functions of the jobs they seek to hold or retain. It requires employers to make

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[17] U.S. Department of Education, Rehabilitation Services Administration.

[18] See table 6-2.

"reasonable accommodations" for those workers. Whether an accommodation is "reasonable" or whether it poses "an undue hardship" on employers is evaluated on a case-by-case basis that depends on the circumstances of the individual, the employer and the employer's ability to bear the cost. Accommodations that are not considered "reasonable" for a particular employer under a particular set of conditions may be "reasonable" for another employer or when circumstances change.

Research has shown that job accommodations, such as those now required by the ADA, have delayed the point at which ill or injured workers leave the work force and turn to Social Security.[19] The focus group interviews in the appendix indicate that beneficiaries often had received accommodations before they turned to DI benefits. They left their jobs when they could no longer perform them even with accommodations.

In general, Social Security is for workers whose impairments, in conjunction with their other abilities and the demands of work, are not usually amenable to reasonable accommodation by their current employers. It provides benefits that partially replace earnings when people are out of work and it is reasonable to conclude that the severity of their impairment is the cause. It is meant to do so in a way that enables workers to retain their dignity and self-respect while they cope with the human and financial losses associated with lost capacity to earn. Without Social Security, those who receive it often would be destitute or dependent on relatives or public assistance for support. By providing wage-replacement income, Social Security promotes individual empowerment and community integration. By basing entitlement to benefits on prior contributions and scaling benefit amounts to the worker's former purchasing power from earnings while working, Social Security promotes economic self-sufficiency.

While Social Security is paid only to those who meet a very strict test of work disability, it is not necessarily paid for life. Some people medically recover and others may gain new skills and abilities that enable them to return to work and leave the benefit rolls. In some cases, persons who legitimately qualify for DI may, with appropriate accommodations in a new setting, be able to return to work. The extent to which society is willing and able to invest in accommodations, jobs and the human capital of workers with significant impairments will affect the numbers who turn to Social Security and the number who return to work and leave the benefit rolls.

At any given time, different people need the civil rights protections of the ADA or earnings-replacement benefits from Social Security. And any particular individual may need both, though at different stages of his or her life or under different environmental circumstances.

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[19] R.V. Burkhauser, et al., "The Importance of Employer Accommodation on the Job Duration of Workers with Disabilities: A Hazard Model Approach," *Labor Economics*, June 1995, pp. 1-22; and K.K. Charles, "Employer Accommodation and the Early Post-Onset Separation of Disabled Workers," unpublished paper, Cornell University, June 1995.

Chapter 5

Operationalizing the Social Security Definition: Assessing the Assessment

For any system of benefits or services, applicants must be assessed to determine their eligibility. For disability-related programs, the assessment must include an evaluation of disability. The assessment of work disability is inherently complex because work disability itself is not a simple concept. As discussed in chapter 1, an impairment is an essential element of work disability. But the assessment of work disability must also consider the person's residual functional capacity in relation to the tasks of work in the context of the broader environment.

Moreover, the assessment of work disability made by different programs will differ according to the type of remedy or benefit offered. The first section of this chapter explores how the assessment of work disability for wage-replacement benefits differs from an assessment of disability for the purpose of offering rehabilitation services. That is, the assessment for cash benefits is concerned with the severity of the disability, and whether it constitutes a legitimate basis for paying benefits based on inability to earn. The assessment for rehabilitation focuses on assessing the individual's needs for particular kinds of services.

The balance of the chapter is about the Social Security disability assessment. It begins with a review of the elements of the definition of disability in the Social Security Act. It then describes the sequential process the Social Security Administration (SSA) uses to determine whether an applicant for Social Security disability benefits meets the definition in the Act. The final sections contain the Disability Policy Panel's evaluation of SSA's assessment process and its findings and recommendations on ways to improve that process.

SOCIAL SECURITY AND REHABILITATION ASSESSMENTS DIFFER

If the purpose of an assessment of disability is to allocate rehabilitation services for persons with impairments, the assessment might pose two questions. First, does the applicant for services have an impairment that interferes with his or her ability to work? If not, the person could be denied services because the scarce resources available for rehabilitation should target only persons with work-limiting impairments, not persons who need other kinds of employment assistance. If the person has a work-limiting impairment, a rehabilitation assessment might then ask the second question: is the person likely to benefit from services the provider can offer? If so, the person would be found eligible for services. When private insurers or workers' compensation programs evaluate whether to pay for rehabilitation, the first question has already been answered in the affirmative because they consider paying for rehabilitation only for persons already found eligible for insurance or compensation payments based on a finding of work disability (see box 5-1).

Box 5-1. Cash Benefits and Rehabilitation: Distinguishing Assessments

Many concerns the Panel has heard about the Social Security assessment of disability appear to reflect the view that it should be more like the kind of assessment that is used for determining rehabilitation potential or service needs.

The Social Security assessment is necessarily different from an assessment of rehabilitation potential. Its purpose is not to determine who should be offered services or what services they should be offered. Rather, its purpose is to determine which applicants for benefits meet the definition of work disability used to award wage-replacement benefits.

Private disability insurance distinguishes between assessing work disability for purposes of wage-replacement insurance and assessing rehabilitation potential. Employees covered by private long-term disability insurance have a contractual entitlement to cash benefits if they meet the eligibility criteria in the insurance contract. It usually requires a medical diagnosis, an evaluation of medical prognosis and a finding that the employee is currently unable to work. The insurer may then arrange for a second kind of assessment to evaluate the employee's rehabilitation potential. In this case, the decision to offer and pay for rehabilitation services takes into account the insurer's future benefit liability as well as the employee's return to work prospects. Favorable indicators for the insurer to invest in rehabilitation services, on a case-by-case basis, include the employee's prospects for medical stability and his or her youth, aptitude, motivation and need for vocational services in order to return to work.

The Panel is recommending ways to increase access to rehabilitation and return-to-work services for Social Security beneficiaries. Because the Social Security Administration does not have the expertise or resources to assess rehabilitation potential, the Panel's proposal draws on the expertise of service providers to make that assessment and offer services (see chapter 6).

When the purpose of an assessment of work disability is to allocate earnings replacement insurance benefits, the assessment necessarily focuses on the severity of the work disability. The purpose of the assessment is to determine whether applicants for benefits should receive them because of their inability to work. A review of disability determinations in the social insurance programs of six countries highlights commonality across countries in the complex assessment of work disability for this purpose:[1]

- Eligibility for disability pension benefits is based on a demonstrated incapacity for work due to sickness, injury or disease. The purpose of these programs is to alleviate the financial disruption that the loss of regular earnings causes.

- In all countries, the disability standard is based ultimately on the inability to earn. However, the formulation of the standard varies: in Germany, the test is whether the applicant can engage in gainful activity only irregularly or can achieve only insubstantial income; in both the United States and Canada, the line is drawn at the inability to perform substantial gainful activity; in the United Kingdom the reference is simply incapacity for work. Each of these is effectively a full incapacity requirement; benefits are paid only if the applicant cannot work at all, at least not at a job reasonably within his or her vocational limits.

- Impairment alone does not trigger the award of a benefit; rather benefits are awarded based on the effect of an impairment on an applicant's capacity for work. Moreover, proof of incapacity for work, while always due to impairment, is measured against an individualized vocational standard

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[1] F.S. Bloch, "Disability Benefit Claims Processing and Appeals in Six Industrialized Countries: Canada, Germany, Sweden, the Netherlands, Great Britain and the United States," *Occasional Papers on Social Security* (Geneva, Switzerland: International Social Security Association, 1994).

appropriate for the particular applicant. As a result, disability assessment procedures must be designed to identify and categorize individual vocational factors such as age, education and past work experience, and then to evaluate how and to what extent these factors may limit the range of work an applicant can be expected to perform.

In brief, the assessment of eligibility for cash benefits in all countries focuses on the severity of the work disability. And the assessment encompasses the varied elements of work disability: the severity of the applicant's impairment, the tasks of work he or she can reasonably be expected to do, and his or her ability to perform those tasks. In each country's system, a particular individual may need and qualify for earnings replacement income and also be a good candidate for rehabilitation services. But the assessment of eligibility for the two kinds of interventions necessarily differs.

DEFINITION OF DISABILITY IN THE SOCIAL SECURITY ACT

The statutory definition of work disability for Social Security benefits is both very strict and quite generic. The exact rules for implementing it are spelled out in regulations issued by SSA. The regulations are updated periodically and any changes in regulations are subject to public review and comment before they become final policy.

Because the statutory definition is generic, its application in regulations can and should be updated over time to reflect changes in the broader society that have an impact on the nature of work disability — such as new disabling diseases, new treatments for existing conditions that make them less disabling than in the past, and environmental changes in the nature of work, the tasks that constitute work, and the skills required to perform those tasks. Key concepts defined in the law are discussed below.

The law defines work disability generically as *inability to engage in any substantial gainful activity* (SGA). The law does not further define SGA, but specifies that the executive branch should prescribe criteria for determining when services performed or earnings derived from services demonstrate an individual's ability to engage in SGA.

The definition of work disability takes account of *vocational factors* and uses a *national economy test.* It asks whether applicants, *given their age, education,* and work *experience,* can do *any kind of work that exists in the national economy,* which is further defined to mean *work that exists in significant numbers in the region where the applicant lives or in several regions of the country.* Because disability is defined in relation to the demands of work, the nature of what constitutes work disability should change as the nature of work changes. Further, the law recognizes that individuals' educational attainment and transferable skills influence what they can do. As educational and skill requirements of jobs change, the evaluation of the interaction between impairments and the ability to do jobs that exist in the national economy should also change.

The Social Security Act specifies that a *medically determinable physical or mental impairment* that is expected to last 12 months is necessary, but not sufficient, for a finding of work disability. The condition must be considered to be directly related to the person's inability to engage in SGA. According to the law, it also must be demonstrable by *medically acceptable clinical and laboratory diagnostic techniques.*

These elements of the statutory definition of work disability in the Social Security Act are brought together as follows:

- Disability means inability to engage in any substantial gainful activity by reason of any medically determinable physical or mental impairment which can be expected to result in death or which has lasted or can be expected to last for a continuous period of not less than 12 months;

- An individual shall be determined to be under a disability only if his physical or mental impairment or impairments are of such severity that he is not only unable to do his previous work but cannot, considering his age, education and work experience, engage in any other kind of substantial gainful work which exists in the national economy, regardless of whether such work exists in the immediate area in which he lives, or whether a specific job vacancy exists for him, or whether he would be hired if he applied for work.

- "Work which exists in the national economy" means work which exists in significant numbers either in the region where such individual lives or in several regions of the country.

  "A physical or mental impairment" is an impairment that results from anatomical, physiological or psychological abnormalities which are demonstrable by medically acceptable clinical and laboratory diagnostic techniques.

- The Commissioner of Social Security shall by regulations prescribe the criteria for determining when services performed or earnings derived from services demonstrate an individual's ability to engage in substantial gainful activity.[2]

SEQUENTIAL DETERMINATION PROCESS

A five-step sequential process is used to determine whether an applicant for Social Security disability benefits meets the definition of work disability in the law. The sequential process is spelled out in regulations and is illustrated in figure 5-1. Each step in the sequence poses a different question about the nature of the disability. At each step a decision is made either to allow or deny the application or to move on to the next step.

- **Step 1** asks, "Is the applicant is engaging in SGA?" If so, the application is denied.

- **Step 2** asks, "Does the applicant have a severe impairment?" If not, the application is denied.

- **Step 3** asks, "Does the applicant have a medically determinable impairment that meets or equals the medical listings?" It refers to listings in regulations of over 100 medical conditions that are considered to be of such severity that the condition can be presumed to constitute work disability.[3] At this step, SSA draws on medical evidence from treating sources or a consultative exam (by a physician paid by SSA) to document the existence, severity, duration and prognosis of the person's impairment. If the applicant's condition meets or equals a listed condition, benefits are allowed. If benefits are not allowed at Step 3, the sequential process calls for an assessment of the person's residual functional capacity (RFC) to do various kinds of work activities.

- **Step 4** asks "Does the impairment(s) prevent doing past work?" The applicant's RFC is compared with functional capacities required to do his or her past work. RFC is classified mainly in terms of the exertional demands of jobs. The current RFC assessment produces a finding that the person is capable of sedentary, light, medium or heavy work. That capacity is then compared with the person's prior work experience to determine whether he or she can do work at the exertional levels required by past work. If the person can do past work, the application is denied. If the person is unable to do past work, the assessment goes to Step 5.

- **Step 5** asks "Does the impairment prevent doing any other work?" Applicants' RFCs are considered in conjunction with their age, education, and work experience to determine whether they can do any other work that exists in significant numbers in the national economy. Their age, education and transferable job skills are taken into account to determine whether they have the residual capacity to do kinds of work they have not done before.

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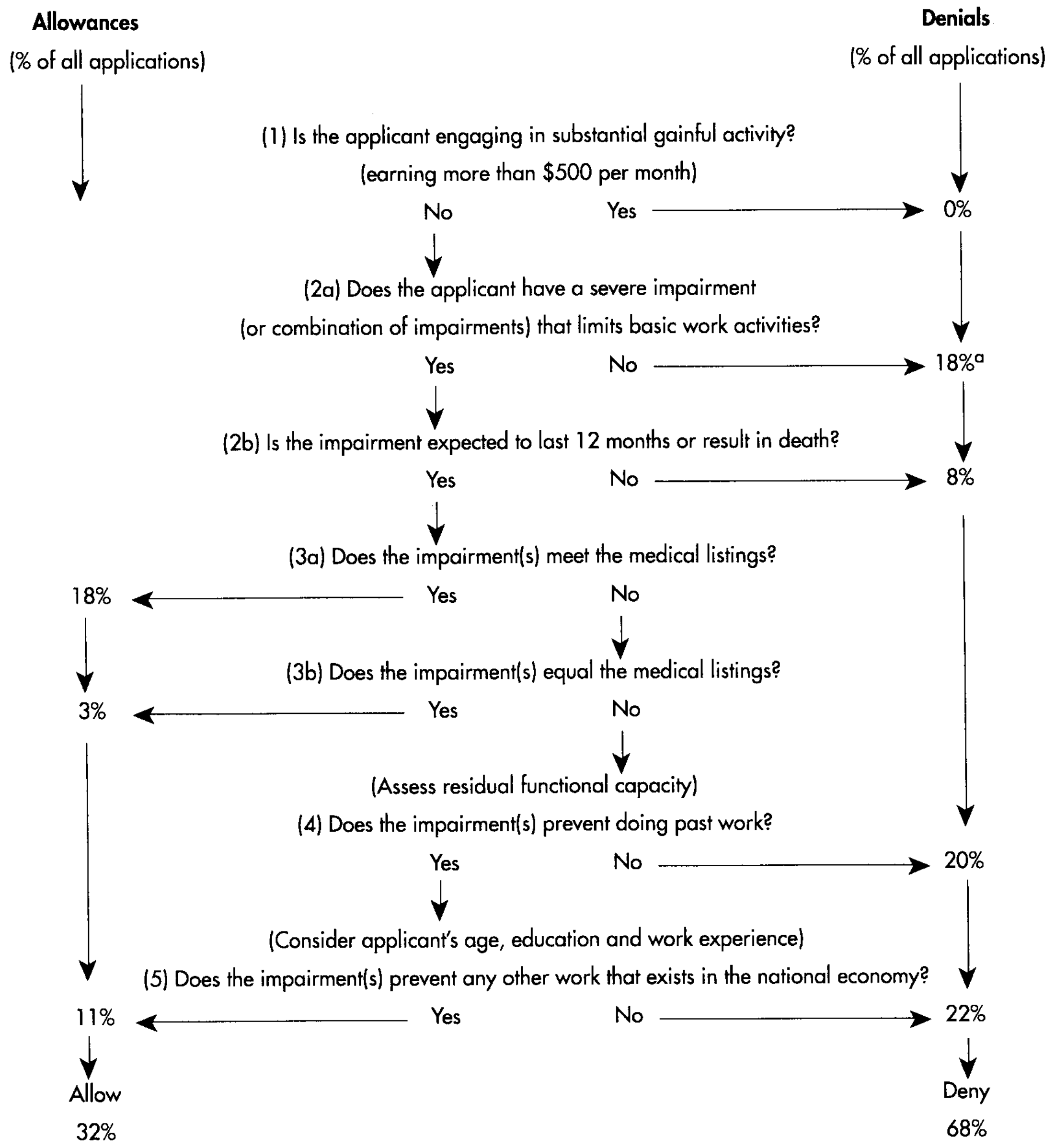
[2] Sections 223(d)(1)(A), 223(d)(2)(A), 223(d)(3) and 223(d)(4) of the Social Security Act.

[3] The other evidence that supports this presumption is discussed in the following section and in box 5-3.

Figure 5-1. Social Security Disability Determinations: Sequential Decisionmaking Process and Outcomes of Decisions on Initial DI Applications, 1994



a. This response includes 5 percent of claims that were denied because the applicant failed to cooperate in obtaining evidence needed for the claim. The other 13 percent were denied for "impairment not severe."

Abbreviation: DI = Social Security disability insurance.

Source: Social Security Administration, Office of Disability.

For persons with solely exertional impairments, the assessment of ability to do other work is aided by the "vocational grid," which was codified in 1979 regulations and has not been updated. The grid dictates a decision about work disability (and eligibility for benefits) based on the person's age, education and transferable skills, in conjunction with his or her RFC to do sedentary, light, medium or heavy work. If the person is found able to do other work, the application is denied. If not, the application is allowed.

For persons with impairments other than exertional ones — such as cognitive, emotional, sensory, postural (stooping, crouching, kneeling) or environmental (inability to tolerate fumes, dust, noise) impairments — the grid does not apply. It is to be used, however, as a "framework" for evaluating the person's ability to do other work. If the grid does not apply, opinions of vocational specialists[4] or vocational experts[5] can be used as evidence that there are, or are not, jobs the particular individual can do.

ASSESSING THE ASSESSMENT: THE PANEL'S FINDINGS

In evaluating the five-step sequential process used to determine which applicants for disability benefits meet the Social Security Act definition, the Panel finds at least four objectives to be traded off against each other:

- the accuracy of the assessment of an individual's work disability *(validity)*,
- the consistency of these assessments across deciders *(reliability)*,
- the perceived legitimacy or credibility of the criteria as viewed by applicants and the public *(credibility)*, and
- the capacity of the system to produce reasonably prompt and low-cost decisions *(administrative efficiency)*.

Using these criteria, the Panel evaluated the sequential determination process and the role of medical evidence, functional assessment and the vocational factors — age, education and work experience — in that determination process.

The Sequential Process

Each step in the five-step disability determination process requires a progressively more in-depth, detailed and individualized assessment of the applicant's ability to work. As such, the sequence as a whole seeks to achieve *administrative efficiency* by allowing or denying applications at early steps in the process when that can be done with acceptable levels of *validity, reliability* and *credibility*.

Steps 1 and 2 are used only to deny applications. They are used to screen out cases that would ultimately be denied, and to do so promptly, to avoid the administrative burdens, costs and delays that applicants, disability adjudicators, private physicians and others experience when asked to provide medical and other evidence needed to make determinations at later stages in the process. As such, both steps rank high on *administrative efficiency* in providing prompt, low-cost decisions.

Step 1 ranks high on *validity, reliability* and *credibility*. If the applicant is engaging in SGA, that is prima facie evidence that the person has the capacity to do so *(validity)*. SGA is measured as a test of monthly earnings, which can be measured with consistency *(reliability)*. And the fact that one is working is easily understood to be evidence of ability to do so *(credibility)*.

The measure of earnings that constitute SGA takes into account certain impairment-related work expenses or employer subsidies. These expenses or subsidies are deducted from earnings when determining whether a given level of work effort constitutes SGA. In order to maintain the validity and

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[4] Used by state agencies in initial decisions.

[5] Used by administrative law judges at hearings on appeals of denied applications.

credibility of the SGA standard, the Panel is recommending that the level of earnings that constitutes SGA be updated and automatically adjusted to keep pace with the economy (see chapter 9). With these changes, the Panel finds that the SGA test is an appropriate first step in the determination of work disability.

Step 2 also ranks high on *administrative efficiency.* This step avoids the need to develop medical evidence and conduct a nonmedical functional assessment in cases where the person is out of work for reasons other than disability, such as unemployment or the person's choice not to work.

Step 3 is the first step at which benefits are allowed. At this step, the medical listings are used as a proxy for work disability. They are used to presume that an applicant whose condition meets the medical listings meets the statutory definition of work disability.

The presumptive validity of the listings is supported by the context of their use. Benefits are allowed at Step 3 if and only if the presumption of work disability based on the severity of the applicant's impairment is corroborated by other circumstantial evidence. In the case of Social Security disability insurance (DI), the presumption of work disability at Step 3 is buttressed by the following findings:

- the person has significant and recent employment prior to the onset of the disabling condition (as shown by meeting insured status requirements, which is ascertained before the disability assessment begins); but
- the person has not been engaging in SGA for at least five months (Step 1); and
- the person has applied for benefits that generally amount to less than half of his or her prior earnings from work; and
- the person has a severe medical condition that is expected to last at least a year or result in death.

Only when all these conditions are met are DI benefits allowed based on the presumption that an impairment that meets or equals the medical listings constitutes work disability.

The use of the medical listings as a proxy for work disability has several advantages. The listings promote *administrative efficiency* because medical assessments are more readily available than functional assessments of ability to work. If properly constructed, medical listings criteria should be *reliable* and *credible.* They are based on consensus medical opinion and are defined, insofar as is possible, in objective terms. Because the listings are used to presume work disability, they are and should be set at a high threshold of impairment severity to achieve *validity.* They are designed only to answer the question, "Is this applicant highly likely to meet the statutory test of disability, without further inquiring into vocational issues?"

In the Panel's view the continued use of the medical listings approach is sound adjudicative practice. As discussed further below, however, we believe that further work needs to be done to ensure that the listings measure equivalent severity of presumptive work disability across body systems and that they are kept current in relation to medical practice and the demands of the work place.

Medical Evidence Is the Foundation of the Social Security Assessment

Some have questioned the reliance on medical evidence to establish work disability, which by its nature is a functional rather than strictly a medical construct. The Panel finds nevertheless that medical evidence has many valuable properties in assessing work disability for Social Security benefit purposes. The Panel recognizes the value of "demedicalizing" disability assessments for other disability-related purposes, such as to allocate nonmedical goods or services (see box 5-2). However, for the purpose of assessing work disability for Social Security benefits, the Panel believes that any attempt to shift to a purely functional assessment would be a mistake — indeed a virtual impossibility for the reasons out-

Box 5-2. Medical versus Functional Assessment

Is a functional assessment always the right way to evaluate disability? Whether it is the "right" way depends on the purpose of the disability assessment.

Over the past 20 years there has been a move to "demedicalize" the assessment of disability when the purpose is to allocate nonmedical goods and services—such as vocational rehabilitation, assistive devices or personal assistance services. All of these goods and services are designed to improve the functioning of persons who have impairments. For this purpose, a functional assessment is greatly preferred over a strictly "medical" or "impairment-based" assessment for a number of reasons. Some of these reasons for preferring a functional assessment do not necessarily apply to the Social Security assessment of work disability.

Is it used to allow or deny eligibility? First, a functional assessment can increase the chances that services being sought will be appropriately allowed. Too often in the past a medical assessment of the person's impairment was used to deny rehabilitation services by concluding that the applicant's impairment was so severe that he or she "could not benefit in terms of an employment outcome." A functional assessment, in contrast, focuses on persons' abilities rather than their impairments. Consequently, services are appropriately allowed to people who can benefit from services despite having significant impairments.

In the Social Security assessment, medical evidence of impairment severity is not used to deny benefits. Rather, it is used to allow the earnings replacement benefits that are being sought, but only when other evidence buttresses the presumption that the severe impairment constitutes work disability (see box 5-3).

What kinds of goods or services will be provided? Second, a functional assessment is associated with more consumer control over the kinds of goods and services that are provided, once the person is found eligible to receive them. For example, in developing a vocational rehabilitation plan, consumers' career goals and assessment of their own training needs are an important part of plan development. In the case of assistive devices, consumers' own assessment of their functional needs are important in selecting the type of device that will maximize their independence in the environment in which they live and work.

Once a beneficiary is found eligible for Social Security, no further decision is needed about what will be provided or how it is used. A benefit allowance provides wage-replacement benefits that are prescribed by law and the beneficiary decides how it will be used.

These reasons for strongly preferring functional over medical assessment for the purpose of allocating nonmedical goods and services do not apply in the same way to the Social Security assessment. Proper assessment of work disability for eligibility for Social Security benefits requires both medical assessment of impairment severity and functional assessment of ability to perform the tasks of work.

lined below. At the same time, functional assessment is a critical part of the disability assessment.

Medical evidence often is functional in nature. For example:

- Treadmill tests are used to measure cardiovascular functioning under work-like exertional conditions; and ejection fraction tests (the proportion of the volume of the left ventricle that is ejected when the heart pumps) are used to measure the heart's functional efficiency.
- Exercise tests are used for respiratory conditions to measure respiratory function similar to treadmill tests for cardiovascular conditions.
- Range of motion tests are a form of functional assessment of musculoskeletal conditions.
- Diagnostic tests that include medical evidence of functioning and symptomatology are used for many mental disorders.

Medical evidence is often essential to establish the prognosis and duration of a particular disease or impairment. If a condition has a very poor prognosis, it would be inhumane to delay a finding of work disability until an individual actually experienced the kind of functional loss that would show up on a solely nonmedical functional assessment. Examples of such a condition may include AIDS, neoplasms and other progressive diseases. If a person is not working and has a very poor medical prognosis, it is appropriate to allow benefits before the expected functional loss becomes evident in nonmedical terms — such as debilitation or total collapse.

A related situation occurs when medical evidence shows that a health problem (such as certain cardiac conditions) would be exacerbated with high risk of catastrophic functional loss if the person returned to usual work activity. In such cases, the humane policy is to allow benefits based on medical evidence showing a high risk of catastrophic functional loss, rather than requiring the person to work until the catastrophe actually occurs.

Medical findings are necessary to predict the duration of a particular impairment. A nonmedical functional assessment is a finding established at a specific point in time. Because benefits are paid only for impairments expected to last a year (or result in death), medical evidence can show that the expected duration is likely to be met, without waiting until death or the required duration has actually occurred.

Evidence from medical sources enhances *validity* and *credibility*. Medical evidence can serve as a check on apparent functional limitations that might be motivational in nature. As such, it also lends legitimacy and public acceptance to the disability determination and the benefits that are paid. Assessments by medical professionals have *credibility* in the public's perception. While well-trained lay persons are quite capable of implementing rules and procedures to assess work disability in many situations, the medical component of the assessment is important for public acceptance that the judgments are valid and fair.

Evidence from medical professionals enhances *validity, administrative efficiency* and *credibility* in other ways as well. Over-reliance on evidence from nonmedical sources — such as neighbors, supervisors or co-workers — poses several risks: it may unduly burden the providers of evidence (a problem that has been raised by schools in the case of child applicants); it may weaken public acceptance that the evidence is, in fact, valid; and it may be viewed as an unnecessary violation of the privacy of the individual, whose disability application, at least arguably, is not the business of neighbors or others who may know the person. In some cases, evidence from nonmedical sources is needed. However, good reasons exist for allowing applications based on medical evidence when that evidence is sufficient.

Medical evidence can, in many instances, improve the consistency and reliability of decisions across decisionmakers. The use of medical criteria enhances objectivity and consistency through the use of scientific findings and by, in effect, borrowing the unifying tendencies of medical judgment that result from medical training and clinical practice.[6]

Medical evidence is often more readily available than are nonmedical functional assessments. When it is available and is adequate for presuming inability to work, relying on medical evidence reduces burdens and delays for both applicants and adjudicators, thereby enhancing *administrative efficiency* (see box 5-3).

In summary, while nonmedical functional assessments are an essential part of the full sequential determination process, the Panel believes that medical evidence is the foundation for assessment of work disability for cash benefits. A finding of a medically determinable impairment is required by

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[6] As greater reliance is placed on evidence provided by a claimant's physician, rather than on evidence from a consultative exam by a physician employed by SSA, there may be a need for more broadly educating the medical community about the kinds of medical evidence that is used to assess work disability.

the statute and it is important for the validity, reliability, credibility and administrative efficiency of disability decisions.

Functional Assessment Is Essential When Work Disability Cannot Be Presumed

When medical evidence is not sufficient to presume that a person is work disabled, a functional assessment is needed to determine whether, in fact, the person is unable to engage in substantial gainful activity. To determine whether applicants can or cannot work requires assessing their residual functional capacity and comparing it with the demands of their past work. If unable to do past work, applicants' residual functional capacities are assessed in light of their age, education and work experience to determine whether they can do any other work that exists in the region in which they live or in several regions of the country.

Functional assessments have valuable properties with regard to the validity of disability determinations. They are an actual test of work disability, rather than a presumption of that finding. A finding of disability based on functional assessment is not a lower standard of severity. Instead, it is a different and more direct test of work disability (see box 5-4). At the same time, the validity of functional assessments depends on how closely the functions being assessed relate to the demands of work that exist in significant numbers in the national economy. As the demands of work change, the functional assessment of work disability needs to be updated.

Vocational Factors Are Essential

The law specifies that vocational factors — age, education and work experience — be taken into account when determining whether a person with a medically determinable impairment is, in fact, able to do his or her past work or any other work despite the existence of a severe impairment.

The Panel believes that age, educational attainment and prior work experience are critical to the *validity* of determinations about whether a person is functionally able to work despite the existence of a severe impairment. With favorable vocational factors — such as advanced education — a person can work despite quite significant physical impairments. On the other hand, with negative vocational factors — such as advanced age, limited education and no transferable skills — impairments that make workers unable to do the kind of work they have done in the past would constitute work disability.

As discussed in chapter 1, the prevalence of work disability in the general population as reported in household surveys rises sharply with advanced age. And the risk of work disability declines with advanced education (table 1-5). While those who report a work disability in household surveys do not necessarily meet the strict test of disability in the Social Security Act, the survey data show the strong connection between age, education and work disability.

The nature of a person's prior work experience is also critical in determining whether he or she can continue to work despite the onset of a significant impairment. The same impairment might constitute total incapacity for a whole range of jobs, yet not interfere with the ability to perform another set of jobs. Whether or not workers are able to return to their prior work has much to do with the nature of that work. If not able to do their prior work, their age, transferable skills (as measured by work experience) and aptitude (as approximated by educational attainment) are key factors in determining whether it is feasible or economically rational for individuals or for society as a whole to invest in retraining for new careers that require new job skills.[7]

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[7] Walter Oi observes that, in addition to the severity of the disabling condition, the disabled worker's expected remaining working-age years — which are a function of the age at onset, expected duration of the condition and its impact on life expectancy — are key determinants of whether it is economically rational for the individual or society at large to invest in training and return to work efforts for the individual. W.Y. Oi, "Employment and Benefits for People with Diverse Disabilities," *Disability, Work and Cash Benefits*, J.L. Mashaw, et al., (eds.) (Kalamazoo, MI: W.E. Upjohn Institute for Employment Research, forthcoming).

Box 5-3. The Role of the Medical Listings

If a person whose impairment meets the medical listings is working, does that mean the listings are flawed?

Not necessarily. It has always been recognized that some people who have impairments that meet the Social Security Administration's (SSA) medical listings are working. That is not a problem, it is a success. President Roosevelt (who used a wheelchair) and perhaps President Kennedy (with Addison's disease) could be counted among those successes.

People who work despite having impairments that meet the listings may have extraordinary motivation and drive. They may also have unique skills and specialized abilities to perform work that is not affected, or only marginally affected, by their impairments. For example, scientists, attorneys, executives and decisionmakers can still think, analyze, lead, direct and decide despite having significant physical impairments that would make it impossible for others to continue their jobs as construction workers, longshoremen, short-order cooks or hospital orderlies. Furthermore, when a person's skills are in high demand, an employer's view of reasonable accommodation may be more expansive than what would be considered reasonable for other workers whose skills are more easily replaced.

In theory, SSA's disability assessment could be tightened to require that all applicants demonstrate that they are unable to do their past work or any other work that exists in the national economy. That would avoid making a *presumption* of work disability. But it would have a significant cost in terms of reduced administrative efficiency. But its greatest impact would be to rule out the *theoretical possibility* of benefit allowances — theoretical because it would "deny" benefits in cases where people do not apply for them, because they are working. This is because the medical listings are used to allow benefits only when the presumption of work disability is buttressed by the following circumstances. The applicant:

- is not engaging in substantial gainful activity (SGA),
- has not been engaging in SGA for at least five months,
- has significant recent work experience, as indicated by having met disability insured status requirements,
- has applied for disability benefits that generally represent less than half of his or her prior earnings level,
- has a severe impairment that is expected to last at least a year or result in death.

Only when all these conditions are met are Social Security disability insurance benefits allowed based on the presumption that an impairment which meets or equals the medical listings constitutes work disability.

The medical listings should be set at a high threshold of impairment severity — one that for most people of average ability would result in work disability. They should also be updated periodically to reflect changes in the nature of work, in environmental accommodations and in medical technology. If some people with specialized skills are working despite severe impairments, that does not mean the listings are flawed. Nor does it mean that everyone else with similar impairments should be presumed able to work and therefore be denied benefits.

For these reasons, the Panel finds that vocational factors such as age, education and transferable skills from work experience are essential to the validity of the assessment of work disability (see box 5-4). It also believes that these criteria need to be updated as the tasks of work and skill levels required for work change.

RECOMMENDATIONS FOR IMPROVING THE ASSESSMENT

Based on its evaluation of the SSA disability determination process, the Panel makes several recommendations for improving this process. Each requires targeted research in order to implement it.

Improve Criteria for Nonexertional Impairments

In response to long-standing concerns about the lack of consistency in disability assessment, SSA in 1979 published in regulations its vocational grid. The grid is used to determine disability based on the interaction between vocational factors and the applicant's residual functional capacity to perform various levels of work, which is defined in exertional terms — sedentary, light, medium or heavy work.

During the last 15 years, disability applications based on nonexertional impairments have become more common. These include conditions such as cognitive, emotional, sensory, postural (stooping, crouching, kneeling) or environmental (such as inability to tolerate such conditions as fumes, dust or noise) impairments. For these conditions, the grid does not apply. Instead, regulations say it is to be used as a framework for evaluating the person's ability to work despite his or her impairment. According to SSA, disagreements as to when the grid applies, and the assessment of work capacity when it does not, are common causes for initial disability decisions to be reversed on appeal.[8]

The obvious question is whether the reliability of decisions on mental and other nonexertional impairment applications could be improved by developing systematic criteria — perhaps in the form of appropriate grids — for evaluating the interaction of specific categories of nonexertional impairments and vocational factors such as age, education and work experience. While the Panel is not in a position to answer this question, it believes it is an important area for research and policy development at SSA.

Periodically Update Criteria

The definition of work disability in the Social Security Act is a dynamic one that can and should be interpreted in light of changes in the broader environment. Impairments that constitute inability to work should be expected to change gradually as medical and rehabilitation techniques change, new assistive technology becomes available and the nature of work changes. Advances in medical care include improvements in diagnostic abilities, as well as therapeutics, that may affect degrees of disability and other functional outcomes. As the Americans with Disabilities Act brings about a more accessible environment for persons with mobility impairments, those impairments may become a lesser barrier to work. At the same time, changing work demands may make cognitive or emotional impairments a greater impediment to work. Updates in the regulations — the medical listings, assessment of RFC and vocational factors — should be expected to gradually change to keep pace with the changing nature of work disability.

Categories of impairments that account for a significant portion of the disability rolls, or where rapid growth has prompted concern, are good candidates for expert review to ensure that recent experience, new research and state-of-the-art knowledge are incorporated into the Social Security assessment of work disability. For example, the mental impairment standards have been in place for 10 years. It would be timely to undertake a full review of the mental impairment standards in light of recent experience and research in the professional mental health community.

The assessment of pain is an important element of disability determination for a range of musculoskeletal impairments. As required by Congress, SSA convened a Commission on the Evaluation of Pain, which reported in 1986, and a Committee on Pain and Disability of the Institute of Medicine, which reported in 1987. Both recommended research to develop pain assessment instruments, which has now been completed.[9] SSA should convene an expert group to determine whether and how to apply what

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[8] Social Security Administration, Deputy Commissioner for Finance, Assessment and Management, memorandum, "The Disability Hearings Quality Review Process," October 17, 1994.

[9] U.S. Department of Health and Human Services, *Report of the Commission on the Evaluation of Pain* (Washington, DC: U.S. Government Printing Office, 1986); M. Osterweis, A. Kleinman, and D. Mechanic, (eds.), *Pain and Disability: Clinical, Behavioral and Public Policy Perspectives* (Washington, DC: National Academy Press, 1987); K.S. Rucker, et al., "Final Report on All Aspects of the Pain Assessment Instruments Development Project," unpublished paper, Virginia Commonwealth University, Richmond, VA, 1994.

Box 5-4. Objective versus Subjective Evidence of Work Disability

There is a belief that meeting the medical listings is "real" disability. It is "objective." Being allowed benefits based on assessment of residual functional capacity in conjunction with age, education and work experience is somehow viewed as "soft" or subjective. This is a misconception.

Medical evidence adds to credibility. But, it is used to support a presumption of work disability, when corroborated by other evidence of labor market disadvantage.

Assessment of residual functional capacity in conjunction with vocational factors is more valid, but it is also more labor intensive. As discussed in chapter 1, work disability, by its very nature, involves the interaction of the individual's impairment with the tasks of work he or she can reasonably be expected do to and his or her offsetting capacities or compounding limitations in performing those tasks. The Social Security assessment of functional capacity in conjunction with the applicant's age, education and prior work experience are necessary parts of the determination of work disability.

In short, neither medical nor functional assessments of work disability are inherently more objective or subjective. Both are essential elements of the assessment of work disability for the purpose of determining eligibility for cash benefits.

has been learned to the Social Security disability determination process.

Improve Criteria to Target CDRs

SSA's initial determination of eligibility for benefits also screens those allowed benefits according to their prospects for medical improvement. The screen is used to diary a date for a later continuing disability review to determine whether medical improvement has occurred. According to SSA, the screens currently used are poor predictors of medical improvement.

The Panel believes that research should be undertaken to refine these initial screens to more accurately predict cases where medical improvement is expected and set a date for subsequent review. That expectation should be communicated to the beneficiary when benefits are awarded to set the expectation for return to work.

The Panel is recommending a wholly new approach to linking beneficiaries with return-to-work services (see chapter 6). The cost effectiveness of this new approach rests on having reasonably valid criteria to identify and screen out beneficiaries who are likely to medically improve and regain the capacity to return to work without receiving services for which providers would be compensated under this plan.

Evaluate the Consistency of the Medical Listings

Experts on SSA's medical listings report that considerable variation exists among the medical listings for different body systems in terms of the severity of impairments that are presumed to constitute work disability. The medical listings for each body system — such as musculoskeletal, cardiovascular, respiratory, or mental conditions — have been developed separately over the years. The listings for each body system are updated separately, usually by convening medical specialists in that particular body system to develop criteria that are believed to constitute work disability. To date, no systematic research has been done to evaluate the consistency of the presumptions underlying the medical listings. The Panel believes that such research should be undertaken and that the Disability Evaluation Study being developed by SSA is an opportunity to do so.

In evaluating and updating the disability adjudication criteria, greater attention needs to be given to issues of specificity and sensitivity. In clinical practice, when a physician seeks to diagnose a patient's condition, *specificity* refers to the desire to avoid making a false diagnosis when the condition is not in fact present. *Sensitivity* refers to the desire to avoid missing the diagnosis of a condition that in fact exists. Whether the diagnostician is more concerned about making a false diagnosis or missing a true one depends on the seriousness of the condition and the dangers involved in treating it. For example, in diagnosing a condition for which open-heart surgery is the proper treatment, the physician wants to be very sure about the specificity of the diagnosis. On the other hand, when diagnosing the risk of a condition that poses great dangers for the patient (or to public health at large) and the treatment for which is relatively benign and cheap, such as preventive vaccine, the physician would emphasize the sensitivity of the diagnosis to ensure that all potential cases are treated.

In the case of Social Security disability determinations, the condition decisionmakers seek to identify is inability to engage in SGA because of a medically determinable impairment. The intervention it offers is cash benefits to partially replace earnings that have been lost for the duration of the work disability. Whether one should be more concerned about "false positives" (allowing benefits when the individual might, in fact, be able to work) or "false negatives" (denying benefits when the person is unable to work) depends on value judgments about the negative consequences of either type of error and the prospects for remedying it.

In the case of Social Security disability, inappropriate denials would mean that the individual would be without support from either earnings or disability benefits. In the absence of a generalized income support safety net, criteria causing wrong denials bring the risk of economic deprivation of those wrongly denied. These adverse consequences are partially mitigated by the ability to appeal the denial or to reapply for benefits.

Criteria that permit inappropriate allowances could result in unwarranted benefit expenditures and the loss of public confidence. These adverse consequences are mitigated to some extent by work incentive provisions that encourage beneficiaries to return to work despite the existence of their impairments. The risk of inappropriate allowances is also mitigated, to some extent, by other program design features that make benefits an unattractive alternative to work for those who can maintain their earnings despite significant impairments.

Given the cost of either type of error, it is clear that proper adjudication of disability applications has high social value. Research needs to be done to evaluate the disability adjudication criteria in terms of both their specificity and their sensitivity. For example, it is not known what proportion of individuals in the general population could meet the medical listings for a particular condition, yet are working, nor how vocational factors, such as age, education and work experience, or other environmental factors serve to compensate for or compound the work limitations posed by the medical condition. SSA's Disability Evaluation Study provides an opportunity to address such questions in a national probability survey.

The answers to these questions are important for various policy reasons. In particular, there should be some consideration of setting standards for sensitivity and specificity for the disability criteria; both for the medical listings in and of themselves and for the sequential process as a whole, which takes account of actual performance of SGA, residual functional capacity and vocational factors.

Research using data on actual work experience, in conjunction with medical and vocational characteristics — such as age, education and work experience — and individualized assessments of work capacity, could be used to evaluate the consistency of the medical listings across body systems and provide a systematic way to validate the criteria used to determine work disability for benefit eligibility. The Panel recommends that resources be devoted to the data collection and analysis necessary to complete such research.

Chapter 6

Vocational Rehabilitation and Return to Work Services: Fostering Innovation

As part of its charge, the Disability Policy Panel was asked: Can an emphasis on rehabilitation and work be incorporated into the disability benefit programs without greatly expanding costs or weakening the right to benefits for those who cannot work?

The Panel is proposing a new approach to financing vocational rehabilitation and return-to-work (RTW) services for beneficiaries. The plan would promote consumer choice and enlist private sector providers in helping beneficiaries return to work, without greatly expanding costs or weakening the right to benefits for those who cannot work.

The early blueprints for the Social Security disability insurance (DI) program envisioned linking DI beneficiaries with rehabilitation services through state vocational rehabilitation (VR) agencies (see box 6-1). In 1965, when Congress authorized use of the trust funds to pay for rehabilitation, the rationale for doing so was to reduce long-run benefit expenditures by assisting beneficiaries to return to work and leave the benefit rolls. Today, relatively few beneficiaries receive services from VR agencies that enable them to engage in substantial gainful activity (SGA). In FY 1994, VR agencies were reimbursed for successfully rehabilitating 3,600 DI or concurrent DI and Supplemental Security Income (SSI) beneficiaries and about 2,100 beneficiaries who receive SSI only (table 6-1).

The Panel's new incentive-based approach to linking disability beneficiaries with rehabilitation services aims to improve the rate of success in returning beneficiaries to work. It is based on the long-standing rationale for using trust fund monies to pay for such services — that is, to produce trust fund savings. The plan enlists private sector providers in helping beneficiaries return to work. It builds on the principles of consumer choice and empowerment, encouraging competition and innovation among service providers, rewarding them for their results rather than the cost of their inputs and encouraging providers to have a continuing interest in their clients' long-term success in remaining employed.

Under the plan, new beneficiaries would receive an RTW ticket, akin to a voucher, that they could use to shop among providers of rehabilitation or RTW services in either the public or private sector. Once a beneficiary deposited the ticket with a provider, it would constitute an obligation for the Social Security Administration (SSA) to pay the provider after the beneficiary returns to work and leaves the benefit rolls. Providers whose clients successfully return to work would, each year, receive in payment a fraction of the benefits savings that accrue to the Social Security trust funds because the former beneficiary is at work and not receiving benefits.

The next section of this chapter describes basic principles of this incentive-based approach and

Table 6-1. Vocational Rehabilitation Experience, FY 1993 and 1994

Type of claim	Total	Number of cases referred: Benefit denials	Number of cases referred: Benefit allowances	Cases reimbursed[a]	Average reimbursement
			FY 1994		
Total	**171,891**	**100,085**	71,806	5,653	**$11,226**
DI only	37,332	22,527	14,805	1,699	10,211
Concurrent	60,650	41,072	19,578	1,880	12,082
SSI only	73,909	36,486	37,423	2,074	11,283
			FY 1993		
Total	**168,836**	91,112	77,724	6,154	**$10,476**
DI only	35,640	20,358	15,282	2,068	9,784
Concurrent	57,524	37,208	20,316	1,928	11,396
SSI only	75,672	33,546	42,126	2,158	10,317

a. Cases reimbursed are not limited to the pool of referrals for that year.
Abbreviations: DI = Social Security disability insurance, SSI = Supplemental Security Income.
Source: Social Security Administration, Office of Disability.

contrasts it with the current VR system. The third section describes current experience in both public and private sector rehabilitation as a basis for considering the expectations of success for this approach. The fourth section discusses specific considerations in designing some of the details of such a proposal, including which beneficiaries should receive tickets and how much providers should be paid. The last section discusses other options the Panel considered for linking persons with VR services before their application for disability benefits is decided by SSA.

PRINCIPLES OF RETURN TO WORK PROPOSAL

The Panel's proposal builds on the principles of promoting consumer choice and empowerment, encouraging competition and innovation among providers, paying providers for results that reduce benefit expenditures and doing so in a way that is administratively efficient. The following discussion explains the basic features of the plan and contrasts it with the current approach to linking beneficiaries with VR.

Offer Consumers a Choice

Beneficiaries would receive an RTW ticket, similar to a voucher,[1] that they could use to shop among private providers and public providers (i.e. state VR agencies or state or local mental health or developmental disability agencies) to learn about the kinds of RTW services the provider is willing to offer. The ticket would constitute an obligation for SSA to pay a provider for its successful result when the beneficiary returns to work and leaves the benefit rolls.

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[1] This proposal builds on work by Carolyn Weaver in proposing vouchers to pay for rehabilitation services. See C.L. Weaver, "Privatizing Vocational Rehabilitation: Options for Increasing Individual Choice and Enhancing Competition," *Journal of Disability Policy Studies*, No. 1, 1994, pp. 53-76; and C.L. Weaver, "Incentives Versus Controls in Federal Disability Policy," *Disability and Work: Incentives, Rights, and Opportunities*, C.L. Weaver (ed.) (Washington, DC: AEI Press, 1991), pp. 3-17.

When a beneficiary decides to accept the services the provider offers, the ticket would be deposited with that provider. Participation by beneficiaries would be voluntary. They would not be required to use the ticket or to deposit it with any particular provider.

This beneficiary-driven approach stands in sharp contrast to the current method of referring disability beneficiaries to state VR agencies. Disability examiners screen disability claims for rehabilitation potential as part of SSA's disability determination process. The evaluation and referral does not usually involve any direct contact with the claimant. Instead, a list of beneficiaries and denied applicants is forwarded to the state VR agency, which may or may not contact individuals on the list.

Foster Competition Among Providers

Private or public sector providers of rehabilitation and job placement services would have an incentive to seek out beneficiaries whom they believe they can successfully assist in returning to work. Under current policy only the federal/state VR program is paid from Social Security funds for successful RTW services it provides to beneficiaries.[2] Under the Panel's proposal, state agencies and other public or private providers of RTW services would compete on an equal footing for the business of assisting Social Security beneficiaries to return to work and leave the benefit rolls. As such, it is designed to increase choices available to beneficiaries, enlarge the supply of providers who would assist in return to work and stimulate innovation in service delivery.

Expand Access to Rehabilitation Services

The proposal aims to expand access to RTW services by allowing private sector service providers and other public agencies to provide RTW services to Social Security beneficiaries.

State VR agencies appear not to have the capacity to serve all who could benefit from rehabilitation services. Yet, they are the main source of public funding for clients whose rehabilitation is not financed by third parties such as private insurers, employers or Social Security. Expanding the supply of service providers for Social Security beneficiaries might increase the chances that other clients, including more denied applicants for Social Security benefits, could be served by state VR agencies. In FY 1994, state agencies processed a total of about 675,000 applications for VR services, accepted 480,000 and successfully placed for 60 days about 200,000 individuals they served.[3] In that same year, SSA referred to state agencies about 100,000 denied applicants for Social Security or SSI benefits along with about 72,000 beneficiaries (table 6-1). Also in FY 1994, SSA paid agencies for rehabilitating about 5,600 DI or SSI beneficiaries. No data are available on the number of denied applicants served or rehabilitated overall.

Moreover, the Panel recognizes that the federal/state VR program has broader purposes than that of producing savings for the Social Security program. Its purpose is to improve the quality of life and community integration of persons who receive services, and success is defined as placement for 60 days in unpaid homemaking or family work and sheltered employment, as well as competitive employment. In fact, the large majority of persons served by state VR agencies are not Social Security or SSI beneficiaries. In FY 1992, DI or SSI beneficiaries accounted for about 2 in 10 persons successfully rehabilitated by state agencies. They accounted for about 15 percent of those placed in competitive employment, about 70 percent of those placed in sheltered employment and nearly 40 percent of those placed in homemaking or unpaid family work (table 6-2).

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[2] New regulations issued in March 1994 permit SSA to refer beneficiaries to alternative providers, but as of the writing of this report, the new policy had not yet been implemented. The option to refer beneficiaries to alternative providers is available only after a beneficiary has first been referred to the state VR agency but has not been accepted for services within four months. The Panel's approach would give beneficiaries and alternative providers a chance to begin promptly a plan for return to work.

[3] Unpublished data from the U.S. Department of Education, Rehabilitation Services Administration, updating its *Annual Report to the President and Congress, FY 1992: On Federal Activities Related to the Rehabilitation Act of 1973, as Amended* (Washington, DC: U.S. Government Printing Office, 1992), table 1, p. C-1.

Box 6-1. Legislative History of Linking Social Security Disability Insurance Beneficiaries With Vocational Rehabilitation

The 1949 Social Security Advisory Council that developed the blueprint for the disability insurance (DI) program called for referring DI beneficiaries to state vocational rehabilitation (VR) agencies:

"Rehabilitation services should be furnished to disability insurance beneficiaries when it appears that the services to be furnished will assist the beneficiary to return to gainful work and so will result in a saving to the trust fund. The services should be furnished through existing facilities with contributions toward the expense of such services being made from the trust fund. Benefits should be terminated if rehabilitation of the beneficiary has been successful."

The Advisory Council further observed that:

"State programs of rehabilitation are already in operation and are coordinated and aided by the federal Government under the authority of the federal Rehabilitation Act of 1920 as amended....The state agencies carrying out rehabilitation would have cases referred to them on the basis of the medical diagnosis and vocational case history developed by the insurance program. The problem of maintenance of the client during rehabilitation, at present a troublesome one in many cases, would be at least partially solved by the disability benefits which would continue to be paid during rehabilitation."

In 1954, when Congress enacted the "disability freeze" provisions to protect the retirement benefits of workers during periods of total disability, it said that applicants for the freeze should be referred to state rehabilitation agencies to be considered for services. Congress did not direct SSA to provide such services or to expend trust fund dollars to purchase them. Instead, it stated in law that:

"It is hereby declared to be the policy of the Congress that disabled individuals applying for a determination of disability...shall be promptly referred to...[the state VR agency] for necessary vocational rehabilitation services, to the end that the maximum number of such individuals may be rehabilitated into productive activity."

This provision was extended to applicants for cash benefits when the DI program was enacted in 1956. The 1956 Amendments provided for the suspension of benefits to individuals who refuse VR services without good cause. The law also provided that beneficiaries who performed work while participating in state VR programs would not, solely by reason of that work, forfeit benefits during the first 12 months of testing their new earning capacity.

Referrals for VR services were made during the first decade of the DI program, although no trust fund monies were expended for these services. Following the recommendations of the 1964 Social Security Advisory Council, Congress in 1965 established the Beneficiary Rehabilitation Program (BRP), under which Social Security trust fund monies were allocated to the Rehabilitation Services Administration (RSA), which in turn disbursed the money to the state VR agencies.

The total amount of allocated funds could not, in any year, exceed 1 percent of the DI benefits paid in the previous year. The law that authorized the BRP stated that the program was established "to the end that savings will result to the Trust Funds as a result of rehabilitating the maximum number of such individuals into productive activity..." In its report explaining the purpose of this provision, the Senate Finance Committee said:

"The committee is recommending that money be made available from the social security trust funds to finance the rehabilitation of selected beneficiaries. The money so used will be allocated, under the provisions the committee is recommending, in such a way that the saving from the amount of benefits that would otherwise have to be paid and the increased contributions to the trust funds paid on the earnings of beneficiaries who return to work would exceed, or at least equal, the money paid from the trust funds for rehabilitation costs."

In 1972, based on reports of the BRP's success, Congress passed legislation that increased authorized trust fund financing of VR to 1.25 percent of expenditures in 1973 and to 1.5 percent in 1974 and thereafter. The 1972 Amendments also authorized financing rehabilitation services for blind and disabled Supplemental Security Income (SSI) recipients with disabilities.

A number of studies of the BRP were done in the 1970s, including two particularly influential ones conducted by the U.S. General Accounting Office (GAO). The first concluded that the BRP was only "marginally successful," saving $1.15 for each $1 spent. The GAO found that many of the DI beneficiaries who had been reported as rehabilitated under the

Box 6-1. Legislative History of Linking Social Security Disability Insurance Beneficiaries with Vocational Rehabilitation (continued)

program had either received few services or had medically improved independently of the services. The second report concluded that the VR program for SSI recipients probably was not meeting the break even requirement. Subsequent, more comprehensive cost-benefit analyses of the DI program found that trust funds savings ranged from $1.39 to $2.72 for each $1 spent.

In 1979, the House of Representatives considered repealing the BRP and replacing it with a funding mechanism wherein "a state could receive twice the state's share of the cost of rehabilitation services if those services result in a disabled beneficiary engaging in SGA or employment in a sheltered workshop for 12 continuous months."

Although this proposal was not adopted, the issue surfaced again in 1981. In that year, the Senate adopted an administration proposal to eliminate the use of DI or SSI funds for VR services. The House favored replacing the BRP with a success-based reimbursement system. The House-Senate conference agreement authorized SSA to reimburse state VR agencies for services that resulted in a beneficiary becoming gainfully employed for a continuous period of nine months. This legislation greatly reduced the amount of trust fund monies available to VR agencies to serve beneficiaries. It was viewed by Congress as a means of making more efficient use of trust fund expenditures. It remains in effect today. Other legislation in 1984 provided that VR agencies could be reimbursed for services furnished to DI beneficiaries who medically recover but continue to receive benefits until they complete an approved VR program, and are expected to remain off the rolls thereafter.

Sources: U.S. Senate, Committee on Finance, *Recommendations for Social Security Legislation: The Reports of the Advisory Council on Social Security*, Document No. 208 (Washington, DC: U.S. Government Printing Office, 1949); Section 222 of the Social Security Act; L.A. McManus, "Evaluation of Disability Insurance Savings Due to Beneficiary Rehabilitation," *Social Security Bulletin*, February 1981, p. 19; and Disability Advisory Council, *Report of the Disability Advisory Council* (Washington, DC: U.S. Government Printing Office, 1988).

Stimulate Innovation

The Panel recognizes that no single return to work strategy is right for everyone. Individual consumers and providers are best able to decide, on a case-by-case basis, what plan of services, education, training and job location assistance is most likely to succeed. Providers could draw on whatever resources they are able to locate in the community. They might act as brokers, assisting their clients to gain access to tuition supports, training and employment programs that are available from colleges and universities or from education and employment assistance programs at the federal, state or local levels.[4] Providers could also work with local businesses to facilitate directly the employment of their clients or to negotiate accommodations with an employer. They would be expected to use their knowledge of local business conditions to help clients secure long-term employment. It is expected that providers would build on lessons learned from private sector employers and long-term disability and workers' compensation insurers about successful return-to-work methods.[5]

Reward Providers for Results

Current law authorizes the use of trust fund monies to reimburse state VR agencies for the "reasonable and necessary cost of vocational rehabilitation services" provided to disability beneficiaries "to the end that savings will accrue to the Trust Funds as a result of rehabilitating such individuals." The law vests with the Commissioner of Social Security the determination whether the VR services contributed

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[4] For a description of these programs and how they serve persons with disabilities, see B.S. Barnow, "Policies for People with Disabilities in U.S. Employment and Training Programs," *Disability, Work and Cash Benefits*, J.L. Mashaw, et al., (eds.), (Kalamazoo, MI: W.E. Upjohn Institute for Employment Research, forthcoming).

[5] H.A. Hunt, et al., "Disability and Work: Lessons from the Private Sector," *Disability, Work and Cash Benefits*, op. cit., footnote 4.

Table 6-2. Type of Placement by Social Security and SSI Benefit Receipt, FY 1992

Type of placement	Total rehabilitated[a] Number	Total rehabilitated[a] Percent	Receipt of Social Security or SSI benefits[b] Total	Social Security only	Both	SSI only	No benefit receipt
	Percent distribution of beneficiary type						
Total rehabilitated	**191,707**	**100**	21	7	3	10	79
Competitive work	155,666	100	15	5	3	8	85
Sheltered work	10,544	100	71	15	11	45	29
Self-employed	5,176	100	20	11	4	5	80
Homemaker or unpaid family worker	18,979	100	39	19	6	15	61

a. Persons successfully placed for at least 60 days by State vocational rehabilitation agencies.
b. Benefit receipt is from Rehabilitation Services Administration records.
Abbreviation: SSI = Supplemental Security Income.
Source: U.S. Department of Education, Rehabilitation Services Administration.

to the successful return of an individual to SGA, and the amount of costs to be reimbursed. Current policy, in effect, calls for a fee-for-service approach to paying for VR services, where a determination must be made that the services were "necessary" and "contributed to a return to work" and that the costs were "reasonable."[6]

The Panel's incentive-based approach builds on the principle in current law that the trust fund pays providers only if they successfully return the beneficiary to work. However, it carries this concept further than current law. First, the Panel's proposal involves a more strict test for the provider. Under current policy, state VR agencies are reimbursed for services if the beneficiary completes nine months of SGA, whether or not the beneficiary keeps working and actually leaves the benefit rolls after completing a trial work period.[7] Under this proposal, the provider is paid only if the beneficiary remains at work and benefits end. Second, the proposal pays the provider based on actual savings to the trust fund. The payment would be a specified fraction of the savings (from benefits not paid) as those savings accrue. Each year (for a specified number of years) after the beneficiary has completed his or her trial work period, the provider would be paid a specified fraction of trust fund savings from benefits not paid because the beneficiary is working. As such, the provider has an ongoing interest in the former beneficiary's continued employment. If additional supports or services were needed after the beneficiary left the rolls, the provider would have an incentive to provide them.

In brief, the provider is paid directly for results — not for the "reasonable or necessary" costs of inputs. The provider has an incentive to work with the beneficiary to find the most effective means of assisting that individual to achieve long-term employment.

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[6] Section 222(d) of the Social Security Act.
[7] The trial work period is a DI work incentive. It allows a DI beneficiary to test his or her ability to work without danger of losing benefits for nine trial work months. Any month in which earnings exceed $200 is considered a month of trial work.

Providers Bear the Financial Risk; Payments Are from Program Savings

Payments to providers would be based on savings to the trust fund resulting from their customers' success in returning to and remaining at work. The providers bear the financial risk by providing services first, and being paid later, according to their results. The payments are a predictable amount, based on the client's benefit level. In return for assuming the financial risk, providers would receive payment that could often exceed the cost of their inputs on a particular case. But they would only be paid when they are successful.

Administrable by SSA

Because payment is based on benefit savings, it can be fairly easily administered by SSA. Information about the amount of benefit savings would come directly from SSA's own records. There would be no need to audit bills submitted by providers to determine whether particular services were "necessary" or whether their costs were "reasonable." These are not the kinds of determinations where SSA has any particular expertise, and they would not be necessary under this plan. Further, providers would have an incentive to assist beneficiaries in accurately and promptly reporting their earnings to SSA as they return to work.

Empowerment, not Coercion

The RTW ticket is designed to empower the beneficiary by enabling him or her to be a true customer and partner in working with a service provider toward returning to work. Under current policy, the VR option can be viewed by the beneficiary as a threat rather than an opportunity. The law specifies that refusal to accept VR services without good cause will lead to the loss of benefits.[8] Therefore, SSA must inform beneficiaries of this sanction. Letters telling applicants that they have been allowed DI benefits include the following statement:

> A state vocational rehabilitation agency may contact you. This agency provides counseling, training and other services that may help you return to work. If they offer you any services, you must accept the services to keep getting disability benefits. This is true unless we decide you have a good reason for not accepting.

As a practical matter, this provision is difficult, if not impossible, to enforce and very few beneficiaries have their benefits withheld for this reason.[9] The provision was enacted in the 1956 Social Security Act amendments, which first provided disability benefits for workers age 50 and older — a time when the relationship between VR counselors and their clients was much different than it is today. As a result of amendments to the Rehabilitation Act enacted in 1973 and 1992,[10] individuals with disabilities are treated more as consumers or partners in the development of their rehabilitation plans than was the case in the 1950s. The Panel's proposal incorporates this philosophy by making clear that the beneficiary's choice to use the RTW ticket to obtain services is a voluntary one; a benefit withholding sanction would not apply to the use of the tickets.

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[8] Section 222(b)(1) of the Social Security Act.

[9] In FY 1993, state VR agencies reported 190 cases in which disability beneficiaries had refused to cooperate with rehabilitation services. Of these: 105 later cooperated after SSA notified them of the consequences, and their benefits continued; 15 were found to have "good cause" for their actions and their benefits continued; 8 had their benefits suspended because of noncooperation; and the rest were in various stages of review.

[10] The 1973 amendments to the Rehabilitation Act for the first time provided that an "individualized written rehabilitation program" (IWRP) had to be drawn up jointly by the client and VR counselor. Before that, the counselor had much more autonomy over the rehabilitation plan. (See G. DeJong, "Independent Living: From Social Movement to Analytic Paradigm," *Archives of Physical Medicine and Rehabilitation,* October 1975, p. 439.)

The 1992 amendments added a requirement that the IWRP be agreed to and signed by the individual. It also required that the IWRP specify how the individual was informed about, and was involved in choosing among, alternative objectives, services, providers and methods to procure VR services. If the individual were not satisfied with the IWRP, the new law allowed him or her to appeal to an impartial hearing officer. The law also prohibited VR agencies from suspending, reducing or terminating services pending the decision of the hearing officer. (See U.S. Congress, Congressional Research Service, "Rehabilitation Act Reauthorization and Funding," Washington, DC, November 30, 1992.)

Table 6-3. Experience with Project NetWork, January 1995

Steps toward return to work	Outcome (percent)	
	At each step	Cumulative
Total persons invited to participate in demonstration	**100.0**	**100.0**
1. Beneficiary expresses interest in receiving RTW services	10.5	10.5
2. Beneficiary volunteers to participate in RTW project	56.0	5.9
3. Beneficiary placed in employment[a]	36.8	2.2
4. Beneficiary working in January 1995[b]	20.6	1.2

a. This percentage represents 1,531 placements out of 4,164 participants. However, individuals could have received more than one placement, so this percentage overstates the numbers of individuals who were placed.

b. Most participants were still in the 24-month waiver period during which they continued to receive benefits regardless of the level of their earnings.

Source: Social Security Administration, Office of Disability, Project NetWork.

EXPECTATIONS OF SUCCESS

The Panel recognizes that Social Security disability benefits are paid to people with very significant work disabilities, only a fraction of whom have prospects for returning to work. As long as DI continues to have very strict eligibility rules, it is reasonable to expect that only a small proportion of beneficiaries will be able to return to work, even with rehabilitation services.

The number of persons who leave the DI benefit rolls — either because of medical recovery or return to work — has always been small, but is at an all-time low.[11] In the past, the annual benefit termination rate for both these reasons combined has been around 1.5 to 2.5 percent of all persons on the DI rolls. Currently, it is about 0.3 percent.[12] Although SSA's historical administrative data do not distinguish between medical recovery and return to work as reasons for benefit terminations, SSA's Office of the Actuary estimates that about 7,000 DI benefit terminations per year are due to return to work. They represent about 0.18 percent of the DI rolls.[13]

The Panel believes its incentive-based system of financing rehabilitation and RTW services could bring a doubling or tripling of the rate at which beneficiaries leave the benefit rolls because they have successfully returned to work. While those numbers are small in relation to the size of the beneficiary population, they represent a significant improvement over current experience. Our estimates of the rate of success are based on the experience of SSA's Project NetWork and on private rehabilitation experience among insurers.

Project NetWork

SSA recently conducted a demonstration, called Project NetWork, to test the effectiveness of various models of offering rehabilitation and employment services to Social Security and SSI disability beneficiaries in eight sites around the country. While evaluation of the project is still underway, early findings are that, of all those invited to participate, about 10 percent expressed an interest in receiving services; roughly half of those agreed to participate once the project was explained to them; and roughly 20 percent of the participants were employed as of January 1995.[14] The employment was not necessar-

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[11] One reason for the low rate of benefit terminations is the low number of continuing disability reviews (CDRs) that SSA conducted in the early 1990s when administrative resources were shifted from conducting CDRs to processing claims.

[12] Social Security Administration, *Annual Statistical Supplement to the Social Security Bulletin* (Washington, DC: U.S. Government Printing Office, August 1995), table 6.F1, p. 292.

[13] Social Security Administration, Office of the Actuary, memorandum, December 17, 1995.

[14] K. Rupp, et al., "Design of the Project NetWork Return-to-Work Experiment for Persons with Disabilities," *Social Security Bulletin*, Summer 1994, pp. 3-20.

ily at a level of earnings that would cause their benefits to end. The number employed as of January, 1995, taken as a proportion of all those invited to participate, was about 1.2 percent (table 6-3).

Private Insurers' Experience

Private long-term disability insurance (LTDI) pays cash benefits to ill or disabled employees whose conditions were not caused on the job. According to a 1994 survey by the Health Insurance Association of America of its member firms that offer disability group coverage, about 2 in 3 have a rehabilitation/case management program as part of their group long-term disability plans. Those who have such programs reported that, on average, about 5 percent of their caseload was actively engaged in insurer-financed rehabilitation. Among those who received rehabilitation/case management services, about one-quarter (26 percent) continued to receive benefits after the rehabilitation concluded. Over one-third (38 percent) returned to work, one-quarter (23 percent) had their benefits terminated (and may or may not have found other work) and 10 percent received lump sum settlements of their claims.[15] Thus, in 1.9 to 3.0 percent of overall cases, the individual returned to work after receiving rehabilitation or case management services.

Some believe there is untapped potential for improving the rate of return to work among private insurers. But if the 2 to 3 percent return to work rate indicated by this study is indicative of the full potential for returning LTDI clients to work, then it is reasonable to expect a lower rate of return to work among Social Security beneficiaries for several reasons.

First, private insurers often use a less strict test of disability. Private LTDI plans often use an occupational test of disability — that is, inability to do one's usual occupation — during the first two years of benefit eligibility.[16] Because the occupational test is a less strict test than that of Social Security — inability to engage in any SGA that exists in the national economy — some workers who qualify for LTDI do not qualify for Social Security. And, one might expect a higher rate of success in aiding LTDI recipients to find other occupations they can perform.

Second, private insurance covers a narrower population that is disproportionately white-collar professional or managerial employees, which makes their aggregate experience not directly transferable to the DI population. The 25 percent of private sector workers covered by LTDI in 1990-91 included: 47 percent of professional, technical and executive employees; 28 percent of clerical and sales employees; and 13 percent of production and service workers.[17] While workers covered by LTDI cover a broad range of occupations, they are disproportionately better educated and higher paid workers, who may be better candidates for rehabilitation and return to work. Finally, private insurers also have the advantage of being able to work directly with the individual's current or recent employer to negotiate job accommodations to return the individual to work. For all of these reasons, one might expect a higher rate of return to work among LTDI recipients than among DI beneficiaries.

Return to Work Among Cohorts of Social Security Beneficiaries

Analysis of the experience of cohorts of DI beneficiaries provides a baseline against which to evaluate the potential success rate of awarding RTW tickets to new beneficiaries as they enter the rolls.

One study using Social Security records followed a cohort of beneficiaries who entered the DI rolls in 1988. After about five years, a little over half the group (52.6 percent) were still on the DI rolls. Over a quarter (26.5 percent) had died and 17.5 percent

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[15] T.D. Musco, et al., *A Survey of Disability Income & Medical Rehabilitation/Case Management Programs* (Washington, DC: Health Insurance Association of America, 1995).

[16] After the initial period, the test may become more strict, to one of inability to perform the duties for any occupation for which one is qualified by training, education or experience.

[17] Disability Policy Panel, *The Environment of Disability Income Policy: Programs, People, History and Context*, Interim Report, J.L. Mashaw and V.P. Reno (eds.) (Washington, DC: National Academy of Social Insurance, March 1996).

Table 6-4. Benefit Status in February 1994 of Persons Awarded DI Disabled-Worker Benefits in 1988 by Age in Month of Award

Benefit status in February 1994	Total	Under age 40 Total	Under age 40 Under 30	Under age 40 30-39	Age 40-49	Age 50-59	Age 60-64
Total awards	409,141	99,810	36,684	62,946	78,475	146,926	84,110
Total percent	**100.0**	**100.0**	**100.0**	**100.0**	**100.0**	**100.0**	**100.0**
Still on DI	52.6	71.8	74.1	70.7	69.3	60.5	0.0
Died	26.5	19.4	14.6	22.2	26.8	32.1	24.7
Converted to retirement benefits	17.5	—	—	—	—	5.7	75.2
Recovered or returned to work	**3.5**	**8.6**	**11.2**	**7.1**	**3.9**	**1.7**	**0.1**
Medical recovery[a]	2.0	4.8	5.6	4.3	2.4	1.1	0.0
Returned to work	1.4	3.8	5.6	2.8	1.4	0.5	0.1
Benefits terminated because of SGA[a]	0.9	2.4	3.5	1.7	0.9	0.4	0.1
Benefits suspended because of SGA[b]	0.5	1.5	2.1	1.1	0.5	0.2	0.0

a. SSA administrative records indicate that benefits were terminated because "disability ceased," which could be due to either medical recovery or earning SGA. Those whose records indicated no trial work period were categorized as medical recoveries; those whose records indicated completion of a trial work period were categorized as benefits terminated due to SGA.
b. Benefits are in suspense and administrative records indicate the beneficiary completed a trial work period.
Abbreviations: DI = Social Security disability insurance, SGA = substantial gainful activity.
Source: Social Security Administration, Office of Disability.

had shifted to the retirement rolls. The remaining 3.5 percent had left the rolls because of medical recovery or return to work (table 6-4):

- About 2.0 percent had left because they were found to have medically recovered. (The number of medical recovery terminations is influenced by the number of continuing disability reviews (CDRs) SSA conducts, which were historically low from 1991 to 1993);
- About 1.4 percent had their benefits terminated or suspended because of return to work.[18]

Another study followed the work experience of a cohort of DI beneficiaries over a 10-year period. It found an overall benefit termination rate because of return to work of 2.8 percent (table 6-5).

Younger Beneficiaries Are More Likely to Return to Work. Both of these studies confirm that, as expected, young DI beneficiaries are the most likely to leave the benefit rolls because of recovery or return to work. Of those under age 40, about 5 percent medically recovered and 4 percent returned to work within five years (table 6-4). After 10 years, about 9 percent had their benefits terminated because of a return to work (table 6-5).

These rates of recovery or return to work for DI beneficiaries under age 40 are much more promising than the overall average in the study of less than 4 percent for entrants to DI of any age. It is higher still when limited to those still alive five years later.

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[18] Social Security Administration, Office of Disability.

Table 6-5. Return to Work Over 10-Year Period Among Persons Awarded DI Benefits in July 1980 - June 1981, by Age at Entitlement

	All Ages	Under 40	Age 40-49	Age 50-59	Age 60-64
Total number[a]	192,770	36,340	29,970	94,360	32,110
	Percent with various indicators of work over 10-year period				
Any work	10.2	29.1	12.4	4.8	2.5
Entered TWP	8.6	24.3	10.7	4.1	1.8
Completed TWP	6.1	18.5	6.8	2.7	1.3
Benefits terminated for return to work	2.8	9.3	3.0	1.1	0.2

a. Based on the New Beneficiary Survey sample of persons newly entitled to DI benefits in July 1980 through June 1981. Number is limited to those whose benefits had been awarded by the spring of 1982, and who remained alive by the end of 1982, when the New Beneficiary Survey was conducted. Excludes persons who had any prior receipt of disability benefits or early retirement benefits.
Abbreviations: DI = Social Security disability insurance, TWP = trial work period.
Source: S. Muller, "Disability Beneficiaries Who Work and Their Experience Under Program Work Incentives," *Social Security Bulletin*, Summer 1992, p. 9.

Of those younger than 40 when they entered the DI rolls who were alive five years later, 11 percent had left because of recovery or return to work — 6 percent had recovered and 5 percent had returned to work despite their continuing impairments.

Some Who Go to Work Return to the Benefit Rolls. SSA studies show that those who leave the benefit rolls because of return to work are at risk of returning to the rolls. The 10-year study found that about 1 in 3 of those who left the rolls because of work returned to the rolls. These findings suggest that giving incentives to service providers to maintain an interest in the beneficiary's continuing success in remaining at work is warranted.

Beneficiaries May Return to Work Without VR Services. Interviews in 1992 with DI beneficiaries who had returned to work from the DI rolls during the prior decade found that most said they did so without benefitting from vocational rehabilitation. Of those who did receive such services (27 percent), job placement services were reported to be the most helpful kinds of services they had received.[19]

CONSIDERATIONS FOR IMPLEMENTATION

Any specific proposal to implement the basic principles of an incentive-based plan for linking Social Security beneficiaries with private or public sector providers of rehabilitation services must specify which beneficiaries should be issued RTW tickets, and when; how much to pay providers as a fraction of annual benefit savings to the trust fund and for how many years; and which providers should be eligible to participate. This section explores trade-offs in determining these details.

Who Should Receive RTW Tickets

Possible candidates for receiving RTW tickets include persons newly allowed Social Security benefits based on disability, persons scheduled for continuing disability reviews (CDRs), persons entering the SSI rolls based on disability or blindness, or all persons on the disability rolls.

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[19] J.C. Hennessey and L.S. Muller, "Work Efforts of Disabled-Worker Beneficiaries: Preliminary Findings From the New Beneficiary Followup Survey," *Social Security Bulletin*, Fall 1994, pp. 42-51.

Persons Newly Allowed DI Benefits. Persons newly awarded DI benefits would be good candidates to receive RTW tickets. However, it may be desirable or practical to exclude some groups. In theory, those who will medically recover or return to work without receiving services should not receive tickets, so as to avoid paying a provider when the person would return to work anyway. In actual practice, however, it is very difficult to identify, in advance, who is likely to return to work and who among them would do so without services. One subset, however, should not be issued tickets. They are persons who, at the time of their initial benefit award, have a very high likelihood of medical recovery within two or three years.[20] If they later receive a CDR and are found not to have medically recovered, a ticket could be issued at that time.

The Panel considered whether to exclude from RTW tickets beneficiaries who are very ill and have little prospect of benefitting from RTW tickets. The government could appear insensitive or wholly out of touch if it routinely issued tickets to people who were very ill. But, if the ticket were presented as a routine part of the benefit award package and use of the ticket were wholly voluntary, then providing tickets to those who have a very low probability of using them may not pose such a risk. The Panel believes it is better to err on the side of issuing tickets, rather than instituting a complicated screening process (other than screening for likely medical recoveries) which might deny a ticket to someone who could potentially benefit.

Persons Selected for CDRs. As noted, there are reasons not to offer tickets to beneficiaries who are scheduled for review shortly after they enter the rolls because they are expected to medically recover in the near term. SSA also conducts CDRs periodically with other beneficiaries: those for whom medical improvement is possible, but not likely, as well as those who are not expected to medically improve.

These latter groups of persons selected for CDRs may be good candidates for receiving an RTW ticket along with their notice that they are scheduled for a CDR. Issuing RTW tickets could increase the likelihood that a beneficiary scheduled for a routine CDR would get services, if needed, to return to work if he or she can. Under current policy, the beneficiary receives little assistance in making the return to work when he or she is up for a continuing review.[21] Issuing RTW tickets to beneficiaries scheduled for a routine CDR also has a secondary benefit. If the tickets led to a return to work for beneficiaries who undergo a CDR, it could reduce the rate of appeal of initial CDR decisions to terminate benefits, which are reversed about half the time. And, it would increase the likelihood that benefits would stop because the beneficiary was successfully back at work, rather than not working yet adjudged to have medical improvement sufficient to perform SGA. A return to work is better than a benefit termination without a return to work over the long-term for the individual, for society at large and for the cost of Social Security.

If a CDR finds that the beneficiary has medically improved and is capable of engaging in SGA, and the beneficiary is in a VR program, current law allows benefits to continue until the rehabilitation program is completed, and state VR agencies are reimbursed for services they provided if the worker completes nine months of SGA.[22] This precedent

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[20] New criteria appropriate for excluding newly-awarded beneficiaries from RTW services based on the strong expectation of medical recovery would need to be developed. SSA's existing criteria for predicting medical improvement, which is part of the CDR process, are poorly predictive of improvement and would be inappropriate to use in denying newly-awarded beneficiaries the chance to receive services that would help them return to work.

[21] After the CDR is completed, SSA refers beneficiaries (both continued and not continued) to state VR agencies on the same basis as new applicants, where they may or may not receive services. Individuals who indicate an interest in receiving VR services in the course of the CDR process are also referred to VR.

[22] Benefits are continued as long as the person remains in and benefits from the VR program. The state VR agency may be reimbursed for services provided to a beneficiary who has medically recovered if VR services contributed to the medical recovery; that is, if the IWRP included medical services and those services contributed to the medical recovery. Even if the IWRP does not include medical services, the VR agency may still be reimbursed if the recovery was not expected by SSA and the impairment is of such a nature that any medical services provided would not ordinarily contribute to medical recovery. 20 CFR 404.2111.

could apply in an incentive-based plan as well. That is, if a beneficiary up for a CDR[23] deposited his or her RTW ticket with a provider and began a return to work plan, benefits would continue until the rehabilitation program was completed and the provider would be paid the incentive-based payments if the beneficiary returned to work and left the rolls. This approach could be used either for beneficiaries issued RTW tickets along with their CDR notice or for beneficiaries issued tickets at the time of their award who later undergo a CDR in the midst of their rehabilitation (see box 6-2).

Newly-Awarded SSI Recipients. Newly-awarded SSI beneficiaries would also be likely candidates to receive RTW tickets. Among SSI recipients reaching age 18, who are required to receive a CDR that uses adult disability criteria, some may be particularly good candidates for assistance in entering the world of work. It may be necessary to adjust the incentive payments in order to induce providers to serve SSI recipients, whose benefits are generally lower than those of DI beneficiaries. Because SSI recipients may leave the benefit rolls for reasons other than return to work — such as increases in other income or a change in marital status or living arrangements — the rules for paying providers would need to distinguish among the reasons why SSI recipients leave the rolls. Providers should be paid only if the former SSI recipient is earning at a level that causes SSI payments to end, not because benefits stopped for other reasons.

All Persons on the Rolls. In theory, it might be desirable to issue RTW tickets to all of the roughly 7 million working-age persons receiving DI or SSI benefits. A gradual phase in, however, would be more manageable. Because the incentive-based approach is new and untested, it may be prudent to issue tickets only to new beneficiaries who are not expected to medically recover in the near term and to those selected for routine CDRs. Another possibility would be to issue RTW tickets to current beneficiaries, but only at their request.

Box 6-2. Continuing Disability Reviews and Work

An incentive-based plan for encouraging private providers to assist beneficiaries to return to work needs to take account of the relationship between continuing disability reviews (CDRs) and return to work.

Evidence that a beneficiary is working may trigger a CDR. If that review finds the beneficiary has some evidence of medical improvement and is able to engage in substantial gainful activity (SGA), benefits end — there is no continuing eligibility for Medicare and no extended period of eligibility during which the beneficiary can return to the rolls without a new application if his or her ability to engage in SGA falters.

In actual practice, the distinction between return to work and a CDR finding of medical improvement can be extremely subtle. For some kinds of impairments, such as paraplegia or deafness, it is evident that the impairment continues when the beneficiary returns to work. For other impairments — that are assessed largely by their functional consequences, as is the case with mental and certain other disorders — evidence that a person is working can influence a finding of medical improvement, leading to an abrupt cessation of benefits.

Under the Panel's return-to-work proposal, if a beneficiary is engaged in a return-to-work plan with a provider at the time of a CDR, benefits could continue until the rehabilitation program is completed and, if the beneficiary successfully returns to work and leaves the benefit rolls, the provider would receive the incentive-based payments.

Providers Eligible to Participate

Providers offering vocational rehabilitation or RTW services would be eligible to participate. A broad diversity of providers would be encouraged, covering

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[23] Other than those scheduled for early CDRs because of expected recovery.

a wide range of philosophies and methodologies. They could range from those offering the traditional services of VR counselors to job developers or those who can serve as liaison with employers or providers of other services for improving employment prospects.

Providers should be certified for eligibility to participate — for example, by drawing on licensing or certification of firms that offer job placement or RTW services. The intent is not to limit participation only to certified rehabilitation professionals, but to include others involved in job development and job placement. Systems would need to be put in place to inform beneficiaries about providers in their area.

Getting the Incentives Right: How Much to Pay Providers

Payments to providers involve two parameters: the annual percentage of savings to the trust fund they would receive, and the number of years they would receive it. Getting the incentives right involves a balance between adequately rewarding providers for the financial risks they face, and protecting the benefit program against unintended cost increases.

From the providers' perspective, payments have to be high enough to encourage them to invest in assisting beneficiaries to work, knowing that:

- **Providers bear the risk of their own failure.** They will be paid only when they successfully aid beneficiaries in returning to work. They bear the financial risk of offering services that are not effective.

- **Providers invest in services first and get paid later.** They will be paid only as their success is demonstrated by their clients remaining at work and off the benefit rolls. They incur the cost first, and are paid later, as savings to the trust funds accrue.

From the perspective of the trust fund, payments should be not be so high that they result in unintended costs to the trust funds. Payments to providers need to be high enough to encourage them to participate without causing the proposal to cost more than the benefit savings. There are two "risks" to the trust funds that would represent new costs under the proposal, and one offsetting source of savings:

- **Risk of "buying the base."** Some beneficiaries now return to work without receiving trust fund-financed rehabilitation services. Because it is impossible to predict with certainty in advance who they are, they would be issued tickets along with others. If such beneficiaries deposited their ticket with a provider, the provider would be paid the specified share of trust fund savings when the beneficiary returns to work. SSA estimates that about 4,000 persons a year return to work without SSA paying for VR services for them. In estimating the impact of this proposal, SSA's actuaries assume that about half of such persons (about 2,000 a year) would deposit their ticket with a provider and therefore a provider would be paid.

- **Risk of induced claims and awards.** Service providers would have an incentive to help their clients qualify for Social Security disability benefits in cases where the client would not otherwise apply for them. Such cases might include individuals whose rehabilitation costs are being paid by a third party such as LTDI or workers' compensation. This incentive exists because it would allow the provider to collect incentive-based payments when they are successful. The size of this effect is unknown. To estimate it, it is necessary to know: (1) the number of disabled clients of private providers who now successfully return to work without receiving Social Security benefits, and (2) of those, how many have impairments of the nature, severity and duration that they would qualify for Social Security if they were helped to apply by their rehabilitation provider. In estimating the cost of this proposal, SSA actuaries estimate that benefits would be awarded in about 1,000 new cases each year because of this incentive.

Table 6-6. Illustrative Provider Payments by Social Security Benefit Amount

Monthly benefit amount	Annual benefit	Total payments[a]	
		50 percent for 5 years	30 percent for 10 years
$400	$4,800	$10,450	$10,660
500	6,000	13,070	13,320
600	7,200	15,680	15,980
700	8,400	18,300	18,650
800	9,600	20,910	21,310
900	10,800	23,520	23,980
1,000	12,000	26,140	26,640

a. Assumes 4 percent inflation, 6.3 percent interest rate, and 5 percent probability the provider would not be paid either because the beneficiary died or stopped earning enough to remain off the benefit rolls.

- **Offsetting cost reduction.** Some of the new costs that may occur under the plan may be offset by reduced payments in cases where VR agencies are now paid when a beneficiary completes nine months of SGA, but does not continue to earn SGA and leave the benefit rolls. The SSA Office of the Actuary estimates that, of about 5,000 VR cases to be reimbursed annually in coming years, about 1,000 are cases that would not be paid under this proposal because the beneficiary did not leave the benefit rolls.[24]

Finally, an alternative provider reimbursement formula could be designed to encourage providers to focus on their clients' long-range earnings potential, by helping their clients receive education, training or on-the-job experience they need to improve their future earnings. Such an approach would base payments on their clients' earnings level as well as on benefit savings to the trust fund. The examples the Panel has developed, however, are based only trust fund savings.

Current Reimbursements to State VR Agencies. SSA's experience in paying VR agencies offers a benchmark for considering payment levels for providers under this proposal. The average reimbursement to state VR agencies was between $11,000 and $12,000 for DI beneficiaries who had completed nine months of SGA in FY 1994 (table 6-1). The actual payments per case vary. The payment was over $15,000 for 19 percent of cases, while for 42 percent it was less than $5,000 in FY 1993. For 12 percent it was less than $2,000.[25] All of these costs include the cost of services purchased from outside vendors as well as an allowance for the VR counselor's salary and agency administration.[26]

Illustrative Payment Formulas. For illustrative purposes, two payment formulas are shown that vary the length of time the provider receives incentive payments for successfully returning the beneficiary to work:

- Incentive payments of 50 percent of benefit savings for 5 years.
- Incentive payments of 30 percent of benefit savings for 10 years.

The advantage of a longer payment period is that it extends the provider's incentive to continue to assist the former beneficiary, if needed, over a longer

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[24] Social Security Administration, Office of the Actuary, memorandum, July 21, 1995.

[25] Data is for initial claims for reimbursements from VR agencies in FY 1993 for DI-only beneficiaries. Social Security Administration, Office of Disability.

[26] Each individual reimbursement is capped at a level not to exceed the estimated savings to the trust fund, using a formula developed by SSA's actuaries.

Table 6-7.—Illustrative Provider Payments - Milestone Payment Plan by Social Security Benefit Amount

Monthly benefit amount	Annual benefit	Total payments:[a] milestone payments of $300 for plan; $1200 for 9 months of SGA; and	
		30 percent for 3 years	30 percent for 5 years
$400	$4,800	$5,530	$7,770
500	6,000	6,540	9,340
600	7,200	7,550	10,910
700	8,400	8,560	12,480
800	9,600	9,560	14,050
900	10,800	10,572	15,620
1,000	12,000	11,580	17,180

a. Assumes 4 percent inflation, 6.3 percent interest rate and 5 percent probability the provider would not be paid either because the beneficiary died or stopped earning enough to remain off the benefit rolls.
Abbreviation: SGA = substantial gainful activity.

period. A shorter payment period might be more attractive to providers by allowing them to receive the return on their investment more quickly, while still maintaining their incentive to support former beneficiaries, if needed, in their first several years after returning to work. Further, a shorter period limits the government's financial commitment. A ticket which is deposited with a provider would represent a firm obligation based on the payment formula that ticket represents. If there were unexpected consequences, the government would not be locked into a lengthy contract with providers.

Providers' Valuation of Payments. The value of a payment schedule to providers depends on how they assess the risks associated with the payments. One risk for providers is simply the time value of money. If they provide services first and are paid later, they would discount the value of future payments by the difference between the value of a dollar spent today and a dollar received some years later. For illustrative purposes, the time value of money was estimated using the long-term interest rate used to project the status of the Social Security trust funds, which is 6.3 percent — made up of 4 percent inflation and 2.3 percent real interest.[27]

A second risk for providers is that their efforts will fail. This probability is difficult if not impossible to predict, because it depends on the effectiveness of the provider in selecting clients and providing appropriate services. The estimates below assume no provider failure — they illustrate the outcome if all clients return to work — but the value of provider payments for success under various formulas should be evaluated with the very real risk of failure in mind.

A third risk for providers is that after they successfully help a beneficiary return to work and leave the benefit rolls, there is a possibility that the beneficiary will return to the rolls or will die. In either case there would be no savings to the trust funds, so providers would not be paid. The illustrative payment schedules assume this risk to be about 5 percent per year; that is, each year's payment is reduced by 5 percent to reflect this average risk.

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[27] Because future Social Security benefits keep pace with inflation, both the inflation adjustment of benefits and the inflation component of the discount rate were ignored. Board of Trustees, Federal Old-Age and Survivors Insurance and Disability Insurance Trust Funds, *1995 Annual Report of the Board of Trustees of the Federal Old-Age and Survivors Insurance and Disability Insurance Trust Funds,* House Document 104-57 (Washington, DC: U.S. Government Printing Office, 1995), table II.D1, p. 56.

Using these assumptions, provider payments are illustrated in table 6-6. Under the discount assumptions used here, the payment options produce similar aggregate payments. They range from about $10,000 to $26,000 depending on the disabled worker's benefit level.

Cost Estimate. SSA actuaries estimate that a plan to pay providers 50 percent of trust fund savings for five years would produce modest savings over a 10-year period. If effective in October 1996, it is estimated to save a total of $440 million through the year 2005. That saving is based on the assumption that new cases of beneficiaries returning to work would gradually rise to about 6,000 annually by the year 2003, nearly doubling the number of beneficiaries who leave the rolls to return to work under current law. If tickets were issued to SSI recipients scheduled for a CDR (other than those for whom recovery is expected) and to newly-awarded SSI recipients, the proposal is estimated to save a total of $235 million through 2005.[28]

Milestone Payments. The Panel believes a pure incentive-based payment plan is the most prudent policy. However, it may be necessary to offer "milestone" payments — payments for attaining specific benchmarks prior to the beneficiary leaving the rolls — in addition to payments based on trust fund savings. Two illustrative payment formulas that include milestone payments are shown below. The first milestone payment would be $300 when a DI beneficiary agrees to and signs an RTW plan. This is significantly less than the typical cost of performing a full vocational assessment and plan development.[29] As such, it is a modest payment to the provider. The second milestone payment would be $1,200, after the beneficiary has completed nine months of SGA.[30] Under current policy, state VR agencies are reimbursed the full cost of their services at this second milestone. Under this proposal, providers would receive most of their payments only after the beneficiary remains at work and leaves the benefit rolls. These milestone payments could be combined with incentive payments as follows:

- Milestone payments of $300 when beneficiary agrees to a plan offered by a provider and deposits the ticket, $1,200 when the beneficiary completes nine months of SGA, and 30 percent of benefit savings for 3 years.
- Milestone payments as above but 30 percent of benefit savings for 5 years.

Milestone payments run the risk to the trust funds of paying for services that do not result in beneficiaries returning to work. Plans for milestone payments are shown for comparison with the pure incentive-based plans (table 6-7). They offer smaller aggregate payments to providers because providers would be assured of milestone payments even if the early services they provided did not result in long-term return to work. As such, the payments would involve new net costs to the trust fund when RTW services are not effective.

Given the modest trust fund savings estimated for the pure incentive-payment proposal and the considerable uncertainty surrounding the estimates — including uncertainty about the number of "induced" new benefit awards — the prudent policy of paying providers only after return to work results are in is the preferred policy.

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[28] Social Security Administration, Office of the Actuary, memoranda, July 21, 1995, September 25, 1995, December 1, 1995, and December 15, 1995.

[29] No estimate is available for the full cost to state VR agencies of the assessment and development of a plan, which includes the VR counselor's time as well as purchased services. However, the average cost of purchased services for diagnosis and evaluation was $304 per client in FY 1994 (U.S. Department of Education, Rehabilitation Services Administration). In the State of Washington, the average cost of an evaluation and plan for workers' compensation is $2,300. (Stephen L. Start and Associates, memorandum, September 11, 1995.)

[30] This illustrative plan is based on one developed by Steven L. Start and Associates, "Assisting Citizens with Disability Toward Gainful Employment: Initiatives for Social Security Legislative and Policy Reform," draft report, June 14, 1995. That plan also provided a $900 milestone payment when the beneficiary completed 60 days in employment. That milestone, which is relevant for state VR agency measures of success, is not a good predictor of success for Social Security beneficiaries.

Implementation Issues Remain

The Panel's proposal lays out the broad outlines of a wholly new approach to linking beneficiaries to RTW services. In addition to the matters of who should receive tickets and how much providers should be paid, a number of technical and administrative issues must be resolved in order to implement such a plan.

Information systems must be established to inform beneficiaries and service providers about each other in ways that offer beneficiaries a choice of providers, give providers an opportunity to seek out likely candidates for rehabilitation from among beneficiaries and have appropriate safeguards for beneficiaries' right to privacy. In addition, a beneficiary or service provider may decide they want to end their agreement before the beneficiary has successfully returned to work. In such cases, the beneficiary should have the option to select another willing provider and the original provider should have the option to sell the RTW ticket to another provider.[31] Finally, a strong evaluation component should be built into the implementation of the return to work proposal. The evaluation should be designed to assess correlates of successful return to work, components of program savings and costs associated with the RTW tickets and beneficiaries' and service providers' satisfaction with the arrangements.

OTHER OPTIONS FOR RETURN TO WORK

The Panel considered other options for linking individuals with rehabilitation services before they apply for Social Security benefits. This is done in some foreign systems that have national systems of short-term disability benefits that are coordinated with long-term disability benefits. In Germany, for example, employers pay an ill or disabled worker full salary for the first six weeks of absence from work, after which sickness funds pay for up to 18 months of temporary disability, during which publicly-financed rehabilitation services are provided before a determination of long-term disability is made.[32]

Short-Term Disability Insurance

The Panel considered a plan for universal short-term disability benefits in the United States. The purpose of such a plan would be to fill gaps in short-term disability income protection; to promote early intervention through a case management system to link individuals with rehabilitation and RTW services; and to reduce reliance on long-term disability benefits from Social Security. Many consider the lack of short-term disability benefits to be a major gap in beneficiary protection and to inhibit early intervention to prevent long-term disability. Fully 30 percent of private sector employees have no formal sick leave or short-term disability insurance. Another 26 percent have only sick leave, which typically provides wage replacement for a few days or weeks, far less than the duration needed to cover the five-month waiting period for DI.[33]

A national plan for short-term disability insurance in the United States was considered when the plan for the Social Security long-term disability insurance program was developed more than four decades ago.[34] It was considered again 20 years ago.[35] The main drawback of such a plan is its cost. If financed equally by employees and employers, short-term disability protection was estimated to cost roughly 1 percent of earnings that are subject to Social Security taxes (0.5 percent each for employees and employers). Given today's very tight constraints on public budgets and lack of interest in new employer mandates, the Panel concluded such a proposal is

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[31] In some cases, it may be necessary to use alternative dispute resolution mechanisms such as final and binding arbitration with provision for an expedited hearing.

[32] L.J.M. Aarts and P.R. de Jong, "European Experience with Disability Policy," *Disability, Work and Cash Benefits*, op. cit., footnote 4.

[33] Disability Policy Panel, op. cit., footnote 17, see discussion in chapter 2.

[34] Social Security Administration, Bureau of Employment Security and Division of Research and Statistics, "Issues in Temporary Disability Insurance," *Social Security Bulletin*, June 1949, pp. 3-8 and 14.

[35] L.D. Haber, "Sickness and Injury Cash Benefits (SICB): Recommendations for a Temporary Incapacity Program," unpublished paper prepared for the U.S. Department of Health, Education and Welfare, Assistant Secretary for Planning and Evaluation, Washington, DC, June 1974.

not feasible. Further, if the United States were to expand social protection for American workers, in the Panel's view, comprehensive health care coverage should be the first priority.

Earlier Referral for State VR Services

If rehabilitation is to be provided before a determination of eligibility for DI or SSI benefits, the federal/state VR program is the main source of public financing for such services. Its availability is not limited to Social Security beneficiaries (table 6-2).

If state VR agencies are willing and able to serve a larger share of applicants before cash benefit claims are decided, SSA and state agencies could promote early intervention by setting up administrative arrangements to more actively promote VR services sooner by:

- Training local SSA staff to actively inform benefit applicants about state VR agencies in their area, what those agencies offer and where and how to apply for such services. The main impediment to this approach appears to be a limitation on field office staff; and

- Locating VR counselors in or near local SSA offices, to seek out Social Security applicants as was tested with reported success in the Project NetWork demonstration in Virginia and New Hampshire.

The Panel's incentive-based plan for engaging private sector providers in assisting beneficiaries to return to work does not preclude improved administrative arrangements between SSA and state VR agencies to more actively inform applicants for Social Security benefits about publicly-financed rehabilitation services available from state agencies.

CONCLUSION

The Panel believes there is room for improvement in the rehabilitation and return to work of Social Security beneficiaries. While many beneficiaries are too ill or too impaired to return to work, some may have the potential to return to work if their residual capacity were enhanced, they developed new skills or they received accommodations.

The Panel's incentive-based approach builds on the principles of consumer choice and empowerment to foster competition and innovation among providers. This new approach is not a substitute for public funding of VR that serves broader social goals and encompasses a broader clientele, including people not receiving cash benefits. Rather, it is intended to expand access to new and innovative RTW services to return those beneficiaries who can do so to productive employment, using the efficiency and creative energy of the private market, in a way that is administrable by SSA. The remaining challenge is to refine the implementation details of such a plan.

Chapter 7 Disabled Worker Tax Credit

The Disability Policy Panel recognizes that work disability is a continuum, ranging from total work incapacity to only partial or periodic limitations in ability to work. Social Security disability insurance (DI) and Supplemental Security Income (SSI) are for those at the far end of the spectrum — those who are unable to work or have very significant work disabilities.

While many people with physical or mental impairments work, their earnings are often limited because of their impairments. Impairments may cause reduced wage rates or reduced hours of work, both of which reduce income from work. In 1993, persons who worked despite having limitations in the kind or amount of work they could do earned, on average, about 60 percent as much as nondisabled workers ($15,600 compared to $25,200).[1] The lower earnings were in part due to greater part-time work among workers with disabilities. It has been noted that disability often "steals time" by increasing the time and effort to perform job tasks. Further, compared to others, a worker with a disability may require more time for medical and personal care, require more rest, have less stamina and require more time for transportation.[2] Consequently, part-time or flexible work schedules may be the kinds of accommodations some employees need, and these accommodations may be accompanied by lower annual earnings.

Structural changes in the economy over the past two decades have differentially affected opportunities for workers with disabilities. Technological changes may bring better opportunities for skilled workers with physical impairments. On the other hand, increased emphasis on intellect, advanced education and flexibility may make cognitive impairments or mental illness greater impediments to work. Changes in the demand for workers of different skill levels have brought about increased disparity in opportunities and earnings between highly educated and less skilled workers, generally.[3] And this disparity is likely to become evident within the highly diverse population of people with disabilities, as well.

Remedies provided by the Americans with Disabilities Act of 1990 — banning discrimination, requiring reasonable accommodation and breaking down architectural barriers — are likely to be most effective for highly skilled workers who have faced these barriers in the past. But workers with physical or mental impairments who have low skills and limited human capital are doubly disadvantaged in today's labor market.

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[1] U.S. Bureau of the Census, Current Population Survey, March 1994 (see table 1-6).

[2] W.Y. Oi, "Employment and Benefits for People with Diverse Disabilities," *Disability, Work and Cash Benefits,* J.L. Mashaw, et al., (eds.) (Kalamazoo, MI: W.E. Upjohn Institute for Employment Research, forthcoming).

[3] Disability Policy Panel, *The Environment of Disability Income Policy: Programs, People, History and Context,* J.L. Mashaw and V.P. Reno (eds.) (Washington, DC: National Academy of Social Insurance, 1996), see chapter 6; and R.V. Burkhauser, et al., "How People with Disabilities Fare When Public Policies Change," *Journal of Policy Analysis and Management,* Spring 1993, pp. 251-269.

Many workers who sustain disabilities during their work careers continue working after the onset of their conditions.[4] For some, a reduction in hours of work or wage rates would cause them to drop below a minimum living standard. For people who sustain partial disabilities, income support policies that subsidize continued employment are promising methods of helping workers meet their basic income needs while encouraging their continued employment.

The Panel recommends a disabled worker tax credit (DWTC) that would be separate from disability benefit programs. The wage subsidy would be paid to low-income persons not because they are unable to work, but because they work despite their impairments.

As a way to encourage and subsidize work among low-income workers with disabilities, the Panel is proposing a wage subsidy that is separate from the DI and SSI programs. It is proposing a DWTC that would be paid to persons not because they are unable to work, but because they work, albeit at low wages, despite their impairments. As such, it rewards work for low earners with disabilities without increasing reliance on disability benefit programs that are designed primarily for persons who are unable to work.

The Panel recognizes that disability is a continuum and that Social Security and SSI beneficiaries are those who have the most significant work disabilities. The DWTC subsidizes the earnings of workers whose capacity to earn is limited by their impairments. It is designed to provide low earners with disabilities an alternative to claiming cash benefits. It would be available to DI or SSI beneficiaries who leave the benefit rolls. It would also be available to low-income workers with significant disabilities who work and do not receive DI or SSI benefits. As such it is designed to:

- Encourage older workers to remain at work even though they experience a decline in hours of work or wage rates due to progressive impairments. By subsidizing low wages, it encourages older workers to delay the point at which they turn to cash benefits.
- Ease the transition from school to work for young people with developmental disabilities whose earnings capacity is doubly limited by their youth and their impairments. By subsidizing their earnings, it encourages work even part-time or at low pay, that over the long run can improve young workers' human capital through on-the-job experience.
- Ease the transition off the DI and SSI benefit rolls for those who return to work. The wage subsidy would compensate for some of the loss of benefits that occurs when beneficiaries return to work. Unlike a partial benefit offset in DI, it would target those with low incomes.

The DWTC is superior to other approaches for providing income support to people with partial work disabilities. The Panel considered other options, including expanding eligibility for Social Security benefits and paying partial benefits (see chapter 4). Experience with workers' compensation, private disability insurance and foreign systems shows that these policies significantly increase disability benefit costs. In contrast with proposals to expand eligibility for Social Security or SSI, the DWTC provides income support to workers with partial disabilities in a way that encourages continued work.

CRITERIA FOR A DWTC

The specific design of the DWTC could take a number of forms. Its cost, impact on the incomes of workers with disabilities, work incentive effects and administrative issues will vary depending on the specific design features. The proposal illustrated

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[4] R.V. Burkhauser and M.C. Daly, "Employment and Economic Well-Being Following the Onset of a Disability: The Role of Public Policy," *Disability, Work and Cash Benefits*, J.L. Mashaw, et al., (eds.) (Kalamazoo, MI: W.E. Upjohn Institute for Employment Research, forthcoming).

here reflects one set of choices about who should be eligible for the credit and about balancing the particular goals to be achieved in deciding the size and shape of the DWTC.

Eligibility for the DWTC

Low-income people whose disabilities represent an impediment to work, but nonetheless have some capacity to earn, should be the target group for the credit. The disability criteria must also be administratively feasible, which involves paying the credit and making a determination of disability for eligibility purposes. The credit would be paid through the existing income tax system, in which there is already a wage subsidy for low-income workers — the Earned Income Tax Credit (EITC). The task of determining eligibility, however, is no easy matter. Although the Internal Revenue Service has a definition of disability which is used for purposes of making a deduction from taxable income,[5] the Panel recognizes that the Internal Revenue Service does not have the capacity to make disability determinations. So in designing its proposal, the Panel chose populations for whom a disability determination would be made by other agencies that already make disability assessments.

The Panel rejected the option of offering the DWTC only to persons receiving DI or SSI benefits for several reasons. First, DI and SSI beneficiaries have the most severe work disabilities; many are unable to work. The purpose of the DWTC is to make income support for persons with disabilities less binary, by targeting individuals who have reduced work capacity, but still are able to work. Targeting only beneficiaries would not achieve this goal. Second, if workers had to establish eligibility for DI or SSI benefits in order to receive the wage subsidy, it would increase claims for these benefits. One purpose of the DWTC is to support people to enable them to remain at work and not claim DI or SSI benefits.

The Panel proposes that the DWTC be available to the following categories of workers with disabilities:

DI and SSI Beneficiaries. A wage subsidy would support DI and SSI beneficiaries in making the transition from benefits to market work when that is feasible. SSI beneficiaries would receive the DWTC as soon as they begin to work. The credit would offset the reduction in SSI benefits as earnings rise. DI beneficiaries would become eligible for the credit after their trial work period (TWP) has been completed and benefits stop.[6] The credit would soften the impact of the loss of DI benefits by supplementing earnings at this point.[7]

Certain Denied Applicants for DI or SSI. Persons denied at the last step of the Social Security Administration's (SSA's) disability assessment have been determined to have a severe impairment and to be unable to do their past work, but their impairment does not meet the medical listings of impairments and they have been found able to do other work that exists in the national economy. They could be made eligible for the DWTC. In its interim report, the Panel found that the economic and self-reported health status of nonworking denied applicants is, on average, poor.[8] The DWTC would subsidize low wages for those who find even part-time work.

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[5] Income tax rules allow a deduction from income for impairment-related work expenses for persons with a disability, defined as "a physical or mental disability that limits your being employed, or substantially limits one or more of your major life activities, such as performing manual tasks, walking, speaking, breathing, learning and working." U.S. Internal Revenue Service, *Your Federal Income Tax for Individuals*, Publication 17 (Washington, DC: U.S. Department of the Treasury, 1994), p. 233.

[6] Unlike SSI beneficiaries, DI beneficiaries do not have their benefits partially withheld when they work. Benefits are paid in full during a TWP and then are withheld when the beneficiary continues to engage in substantial gainful activity after the TWP. For DI beneficiaries, the DWTC would begin only when benefits are withheld due to work.

[7] The Panel believes that a DWTC should not be extended to recipients of disability payments other than DI or SSI until the consequences of such a policy have been explored. These disability payments include: veterans' pensions; veterans' compensation; disability pensions from private employment or pensions from federal, state or local government employment; private long-term disability insurance; and workers' compensation. Each of these programs has its own eligibility criteria, and the appropriateness of basing DWTC eligibility on receipt of these benefits will depend upon the particular program's eligibility criteria and the interaction of program rules with the DWTC.

[8] Disability Policy Panel, op. cit., footnote 3, see discussion of denied applicants in chapter 3.

For DI and SSI beneficiaries, and for applicants denied at the last step, information from SSA could be used to certify eligibility for the DWTC.

Persons Eligibile for Vocational Rehabilitation Services. To meet this test, an individual must have "a physical or mental impairment which for such individual constitutes or results in a substantial impediment to employment."[9] State vocational rehabilitation (VR) agencies could be responsible for certifying individuals who meet this eligibility test.

Alternatively, state VR agencies could implement a stricter test of eligibility for the DWTC. Eligibility could be limited to individuals who meet the VR definition of severe disability. Section 7, paragraph (15) of the Rehabilitation Act defines severe disability as follows:

> the term "individual with a severe disability" means an individual with a disability (as defined above) —
>
> (i) who has a severe physical or mental impairment which seriously limits one or more functional capacities (such as mobility, communication, self-care, self-direction, interpersonal skills, work tolerance, or work skills) in terms of an employment outcome; ... [and]
>
> (iii) who has one or more physical or mental disabilities resulting from amputation, arthritis, autism, blindness, burn injury, cancer, cerebral palsy, cystic fibrosis, deafness, head injury, heart disease, hemiplegia, hemophilia, respiratory or pulmonary dysfunction, mental retardation, mental illness, multiple sclerosis, muscular dystrophy, musculoskeletal disorders, neurological disorders (including stroke and epilepsy), paraplegia, quadriplegia and other spinal cord conditions, sickle-cell anemia, specific learning disabilities, end-stage renal disease, or another disability or combination or disabilities determined ... to cause comparable substantial functional limitation.

State VR agencies have several advantages as a locus for certifying DWTC eligibility. Their purpose is to help people work rather than to pay benefits based on inability to work. Consequently, workers who go to VR to establish DWTC eligibility may benefit from their contact with the agency and gain access to other services that VR offers.

Furthermore, VR agencies already have experience in certifying people with disabilities for other federal programs. VR agencies certify individuals with disabilities for special treatment with regard to federal hiring rules and they certify eligibility for the Targeted Jobs Tax Credit, which is administered by the U.S. Department of Labor. Although DWTC certification criteria would be derived from VR's own eligibility criteria and thus would not require a new type of assessment, the U.S. Department of the Treasury would need to review the specific criteria to assure that they were appropriate for DWTC certification, have mechanisms to monitor their application and have funds to reimburse state agencies for the cost of making such determinations.

The Size and Shape of the DWTC

Under the DWTC, workers with low earnings would receive a credit equal to a certain percentage of their earnings. As earnings rose from zero, so would the amount of the credit up to a maximum credit amount. Once the maximum was reached, the credit would plateau over a range of earnings and then would begin to decrease as income continued to rise until it was fully phased out. Only persons with earnings would be eligible for the credit.

The size and shape of the DWTC as earnings rise depends on the following parameters:

- **A phase-in range.** During the phase-in range of the DWTC, each additional dollar of earnings increases the amount of the credit by a specified percentage of the additional earnings. This

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[9] The second part of this test requires that individuals be able to "benefit in terms of an employment outcome from vocational rehabilitation services ...." (Section 7(8)(A)(i) and (ii) of the Rehabilitation Act.)

percentage is referred to as the phase-in rate of the credit.

- **A maximum credit amount.** The DWTC continues to phase in as earnings rise until the maximum dollar amount of the credit is reached.
- **A plateau range.** When the maximum credit amount is reached, the credit plateaus over a fixed range of earnings. The worker receives the maximum credit amount of his or her earnings are within the plateau range.
- **A phase-out range.** When earnings rise above the ending income for the plateau range, the credit begins to phase out. The maximum credit amount is decreased by a specified percentage of the excess of adjusted gross income (or, if greater, earned income)[10] over the ending income of the plateau range. This percentage is referred to as the phase-out rate of the credit.
- **A break-even point.** The tax credit continues to phase out as earnings rise until it is fully phased out. This point is referred to as the break-even point.

In designing its illustrative DWTC proposal, the Panel considered the following goals in setting these parameters.

Goal 1: Work subsidies for disabled workers, with or without children, that are larger than those provided through the existing EITC. The DWTC recognizes that many people with disabilities experience special impediments and added costs when they go to work, and the DWTC is designed, in part, to lessen these added burdens. Workers with disabilities should, therefore, receive larger work subsidies through the DWTC than other workers of the same family size receive through the EITC.

Goal 2: A high phase-in rate at the front end of the credit in order to provide strong work incentives for those with very low earnings. A high phase-in rate for the DWTC provides stronger work incentives for workers with very low earnings, including young workers who are making the transition from school to work. It recognizes that some workers with disabilities may not be able to work full-time or may have a significantly reduced earnings potential. The income support provided through the DWTC may make it possible for some of these workers to enter or remain in the work force rather than turn to benefits to meet basic needs.

Goal 3: A plateau range that is well-coordinated with the DI and SSI work incentives. The DWTC is intended, in part, to ease the transition off the DI and SSI rolls for beneficiaries who have the capacity to do so. DI beneficiaries would be eligible for the credit after benefits stop due to work. The credit is intended to soften the impact of the loss of DI benefits by providing an increasing marginal return to work as earnings rise. As long as the DWTC is designed so that the DI beneficiary is in the phase-in range of the credit when benefits stop, the worker continues to experience an increasing marginal return to work as earnings rise. A plateau range for the DWTC that begins no lower than $10,000[11] achieves that aim.

In order to coordinate the DWTC with the SSI work incentives, the plateau range should end at earnings no lower than about $13,000 annually. This will ensure that the DWTC does not begin to phase out until after SSI benefits are fully phased out.[12] If the DWTC begins to phase out before SSI

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[10] Like the EITC, the phase-in of the DWTC is based on earnings while the credit phase-out is based on adjusted gross income (AGI) unless earnings exceed AGI. Basing the credit phase-out on AGI is designed to ensure that workers with low earnings but significant unearned income do not benefit from the credit.

[11] DI benefits stop when earnings rise above substantial gainful activity (SGA) level and the beneficiary completes the nine-month TWP. The SGA level is $500 per month ($6,000 annually) under existing rules and $720 per month in 1996 ($8,640 annually) in the Panel's proposed changes to enhance the work incentives.

[12] Unlike DI benefits, SSI benefits are gradually reduced as earnings rise. SSI benefits phased out at $1,001 of earnings per month ($12,012 annually) in 1995. The SSI earned income exclusion allows beneficiaries to exclude the first $65 of monthly earned income and one-half of earnings above that amount from countable income. The earned income exclusion is applied in addition to a general exclusion of $20 of monthly income from any source. The monthly SSI benefit is then computed by subtracting the remaining countable income from the federal benefit rate. The result is a marginal tax rate of 50 percent on monthly earnings above the $85 disregard.

Table 7-1. Illustrative DWTC and 1996 EITC[a] Parameters

	Phase-in rate (percent)	Plateau income range		Maximum credit amount	Phase-out rate (percent)	Break-even point
		Begins	Ends			
			No-child credit			
DWTC	25	$10,000	$13,000	$2,500	25	$23,000
EITC	7.65	4,000	5,000	306	7.65	9,000
			One-child credit			
DWTC	38	$10,000	$13,000	$3,800	25	$28,200
EITC	34	6,160	11,290	2,094	15.98	24,395
			Two-child credit			
DWTC	45	$10,000	$13,000	$4,500	25	$31,000
EITC	40	8,900	11,620	3,560	21.06	28,524

a. Rules scheduled to be in place for the 1996 tax year, as established by the Omnibus Budget Reconciliation Act of 1993.
Abbreviations: DWTC = disabled worker tax credit, EITC = earned income tax credit.
Source: U.S. House of Representatives, Committee on Ways and Means, *Overview of Entitlement Programs (1994 Green Book)*, WMCP: 103-27, (Washington, DC: U.S. Government Printing Office, July 1994), table 16-11, p. 700.

benefits are fully phased out, the result will be a high cumulative marginal tax rate.

Goal 4: A reasonable phase-out rate for the credit. During the phase-out, the credit is reduced for each additional dollar of earnings. A high phase-out rate will mean high marginal tax rates and potential work disincentives for workers with disabilities. In the phase-out range of the credit, the worker will already be experiencing a marginal tax rate that includes the 7.65 percent payroll tax for Social Security and Medicare, the 15 percent federal income tax that comes into effect at about $534 of monthly earnings for single workers with no dependents,[13] and any state and local taxes.

Goal 5: Minimize cost by having break-even points that target the DWTC to workers with only modest incomes. Balancing the goals set forth so far requires extending the phase-out range beyond the break-even points for the existing EITC. When setting the credit's parameters, break-even points should be chosen that will ensure that the DWTC remains targeted only to workers with modest incomes as a way to minimize costs.

AN ILLUSTRATIVE DWTC

Based on these goals, a set of parameters was chosen for the Panel's illustrative DWTC for workers with no qualifying children, one child, and two or more children (table 7-1). Figure 7-1 graphically illustrates how the DWTC and EITC phase in and phase out as earnings levels rise. The illustrative proposal achieves the five goals laid out above in the following ways:

- At all earnings levels, the DWTC is larger than the EITC, thereby achieving a higher wage

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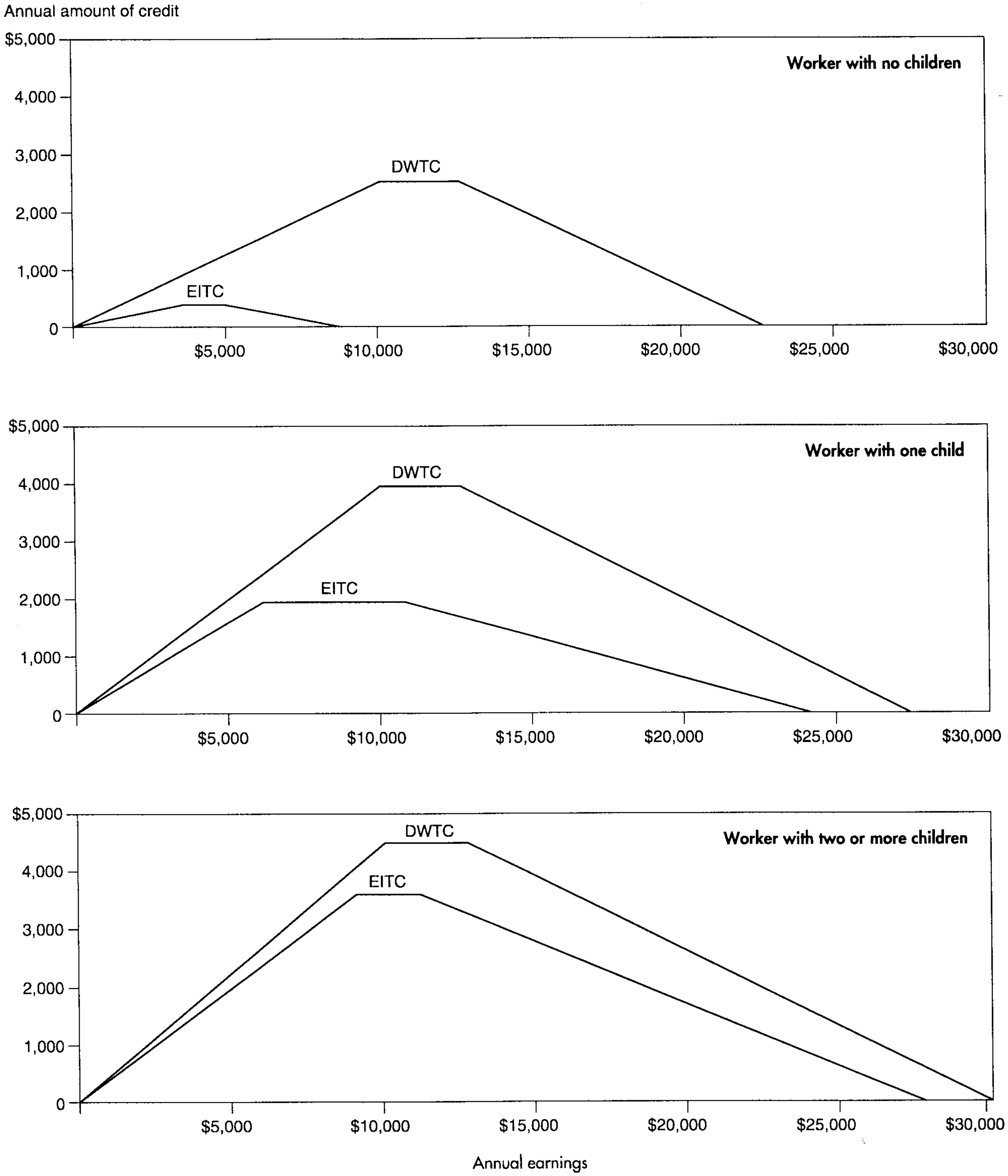
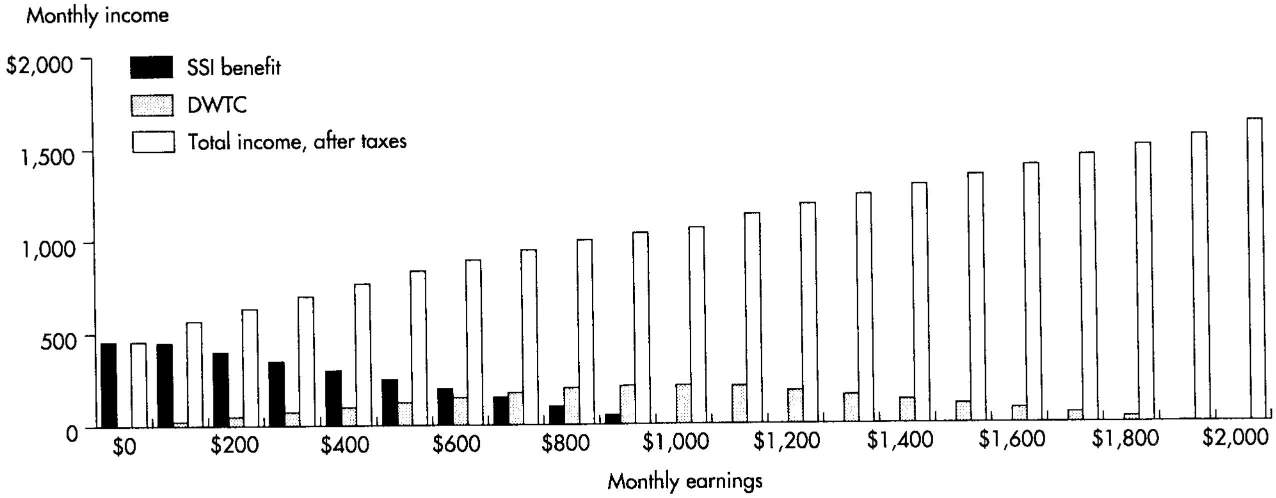
[13] This figure is based on 1995 federal income tax rules.

Figure 7-1. Comparisons of Illustrative DWTC and 1996 EITC



Abbreviations: DWTC = disabled worker tax credit, EITC = earned income tax credit.

Figure 7-2. Income of an SSI Recipient as Earnings Rise



Note: The figure reflects 1995 federal income tax rules, the 1995 SSI benefit of $458 per month and the no-child DWTC. The parameters for the DWTC are in table 7-1.
Abbreviations: SSI = Supplemental Security Income, DWTC = disabled worker tax credit.

subsidy for workers with disabilities than for other workers of similar family size (goal 1).

- In each case, the phase-in rate is more generous than the EITC, thereby creating additional work incentives for workers with very low earnings (goal 2).

- The plateau range — from $10,000 to $13,000 — applies to workers of all family sizes and is coordinated with the work incentive features of DI and SSI (goal 3).

- The phase-out rate of 25 percent for all workers with disabilities is set as low as possible to minimize work disincentives in the phase-out range, and yet avoid paying the DWTC to workers with more than modest incomes as a way to minimize costs (goals 4 and 5).

Comparing the Maximum DWTC with the EITC

In this proposal, the maximum credit varies by family size, with the greatest increase over the existing EITC going to low-income childless workers with disabilities because they are eligible for only a very small credit from the EITC.

- For workers without qualifying children, the maximum DWTC is $2,500 annually, nearly $2,200 more than the maximum EITC for childless workers. The EITC is based on the 1996 EITC rules established by the Omnibus Budget Reconciliation Act of 1993.[14]

- For workers with one child, the maximum DWTC is $3,800, about $1,900 more than the maximum EITC.

- For workers with two or more children, the maximum DWTC is $4,500, about $940 more than the maximum EITC.

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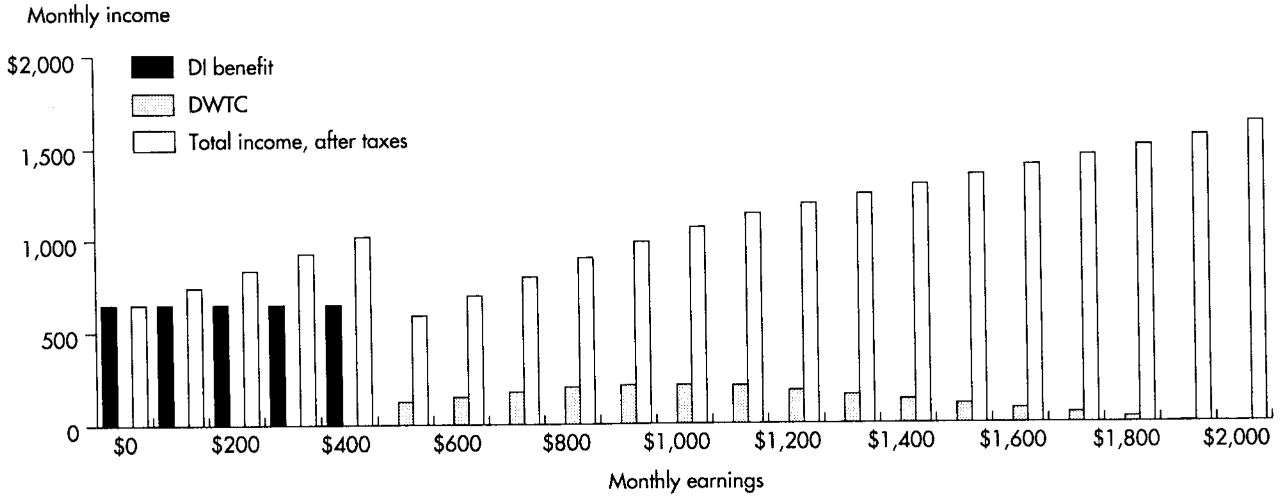
[14] At the time this report was prepared, legislation was under consideration in Congress to revise the 1996 rules.

Figure 7-3. Income of a DI Beneficiary as Earnings Rise



Note: The figure reflects 1995 federal income tax rules, a DI benefit of $650 per month and the no-child DWTC.
The parameters for the DWTC are in table 7-1.
Abbreviations: DI = Social Security disability insurance, DWTC = disabled worker tax credit.

The Fit With SSI and DI Work Incentives

Figure 7-2 illustrates how the income of a single SSI recipient with no children would be affected as his or her earnings rise.[15] The DWTC initially serves to reduce the marginal tax rate, as the 50-percent reduction in SSI benefits is offset by the credit phase-in rate of 25 percent. During the phase-in range, the individual's marginal tax rate is 32.65 percent (the 50-percent reduction in SSI benefits plus the 7.65 percent FICA tax offset by the 25-percent DWTC). The marginal tax rate climbs to 47.65 percent when the federal income tax comes into effect at about $534 of monthly earnings ($6,400 annually). When SSI benefits are fully phased out at $1,001 of monthly earnings ($12,012 annually), the marginal tax rate drops by 25 percentage points until the DWTC begins to phase out at $13,000 of earnings.[16]

Figure 7-3 illustrates how the income of a DI beneficiary with a benefit of $650 would be affected by the DWTC as earnings rise. The beneficiary retains full benefits as long as earnings remain below substantial gainful activity (SGA).[17] Once earnings rise above SGA, benefits stop (after the nine-month trial work period). The credit softens the impact of the loss of DI benefits by supplementing earnings at this point.[18]

Estimated Benefits and Cost

The estimated costs and benefits of the illustrative DWTC proposal are for 1996 and, unless otherwise noted, represent the increased tax credits and cost of the DWTC, over and above any EITC that workers might receive.[19] The estimates assume no changes in behavior as a result of the new DWTC, although it is expected that the DWTC will influence the work

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[15] The illustrations use 1995 federal income tax and SSI benefit amounts.

[16] To illustrate how DI and SSI work incentives interact with the DWTC, if the $85 monthly SSI disregard were eliminated, as some have suggested, the earnings level at which the marginal tax rate falls by 25 points would be $10,992.

[17] The illustration assumes SGA is at its current level of $500 per month.

[18] The size of this income loss or "notch" as earnings rise above SGA varies according to the size of the DI benefit.

[19] The estimates are based on the 1996 EITC rules established by the Omnibus Budget Reconciliation Act of 1993.

Box 7-1. What Effect Would the DWTC Have on the Work Effort of Workers with Disabilities?

The estimate of a $3 billion annual cost of the disabled worker tax credit (DWTC) contained in this report is based on an assumption of no change in work effort -- either hours worked or participation in the labor force. To estimate the change in work effort requires complex modeling techniques that we did not discuss here. Thus the cost estimated here reflects no offsetting reduction from increases in tax revenues and decreases in program expenditures for persons who increase their work in response to the subsidy offered by the DWTC; nor is the cost increased by reductions in tax revenues and increases in benefit expenditures for persons who decrease their work effort in response to the additional income provided by the credit.

Economic theory suggests that an earned income tax credit (EITC) or DWTC is likely to have different incentive effects on work effort in each of its three earnings ranges: the phase-in range, the plateau range and the phase-out range. In the phase-in range, the effect of the credit is thought to be positive: it encourages additional work. In the plateau and phase-out ranges, it is expected to be negative and to discourage work, with the negative effects being the strongest in the phase-out range.

Economic studies have looked at the effects of increases in the EITC on work effort among those already in the labor force. Because the majority of EITC recipients have earnings in the plateau or phase-out range of the credit (where the credit exerts a negative influence on additional hours of work), estimates of the impact of the credit show a negative (albeit small) overall effect on hours worked.[a]

In contrast, another study estimated the increased labor supply of those not working prior to expansion of the EITC (who are drawn into the work force by the EITC) as well as the effect on current workers.[b] While that study, too, finds that the wage subsidy's effect on current workers is negative, its overall effect is positive when new workers are included.

No studies have been done on whether people with disabilities are more or less likely than the general population to enter the work force in response to a wage subsidy. They are, however, much more likely to be out of the work force. A DWTC that applies only to persons with disabilities is intended to encourage disabled workers to enter the labor force (the incentive effect of the DWTC is strongest when earnings start at zero) as an alternative to benefit receipt; and to prevent or forestall exit from the labor force for those whose earnings are very low, such as might be in the phase-in range, where the incentive is strongest.

a. M. Kosters, "The Earned Income Tax Credit and the Working Poor," *American Enterprise*, May/June 1993, pp. 65-72; J. Holtzblatt, et al., "Promoting Work Through the EITC," *National Tax Journal*, September 1994, pp. 591-607.

b. S. Dickert, et al., "The Earned Income Tax Credit and Transfer Programs: A Study of Labor Market and Program Participation," unpublished paper presented at a conference sponsored by the National Bureau of Economic Research, Washington, DC, November 1994.

Abbreviations: DWTC=disabled worker tax credit, EITC=earned income tax credit.

effort of people with disabilities (box 7-1). The result of the simulations are summarized below and in tables 7-2 and 7-3.

- About 3.1 million low-income working people with disabilities would receive the DWTC, at a total cost of about $3 billion in 1996. The average wage subsidy from the DWTC is about $1,000 a year (over any subsidy the individual might receive from the EITC).
- Workers without children are the most likely to gain from the DWTC. They account for about 2.1 million of those who receive the DWTC and about $2.3 billion of the total DWTC paid. Their average wage subsidy from the DWTC is about $1,100. The targeting of individuals without qualifying children is intended because they receive very little from the current EITC. The EITC for workers without qualifying children is a maximum of just $306 and is

payable only to those ages 25 to 64.

- The DWTC would also benefit about 983,000 low-income workers with disabilities who have children. Their average wage subsidy based on the DWTC is about $750 per year.
- Most who would benefit from the DWTC are not receiving Social Security, SSI or other payments based on their disability, such as workers' compensation; federal, state or local government employee disability; or company or union disability. About 3 in 4 are not receiving any disability-based income. As such, the DWTC holds potential for encouraging and assisting low-income workers with disabilities to remain at work and not turn to disability income support.
- Young workers account for the majority of those who would receive the DWTC. About 2 in 3 of those who would receive the DWTC are under age 45. To the extent that the DWTC encourages and enables them to remain in the work force and add to their human capital through on-the-job experience, it holds potential for enhancing their independence and self-sufficiency over the long run.
- The youngest workers — those ages 18 to 24 — account for about 1 in 6 of those who would gain a wage subsidy from the DWTC. Workers in this age group are not eligible for the current EITC unless they have children.[20]

The benefits of the DWTC are targeted on low-income workers. The target efficiency of the DWTC is shown by comparing the recipients' income before the DWTC to the official poverty

Table 7-2. Distribution of DWTC Recipients and Total DWTC Benefits, 1996

	Recipients (thousands)	Total DWTC benefits (millions)
Total	**3,088**	**3,053**
Disabled workers — family status		
No children	2,133	2,321
One child	474	418
Two or more children	509	315
Percent distribution — age		
Total percent	**100**	**100**
18-24	17	19
25-34	27	26
35-44	22	22
45-54	16	16
55-64	19	17
Percent distribution — receipt of other benefits		
Percent receiving:[a]		
SSI	18	15
DI	10	8
Veterans' disability	2	2
Other disability income[b]	9	10
None	74	78

a. Percentages do not add to 100 because some individuals receive benefits from more than one program.

b. Other disability income includes: workers' compensation, company or union disability, federal government disability, U.S. Military Retirement Disability, U.S. Railroad Retirement disability, state or local government employee disability, and accident or disability insurance.

Abbreviations: DI = Social Security disability insurance, DWTC = disabled worker tax credit, SSI = Supplemental Security Income.

Source: Estimates prepared by R.V. Burkhauser and D. Wittenburg, Syracuse University, Syracuse, NY. See the technical note at the end of this chapter.

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[20] The current modest EITC for childless workers is not available to those under the age 25 on the theory that low-earning individuals in this age group include college students or others who are not genuinely at risk of long-term economic disadvantage. The DWTC targets only those in this age group who have significant disabilities and, therefore, are at considerable risk of long-term economic disadvantage.

Table 7-3. Distribution of DWTC Recipients and Payments by Ratio of Income to Poverty Threshold, 1996

	DWTC recipients (thousands)		DWTC payments (millions)	
Ration of income to poverty threshold[a]	Family unit	Tax unit	Family unit	Tax unit
Total	**3,088**	**3,088**	**$3,053**	**$3,053**
Total percent	**100**	**100**	**100**	**100**
Less than 1.0	24	34	14	18
1.00 - 1.49	17	19	20	26
1.50 - 1.99	17	20	22	27
2.00 - 2.99	23	21	24	23
3.00 or more	18	6	21	6

a. This is known as the income-to-needs ratio. The "family unit" incomes-to-needs ratio is based on the total income of the family in which the disabled worker resides. The income-to-needs ratio is the ratio of the family's income divided by the family's size adjusted poverty line. The "tax unit" income-to-needs ratio is based on the income of the tax filing unit rather than the total income of the family unit in which the worker resides.
Abbreviation: DWTC = disabled worker tax credit.
Source: R.V. Burkhauser and D. Wittenburg. See the technical note at the end of this chapter.

threshold (table 7-3). Nearly 1 in 4 workers with disabilities who would receive the DWTC have family incomes below the poverty threshold for a family of their size. Nearly 6 in 10 have incomes below twice the poverty threshold.

The DWTC is even more targeted on low-income persons when only the income of the tax filing unit is considered, rather than the total income of the family where the worker resides.[21] Some workers with disabilities, particularly young workers without children, live in families with additional earners even though these earners are not included as part of their tax filing unit. For example, young adults with disabilities may be living with their parents but qualify as an individual tax filing unit. Using tax unit income as the measure of economic status, about 1 in 3 workers who would receive the DWTC have incomes below the poverty threshold. Nearly 3 in 4 had tax unit incomes below twice the poverty threshold.

CONCLUSION

The DWTC recognizes that work disability is a continuum. The DI and SSI programs target those with the most severe work disabilities, and the benefits are designed as wage replacements for those who cannot work. The DWTC complements existing cash benefit programs by targeting those who have significant work impediments but, nevertheless, have some residual work capacity. The DWTC provides income support to low-income workers with disabilities in a way that subsidizes work and, thereby, encourages them to remain in the work force. The DWTC is superior to other options for providing income support to persons with partial disabilities.

Those helped by the DWTC include young people with disabilities, who are helped in making the transition from school to work, as well as older workers whose reliance on DI benefits may be

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[21] In these simulations, family income includes the incomes of all related people living in the household. Tax-filing unit income would determine eligibility and the amount of the DWTC. In these data, a tax-filing unit consists of married couples or single individuals plus their minor children. An unmarried adult who lives with adult relatives is considered a single individual as a tax-filing unit.

postponed or avoided through increased work subsidies. The DWTC also eases the transition off the benefit rolls for DI and SSI beneficiaries who have the capacity to do so. Low-income workers who do not qualify for DI or SSI benefits but nevertheless have significant work disabilities also receive a wage subsidy from the DWTC.

The Panel has provided an illustrative proposal for the specific design of the DWTC. The proposed eligibility criteria are designed with administrative feasibility in mind and target individuals whose disabilities pose a significant impediment to employment. The parameters for the size and shape of the DWTC are designed to address the special work impediments faced by many people with disabilities, to target those with modest incomes and to coordinate well with the DI and SSI work incentives. The design of the DWTC could take other forms, and the program rules that are chosen will affect the cost, distribution of benefits, work incentives and administrative issues associated with the credit.

TECHNICAL NOTE

Estimates of the impact of the DWTC that are shown in tables 7-2 and 7-3 were prepared by Richard V. Burkhauser and David Wittenburg of Syracuse University. Data from the 1990 Current Population Survey (CPS) were used to estimate the size of the eligible population with disabilities. That population is defined as those who provided any of the following responses to questions in the CPS:

1. "Yes" to "Do you have a health problem or disability which prevents you from working or which limits the kind or amount of work you can do?"
2. The main reason for not working last year is "ill or disabled."
3. The current activity/reason for not looking for work is "ill or disabled."
4. "Unable to work" was the activity most of last week and responds "no" to "Did you have a job or business from which you were temporarily absent or on layoff last week?"
5. "Own illness" is the reason for working less than 35 hours per week last year.
6. Receipt of any of the following: DI or SSI disability benefits, Railroad Retirement disability, company or union disability, accident or disability insurance, or state or local government disability.

While this definition is not identical to that of the Panel's proposal, it is conceptually similar and provides a basis for estimating the impact of the proposal.

To estimate the cost of the DWTC in 1996, income and earnings from the 1990 CPS were adjusted by the actual increases in the Consumer Price Index through 1993 and by 3 percent thereafter. The estimates assume no demographic changes, such as changes in population size, health and disability status, family size and so forth. In addition, they assume no changes in behavior as a result of the new DWTC, although it is expected that the DWTC will influence the work effort of people with disabilities.

Chapter 8

The Vital Role of Health Care and Personal Assistance Services

Health care is important to all Americans. It is particularly important for people with chronic health conditions or disabilities because many are at risk of very high health care costs; they often cannot obtain coverage in the private insurance market; and insurance coverage, when available, often does not cover the range of services and long-term supports that they need in order to live independently.

The United States is unique among industrialized nations of the world in its lack of universal protection against health care costs for all citizens. The Disability Policy Panel's interim report, *The Environment of Disability Income Policy: Programs, People, History and Context,* emphasized that comprehensive health care reform would be a major step forward for people with disabilities. We recognize that today, universal health care is a more elusive goal than it appeared to be when the interim report was issued in March 1994. Nonetheless, those findings remain valid today:

> Universal protection against health care costs would be a major breakthrough in national policy with regard to disability income and work. Such a guarantee of necessary health care — independent of work, disability, health or cash benefit status — would be a significant gain in:
>
> - enabling persons with disabilities to maximize their independence by remaining in or returning to the paid work force as well as participating in other productive activities;
> - fostering cash benefit policies that provide a decent level of living to those who are unable to work, while encouraging work among persons with disabilities who have the capacity to do so;
> - fostering early intervention to prevent diseases or impairments from becoming permanent work disabilities; and
> - improving access to uniform health care information, which would also improve the decision-making process for cash disability programs.

Certain health-related benefits are particularly important for persons with disabilities, including children. In addition to hospital and medical care, they include prescription drugs, durable medical equipment, personal assistance services and devices and rehabilitation services for congenital or chronic conditions, including mental illness.

In its final report, the Panel makes two specific recommendations for incremental reforms in Medicare and personal assistance services: an improved Medicare buy-in for Social Security disability insurance (DI) beneficiaries who return to work and a tax credit for personal assistance services to compensate working people for part of the cost of the services they need in order to work. The Panel also endorses the efforts of states to create affordable buy-ins to their Medicaid programs for working people with disabilities.

Figure 8-1. Health Care Utilization in Working-Age Population by Work Limitations, 1987

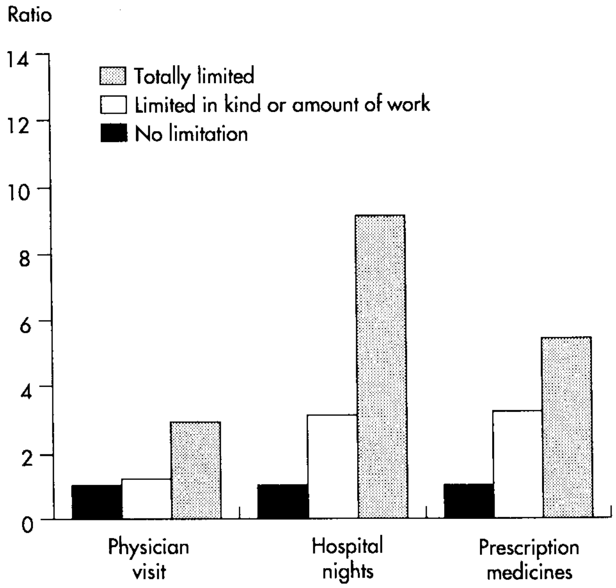


Figure 8-2. Health Care Expenditures in Working-Age Population by Work Limitations, 1987

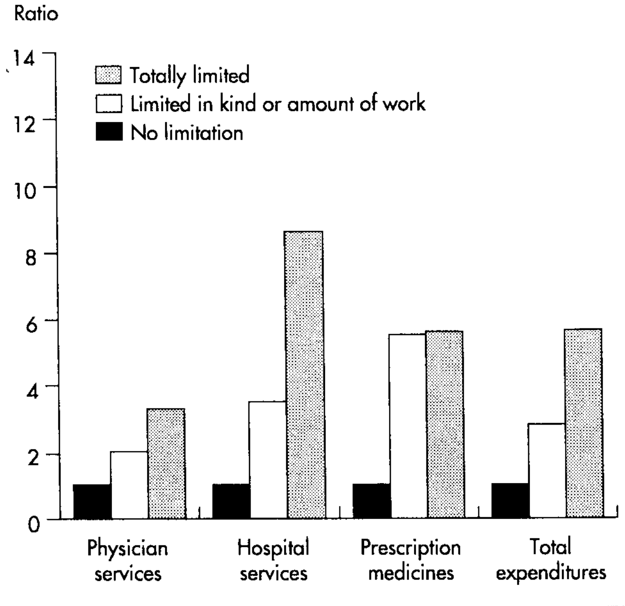


Figure 8-3. Health Care Utilization in Working-Age Population by ADL Limitations, 1987

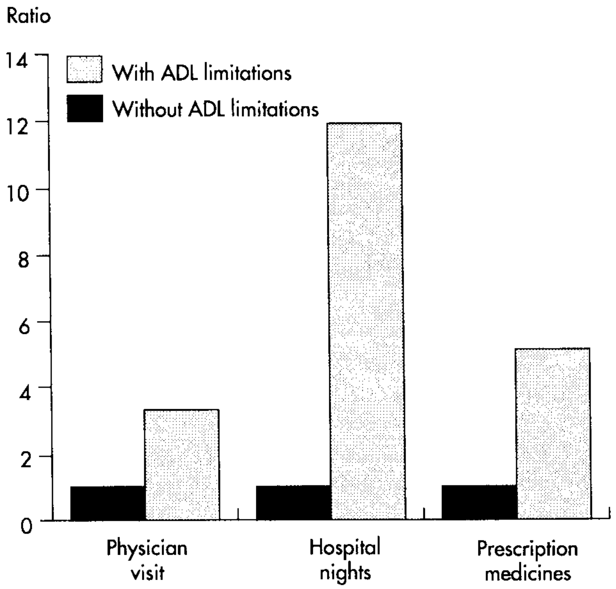
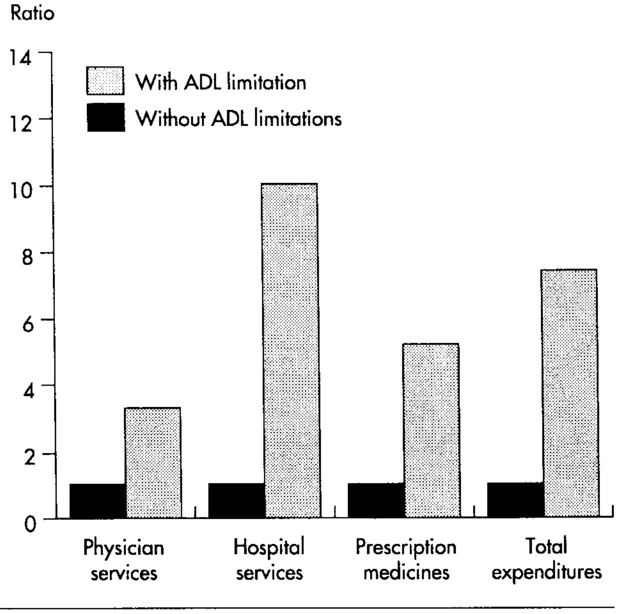


Figure 8-4. Health Care Expenditures in Working-Age Population by ADL Limitations, 1987



Abbreviations: ADL = activities of daily living.
Source: National Rehabilitation Hospital - Research Center. Data are from the National Medical Expenditure Survey, 1987.

The Panel recognizes that these are piecemeal solutions to a much broader problem. Its proposals are limited both in scope and cost, and derive from the Panel's charge to improve incentives to return to work for persons who may now rely on cash benefit programs for support. The proposals offered have in common that they make health care — both acute care and long-term services and supports — more affordable for working people with disabilities. The broader challenge, to control health care costs and expand access to needed care, remains.

The chapter begins by outlining the nature of the problem posed by the incomplete health care financing system for people with disabilities. It then reviews the importance of Medicare for Social Security disability beneficiaries and the Panel's proposal for improving the terms under which former beneficiaries can purchase continued Medicare coverage when they work. The third section presents our proposal for a tax credit to compensate for part of the cost of personal assistance services that persons with disabilities need in order to work. The fourth section reviews the importance of Medicaid for persons with disabilities and briefly reviews two state plans that offer working people with disabilities options to buy Medicaid-type coverage.

THE NATURE OF THE PROBLEM

The principal methods of insuring individuals against the cost of health care are employer-sponsored health insurance for a majority (but not all) of the working population and public programs — Medicare and Medicaid — for some others. Some individuals, though not a large number, purchase health insurance individually. Each of these three systems are important sources of health care coverage for persons with disabilities. But each has gaps, and taken together, they constitute an incomplete system of health care financing for persons with disabilities who seek to enter or reenter the work force. Gaps in health care coverage are a particular problem for persons with disabilities because of their increased risk of high health care costs.

Risk of High Health Care Costs

National survey data indicate that working-age people with disabilities use disproportionately far more health care than do their counterparts without disabilities. Figures 8-1 through 8-4 show the use of health care services and health care expenditures among working-age people with disabilities relative to their nondisabled counterparts as reported in the 1987 National Medical Expenditure Survey, the most in-depth health care utilization survey of the last decade.

The 9.0 million working-age people who indicate they are "totally limited" because of a health condition[1] incur, on average, 5.6 times the health care costs of their nondisabled counterparts (figure 8-1). Persons with one or more limitations in activities of daily living (ADL), a fairly restrictive definition of disability, experience almost 12 times the amount of hospitalization of their nondisabled peers in any one year (figure 8-3). Overall, people with ADL limitations incur 7.4 times the health care costs of their nondisabled counterparts (figure 8-4).

These data indicate that working-age people with disabilities face a considerable financial risk compared to their nondisabled counterparts because of their health care needs.

Protection Against These Costs is Incomplete

People with disabilities, almost by definition, have "pre-existing conditions" that make them unattractive risks in a private, market-driven system of financing health insurance that competes on price and risk. Consequently, they often cannot purchase insurance individually. For those who work, their employer may not offer health insurance coverage, or the plan may exclude the individual's preexisting condition or not offer the types of services needed.

Medicare and Medicaid target people who have been found unable to work. This targeting would not be

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[1] Persons are deemed "totally limited" if they have a health condition that precludes their participation in work, household work or school.

so problematic if private coverage were available to all who work, but it is not. Moreover, the public programs themselves are incomplete.

Medicare is, in a sense, a substitute for private, employment-based insurance for workers who sustain illness or impairments that render them unable to work. Medicare provides important coverage of medical, hospital and post-hospital care to former workers who receive Social Security disability benefits. However, there are gaps in its coverage. It does not cover disabled workers during the first 29 months after the onset of their disabling conditions.[2] It does not cover prescription drugs and it has large co-payments for most outpatient mental health services. Finally, it does not cover ongoing health-related supports and services that some disabled individuals need in order to live independently.

Medicaid is the program of last resort to finance health care for the nation's poor, including some individuals with disabilities. For persons with disabilities, it fulfills two different roles. First, it covers basic preventive and acute care for low-income persons who do not have private insurance or Medicare. Second, and critically important for some individuals with disabilities, it covers ongoing supports or long-term services that neither private insurance nor Medicare cover, such as personal assistance services, psychosocial rehabilitation services, day treatment and case management for persons with severe mental illness or developmental disabilities, and other long-term care in institutions or community-based alternatives. The incompleteness of Medicaid coverage arises from the gaps in the benefit packages offered in different states (which are allowed to determine which services to cover within broad federal guidelines), and in its targeting, generally, only to those with very low incomes and little or no financial assets.

Long-Term Care. Some people with disabilities need long-term care services in order to work or to live independently. Coverage for long-term institutional or community-based care and ongoing health-related supports and services exists largely in the public, means-tested program — Medicaid. It is not widely available, or purchased, in the private health insurance market. It can be very expensive when it is needed. And it is not included in Medicare. Hence, those who need long-term care services turn to Medicaid. But Medicaid is generally available only to those found unable to work, poor and without savings.

This system of financing long-term care is based on a model in which long-term care was provided largely in institutions rather than in the community, and for people who were not expected to be able to work or lead independent lives, or even to live very long. It is a model ill-suited to younger people with full lives ahead of them and who, if they received those services, could function in the community and in some cases earn a living.

A better system of rationing the public subsidy of long-term care for people who live in the community might be based on two kinds of criteria[3]:

- An assessment of functional need for long-term care services. An assessment of work disability, which is often the basis for Medicaid coverage for working-age individuals with disabilities, is neither necessary nor sufficient to target eligibility for coverage of long-term care services; and

- Cost sharing related to ability to pay. If costly services are made available to those who are not poor, there should be a reasonable contribution from the individual who receives the services. Under the present system of financing such

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[2] When Medicare was extended to Social Security disability beneficiaries in 1972, the 24-month waiting period was adopted to limit the cost of the extension. The Health Care Financing Administration several years ago estimated that the net increase in Medicare and Medicaid expenditures from eliminating the 24-month waiting period would be $9 billion in 1996. That cost reflects a $13 billion increase in Medicare and a $4 billion reduction in Medicaid costs for Social Security disability beneficiaries. Eliminating the waiting period would fill an important gap in health care coverage. It also would create pressures for uninsured workers with high health care costs to establish eligibility for DI in order to get immediate access to Medicare coverage.

[3] While the Panel believes these are appropriate concepts for allocating long-term care services, it recognizes that many complex issues are involved in operationalizing them.

services, they are virtually free if one is eligible for Medicaid and nearly unattainable if one is not.

Effects on Employment

The current structure and gaps in health care coverage for people with disabilities can limit their labor market options in several ways. First, on the demand side of the labor market, employers, despite the Americans with Disabilities Act of 1990, may be reluctant to hire persons who are at risk of high health care costs if they would be covered under the employer's plan. Second, on the supply side of the labor market, if persons with disabilities cannot get private insurance, work may not be an economically attractive option. Fear of losing Medicaid or Medicare coverage is often cited as a reason why some persons with disabilities work less than they would if secure health care coverage were available. Finally, gaps in health care coverage can result in unnecessary losses in employment when uninsured people fail to get the care they need in order to treat, cure or ameliorate the disabling consequences of their conditions.

Health Insurance Coverage of People with Disabilities

Persons with work disabilities rely on all three sources of coverage — private, employer-sponsored coverage, Medicare and Medicaid — but are more likely to be covered by Medicare or Medicaid than nondisabled persons. As a group, persons with disabilities are no more likely than nondisabled persons to be without insurance. But, as noted, on average they have a higher risk of incurring large health care costs. And the insurance they have may be inadequate.

Having a work disability reduces the likelihood of having employer-sponsored insurance. Nonetheless, in 1993, employment-based insurance covered about one-third of persons who reported having a health condition that limited their ability to work. Of those who were working, about half had employment-based insurance, as did about one-fourth of people with disabilities who were not working. They may have received their employment-based insurance from a family member's job (table 8-1). Part-time workers are more likely than full-time workers to be without insurance from either their jobs or from public programs. For those with disabilities, part-time work may be either a "step down" from full-time employment or a "step up" from being out of the work force.

Trends in Health Coverage

In recent years, health insurance coverage has declined and the number of uninsured has grown for the entire nonelderly population and for working-aged adults who have work disabilities.

Private, employment-based coverage is an employee benefit that is voluntarily offered by employers to their employees, or it can be the result of union negotiations. As the unionized share of the work force has declined, so has employee bargaining power for fringe benefits such as health care. And as health care costs have risen, and employers are under competitive pressure to lower their cost of doing business, coverage under employment-based insurance has declined. Employers who offer health insurance coverage are introducing ways to control their liability for these costs, by using managed care; requiring more employee contributions for premiums or higher employee cost sharing when services are used; limiting benefit packages for certain specialized services, such as for mental illness; and adopting insurance contracts that have pre-existing condition exclusion clauses.

Trends for the Total Nonelderly Population. In recent years, employer-sponsored coverage has declined and Medicaid coverage has increased. Between 1988 and 1993, the proportion of the total nonelderly population that is covered by employment-based health insurance declined from 67 to 61 percent, while the number of persons without health insurance from any source rose from 34 million to 41 million, or by roughly 1 million per year (table 8-2).[4]

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[4] Part of the numerical increase is due to recallibrating the estimates to the 1990 Census, which in the 1992 Current Population Survey increased the estimate of the nonelderly population by 3.0 million and increased the estimate of the noninsured by 1.4 million.

Table 8-1. Health Insurance Coverage by Work Disability Status for Persons Ages 18 to 64, 1993

	Total ages 18-64		Percent by source of health insurance[a]					
					Public programs			
	Number (millions)	Percent	Employer sponsored	Other private	Medicaid (total)	Other public[b]	Not insured	Not insured (millions)
			Limited in kind or amount of work					
Total	**16.5**	**100.0**	**34.1**	**9.7**	**32.4**	**19.2**	**17.4**	**2.9**
Not employed	10.2	100.0	23.2	9.3	41.0	23.1	16.4	1.7
Employed	6.3	100.0	51.7	10.3	18.4	12.9	19.0	1.2
Full-year, full-time	2.3	100.0	71.3	6.1	9.1	15.0	14.8	0.3
Other[c]	4.0	100.0	40.5	12.5	23.5	11.9	21.5	0.9
			Not limited					
Total	**141.0**	**100.0**	**65.6**	**10.4**	**5.0**	**2.2**	**19.1**	**26.9**
Not employed	20.3	100.0	41.8	14.8	16.7	2.8	26.7	5.4
Employed	120.7	100.0	69.6	9.7	3.0	2.1	17.8	21.5
Full-year, full-time	78.5	100.0	78.6	7.1	1.0	1.8	13.3	10.5
Other[c]	42.2	100.0	52.8	14.5	6.6	2.7	26.1	11.0

a. Percentages may add to more than 100 because individuals may be eligible for more than one type of coverage.
b. Persons with Medicare or CHAMPUS coverage, but not Medicaid.
c. Other includes seasonal and part-time employment.
Abbreviation: CHAMPUS = Civilian Health and Medical Program of the Uniformed Services.
Source: Employee Benefit Research Institute, memorandum, November 14, 1995 (tabulations based U.S. Bureau of the Census, Current Population Survey, 1990 and 1994).

Working adults experienced a decline in employment-based coverage from 73 percent in 1988 to 69 percent in 1993, with very little offsetting increase in public coverage. This left 23 million working adults without health insurance in 1993. Nonworking adults, who may get employment-based insurance through their spouses' jobs, also experienced a decline in that coverage, from 44 to 36 percent. Partly offsetting that trend was an increase in the proportion of nonworkers covered by Medicaid from 20 to 25 percent.

Among children, the proportion with insurance through their parents' employment declined from 65 to 57 percent. That decline was partly offset by congressionally-authorized expansions of Medicaid coverage.[5] But while the proportion of children covered by Medicaid rose from 16 to 24 percent, the number of uninsured children grew from under 10 million in 1988 to 11 million in 1993.

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[5] Beginning with the Deficit Reduction Act of 1984, Congress moved to expand Medicaid eligibility to increasing numbers of pregnant women and children. These expansions often began by making coverage of the designated population optional, with the following year's bill making the coverage mandatory. The changes expanded Medicaid beyond the traditional Aid to Families with Dependent Children (AFDC) population to persons with somewhat higher incomes (though still very modest). The most recent expansion, in the Omnibus Budget Reconciliation Act of 1990, required states to phase-in coverage of all children under age 19 whose family incomes are under 100 percent of the poverty level.

Table 8-2. Health Insurance Status of the Nonelderly Population, 1988-93

	Total population under age 65		Percent by source of health insurance[a]					Number not insured (millions)
	Number	Percent	Employment based	Other private	Medicaid	Other public	Not insured	
All children and adults under age 65								
1993	226.2	100.0	60.8	9.2	12.8	3.3	18.1	40.9
1992[b]	223.8	100.0	62.0	8.5	11.8	3.5	17.8	39.8
1992[c]	220.8	100.0	62.5	8.5	11.6	3.5	17.4	38.4
1991	218.1	100.0	64.1	8.2	11.0	3.5	16.6	36.2
1990	215.9	100.0	64.2	9.1	10.0	3.5	16.6	35.8
1989	213.7	100.0	65.9	9.2	8.7	3.5	16.1	34.4
1988	211.8	100.0	66.8	8.4	8.6	3.8	15.9	33.7
Children								
1993	68.8	100.0	57.2	6.5	24.2	1.5	16.2	11.1
1988	62.8	100.0	64.8	5.9	15.8	2.0	15.3	9.6
Working adults								
1993	127.0	100.0	68.8	9.7	3.7	2.7	19.9	22.7
1988	121.6	100.0	73.0	8.9	2.4	3.0	15.2	18.5
Nonworking adults								
1993	30.4	100.0	35.7	13.0	24.9	9.6	23.2	7.1
1988	27.5	100.0	43.7	12.0	19.7	11.3	20.0	5.5

a. Other sources of public health insurance include Medicare; CHAMPUS (Civilian Health and Medical Program of the Uniformed Services, which covers dependents of active duty and retired members of the armed forces); and CHAMPVA (Civilian Health and Medical Program of the U.S. Department of Veterans Affairs, which covers dependents of totally disabled veterans).

b. Revised — weight based on the 1990 census, consistent with more recent data.

c. Weight based on the 1980 census, consistent with prior data.

Source: Employee Benefit Research Institute, "Sources of Health Insurance and Characteristics of the Uninsured: Analysis of the March 1994 Current Population Survey," *EBRI Issue Brief*, No. 158, February 1995, p. 7.

The lack of health insurance coverage is particularly common among young adults, where fully 23 percent of those age 18 to 20 were without insurance. In this age group, most who had employment-based insurance received it through a parent's employment. That coverage typically ends by age 21. Among persons age 21 to 24, fully one-third are without any form of health insurance.[6] These rates are for the total population of young adults, most of whom are in good health. Nonetheless, the lack of insurance is a serious problem for those who become ill or injured or have chronic conditions that began in childhood.

Trends for Persons with Disabilities. As is true for the total nonelderly population, persons with work disabilities show a decline in employer-sponsored insurance and an increase in Medicaid coverage between 1989 and 1993, while Medicare coverage remained fairly constant. The net result is an increase in the number of working-age persons with work limitations who are uninsured from 2.3 million to 2.9 million (table 8-3).

MEDICARE

Social Security disability beneficiaries — disabled workers, disabled adult children and disabled widows — are eligible for Medicare coverage after a 24-month waiting period, or 29 months after the onset of their work disability. Today, disability beneficiaries represent 10 percent of persons covered and 11 percent of benefits paid by Medicare, or about $18.3 billion in 1994.[7] Elderly persons account for the rest.

In general, the Medicare benefit package covers acute care services in hospitals, care in skilled nursing facilities following a hospital stay and outpatient services by physicians or other approved practitioners. It does not cover outpatient prescription drugs and generally does not cover long-term care services — such as in nursing homes or community-based alternatives to institutional care. Medicare consists of two parts that are financed separately:

- Hospital Insurance (HI), which covers inpatient hospital care, skilled nursing care, home health and hospice care, is financed by the HI portion of the Federal Insurance Contributions Act (FICA) tax that also pays for Social Security. Of the 7.65 percent FICA tax that employees and employers each pay, 1.45 percent goes to finance HI.[8] Medicare beneficiaries who are insured for Social Security benefits contributed to the cost of HI through the FICA tax while they were working. They are not charged a premium for HI coverage when they receive it.

- Supplementary Medical Insurance (SMI) covers services of physicians and other Medicare-approved practitioners, as well as diagnostic tests and other medical items. SMI coverage is voluntary and beneficiaries pay a premium for it which is deducted from their monthly Social Security benefits. The 1995 premium was $46.10 per month and covered 31.5 percent of program costs, with the rest financed from general revenues of the federal government.[9]

In 1994, about 4.1 million disabled persons under 65 were enrolled in HI and 3.7 million were enrolled in SMI.[10]

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[6] Employee Benefit Research Institute, "Sources of Health Insurance and Characteristics of the Uninsured, Analysis of the March 1993 Current Population Survey," *Special Report and Issue Brief*, No. 145, January 1994, table 24.

[7] Social Security Administration, *Annual Statistical Supplement to the Social Security Bulletin* (Washington, DC: U.S. Government Printing Office, August 1995), tables 8.B6 and 8.B9, pp. 329 and 333.

[8] The 1.45-percent tax for HI is paid on total earnings. The 6.2-percent share for Social Security is paid on earnings up to the taxable maximum, which was $61,200 in 1995.

[9] The Omnibus Budget Reconciliation Act (OBRA) of 1990 set statutory amounts for the SMI premium through 1995, and these amounts were designed to cover 25 percent of program costs. Currently, the statutory premium covers a slightly larger percent of program costs. OBRA of 1993 extended the provision requiring that SMI premiums cover 25 percent of program costs through 1996, 1997 and 1998. Social Security Administration, *Annual Statistical Supplement to the Social Security Bulletin* (Washington, DC: U.S. Government Printing Office, August 1994), p. 87.

[10] Social Security Administration, op. cit., footnote 7, table 8.B5, p. 328.

Table 8-3. Health Insurance Coverage for Those with a Work Limitation for Persons Ages 18 to 64, 1989 and 1993

	Total ages 18-64		Percent by source of health insurance[a]					
					Public programs			
	Number (millions)	Percent	Employer sponsored	Other private	Medicaid (total)	Other public[b]	Not insured	Number Not insured (millions)
Total								
1993	16.5	100.0	34.1	9.7	32.4	19.2	17.4	2.9
1989	13.8	100.0	39.1	10.4	25.4	22.0	16.8	2.3
Not employed								
1993	10.2	100.0	23.2	9.3	41.0	23.1	16.4	1.7
1989	8.0	100.0	26.6	10.4	34.6	27.9	15.9	1.3
Employed — total								
1993	6.3	100.0	51.7	10.3	18.4	12.9	19.0	1.2
1989	5.8	100.0	56.4	10.3	12.6	14.0	18.1	1.0
Full-year, full-time employed								
1993	2.3	100.0	71.3	6.1	9.1	15.0	14.8	0.3
1989	2.1	100.0	73.8	7.1	5.7	16.2	11.0	0.2
Other employed								
1993	4.0	100.0	40.5	12.5	23.5	11.9	21.5	0.9
1989	3.7	100.0	46.2	11.9	16.5	13.0	22.2	0.8

a. Percentages may add to more than 100 because individuals may be eligible for more than one type of coverage.

b. Persons with Medicare or CHAMPUS coverage, but not Medicaid.

Abbreviation: CHAMPUS = Civilian Health and Medical Program of the Uniformed Services.

Source: Employee Benefit Research Institute, memorandum, November 14, 1995 (tabulations based on U.S. Bureau of the Census, Current Population Survey, 1990 and 1994).

Beneficiaries pay out of their own pockets (or through private Medigap or employer-sponsored insurance) for part of the cost of services covered by Medicare. Under HI, the beneficiary was responsible for the first $716 incurred for a hospital stay in 1995, plus significant additional copayments after 60 days.[11] Under SMI, the beneficiary is responsible for paying the first $100 of covered services in a year, plus 20 percent of approved charges over that amount.[12] For many outpatient mental health services, particularly psychotherapy, the co-payment is 50 percent.

Medicare is Essential Protection Against Health Costs

Despite its gaps in covered services, Medicare is an essential source of health care coverage for Social Security disability beneficiaries. In 1993, those who filed Medicare claims had an average of about $5,500 reimbursed (about 3 in 4 disabled enrollees).[13] They include:

- About 2 in 10 who had hospital bills paid. After the beneficiary paid the first day charges of $676, the average payment to hospitals was about $9,500.
- About 8 in 10 disability beneficiaries who were enrolled in SMI had physician or other medical bills paid by Medicare, at an average payment of $3,700. Since Medicare pays 80 percent of approved charges after a $100 deductible, the $3,700 paid by Medicare suggests that beneficiaries themselves were responsible for paying an additional $1,200 for those medical services out of their own pockets or through individually-purchased Medigap insurance.[14]

The average expenditures covered by Medicare and the out-of-pocket expenses incurred by disabled-worker beneficiaries loom large in relation to their monthly income from Social Security benefits. In 1995, the average monthly disabled-worker benefit produced an annual income from Social Security of about $7,400, after the SMI premium ($46) was deducted. Beneficiaries attempting to return to work might well earn more than their benefits but still not be able to buy private health insurance or risk paying for health care out of pocket.

The Medicare Buy-In

Disability beneficiaries who want to return to work despite the continuation of their impairments have a period of time to test their ability to work before cash benefits and Medicare coverage end.[15] Once Medicare ends, those former beneficiaries who continue to have a disabling impairment may purchase Medicare coverage — or "buy-in" — by paying monthly premiums for both HI and SMI.

Few Buy It. Although it is estimated that 5,000-7,000[16] DI beneficiaries leave the rolls each year due to a return to work, only 170 are currently purchasing Medicare coverage. Since the buy-in began in 1990, only 404 former beneficiaries have ever purchased coverage[17] — although SSA notified nearly 80,000 former DI beneficiaries when the buy-in began, and several thousand additional beneficiaries have become eligible each year since.

The Panel has heard that the fear of losing health care coverage is a significant deterrent to returning to work. While some former beneficiaries who are working may have employer-provided health

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[11] Medicare will pay for care in a skilled nursing facility following a hospital stay, subject to a 100-day limit per benefit period/episode of illness. The beneficiary was responsible for paying $89.50 in 1995 per day after the first 20 days of care.

[12] Individuals are also responsible for charges above the Medicare-allowed charge for claims not on assignment. Doctors who do not accept assignment may charge no more than 115 percent of Medicare-approved fees.

[13] Social Security Administration, op. cit., footnote 7, table 8.B2, p. 324.

[14] SMI reimbursed about 76 percent of approved physician charges. Social Security Administration, op. cit., footnote 7, table 8.B9, p. 333.

[15] There is a nine-month trial work period during which cash benefits and Medicare continue, regardless of the beneficiary's earnings level. Then there is a three-year extended period of eligibility (EPE) during which Medicare continues, but Social Security benefits are withheld during any month in which the persons performs substantial gainful activity (SGA). When earnings exceed SGA after the EPE, cash benefits end and Medicare coverage ends three months later. However, Medicare and Social Security cash benefits stop altogether if a beneficiary is found to have medically recovered.

[16] Social Security Administration, Office of the Actuary, memorandum, December 17, 1995.

[17] Health Care Financing Administration, Office of the Actuary.

insurance,[18] for those who do not, the Medicare buy-in is essentially the only health care option available. To be effective in reducing barriers to work, the buy-in has to be affordable, understandable and predictable for beneficiaries contemplating a return to work, so that it truly is an assurance of affordable health care. The existing buy-in is not.

It is Expensive to Purchase. The full monthly premium for HI and SMI combined amounted to nearly $3,700 a year in 1995. The premium for HI was $261 per month, which is the amount charged to the uninsured elderly who purchase Medicare. It is the full actuarial cost of HI coverage. The SMI premium is the same as all enrollees pay, or $46.10 per month in 1995. For a former beneficiary earning $15,000 annually, the combined premiums amounted to 25 percent of earnings.

There are two separate provisions in current law that seek to make the buy-in more affordable. These provisions are extremely complicated, and the second one, which is aimed specifically at low-income workers, is virtually unused.

- First, the Omnibus Budget Reconciliation Act (OBRA) of 1993 reduced the HI premium for former disability beneficiaries who have at least 30 quarters of Social Security coverage — or 7-1/2 years of employment covered by Social Security. It is reasonable to expect that most former disabled-worker beneficiaries would have that amount of covered employment. The premium reduction is to phase in gradually from 25 percent in 1994 to 30 percent in 1995, and increase 5 percent each year until it reaches 45 percent in 1998 and thereafter. Yet the program remains expensive for low-wage workers. A former beneficiary earning $15,000 and paying the reduced premium in 1995 would still pay 17 percent of earnings for Medicare premiums.

- Second, OBRA of 1989 required states, through their Medicaid programs, to pay the HI premium for former Social Security disability beneficiaries who have low incomes, so-called "qualified disabled and working individuals" (QDWIs). In theory, former DI beneficiaries are eligible to have their HI premiums paid by Medicaid if their income is below 200 percent of the poverty threshold and they have resources no greater than twice the Supplemental Security Income (SSI) limit (or $4,000). (States are permitted to charge a sliding-scale premium to QDWIs whose income is between 150 and 200 percent of poverty.) Income and resources eligibility is determined using the SSI rules. As of June 1995, only 16 former DI beneficiaries across the country were receiving the QDWI subsidy.[19]

The Buy-in is Exceedingly Complex and its Cost is Unpredictable. The two provisions that aim to make the buy-in affordable are too complex to be easily understood, and thus offer very little assurance to a beneficiary deciding to attempt work. For example, the 1993 law reduces the premium amounts, but by a gradually increasing percentage each year, and the underlying premium is itself set anew every year. Since the time when the beneficiary might buy Medicare is at least four years after the first work attempt, this policy aimed at making the buy-in affordable offers little that a beneficiary can use to plan for the actual future cost of health insurance. In addition, since beneficiaries do not ordinarily know how many quarters of Social Security they or their spouses have earned, they would not know whether they are even eligible for the reduction.[20] A scheduled reduction in an

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[18] Beneficiaries leaving the rolls because of work have completed both a nine-month trial work period as well as a three-year extended period of eligibility, and thus they have at least a four-year work history.

Moreover, if a Medicare beneficiary has been insured through his or her job and that employer has at least 100 employees, Medicare is secondary payer to the employer's coverage during the 39-month period after the beneficiary's trial work period. Thus, the beneficiary may not even be aware of the continuation of Medicare coverage during the first 4 years of work. (Regular Medicare coverage is generally secondary payer when beneficiaries are covered by other health insurance.) However, when former beneficiaries purchase Medicare through the buy-in, it is primary payer for their health care.

[19] Health Care Financing Administration, Office of the Actuary.

[20] Individuals are entitled to the reduced premium if they have 30 quarters of Social Security coverage; have been married for at least one year to an individual with 30 quarters; were married for at least a year to a deceased individual with 30 quarters; or are divorced after at least 10 years of marriage from an individual who had acquired 30 quarters at the time the divorce became final.

unknown amount that the beneficiary may or may not qualify for does not provide much assurance or predictability to a beneficiary evaluating the consequences of working.

The QDWI subsidy is even less predictable. The QDWI law relies on state Medicaid offices to determine eligibility under a set of rules that neither the state office nor the former DI beneficiary may have any experience with. Eligibility depends on SSI income counting rules. But states that rely on the Social Security Administration (SSA) to determine eligibility for SSI, and therefore Medicaid, may have no experience applying SSI rules.

DI beneficiaries who have not received SSI would have no experience with SSI rules. Beneficiaries contemplating a work attempt would have no basis on which to expect to receive the subsidy, since they would have no reason to know the poverty threshold or that half their earnings are disregarded in determining their eligibility. In addition, in order to receive the subsidy, the individual must go to a new agency, outside of SSA, to apply for the subsidy and fill out a lengthy form requiring extensive documentation of income and resources.

The complexity and unpredictability of the buy-in provisions act as a barrier to its practical value as an assurance of affordable health care for beneficiaries contemplating a return to work. The premiums themselves and the separate provisions which aim to make the premiums affordable are not based on anything that relates to the beneficiary, such as his or her own potential earnings.

The Panel recommends an improved Medicare buy-in that is more affordable and understandable for DI beneficiaries who return to work despite the continuation of their impairments. The Panel recommends a centrally-administered Medicare buy-in with a simplified premium structure scaled to earnings.

The Panel's proposal would make the premium for the Medicare buy-in predictable and affordable for former DI beneficiaries by setting the premium as a fraction of their earnings while they are working. The premium could be set at 7 percent of earnings in excess of, say, $15,000 per year ($1,250 per month), capped at the full premium paid under current law, which would be reached at about $68,000 of annual earnings. This system would replace the existing reduction in HI premiums for former beneficiaries with at least 30 work credits as well as the QDWI subsidy. Figure 8-5 contrasts the Panel's proposal with current law for workers at various earnings levels.

Under this simplified plan, beneficiaries would be able to find out about the option of continued Medicare coverage and anticipate its consequences for them. They could factor in the cost of continued Medicare coverage in considering their financial gains from working. A simplified premium structure could also be explained clearly in written materials, and SSA staff could more readily assist beneficiaries to determine its impact on their own future financial situation.[21] In addition, Medicaid offices would no longer be involved in administering part of the Medicare buy-in for former Social Security beneficiaries.

SSA, the Health Care Financing Administration (HCFA) or a contractor could administer the buy-in. HCFA currently uses a contractor to collect HI and SMI premiums from former DI beneficiaries, as does the Massachusetts CommonHealth program, a state health insurance program for workers with disabilities. It uses a contractor to make eligibility determinations and collect premiums. Under the Panel's proposal, the administering agency would

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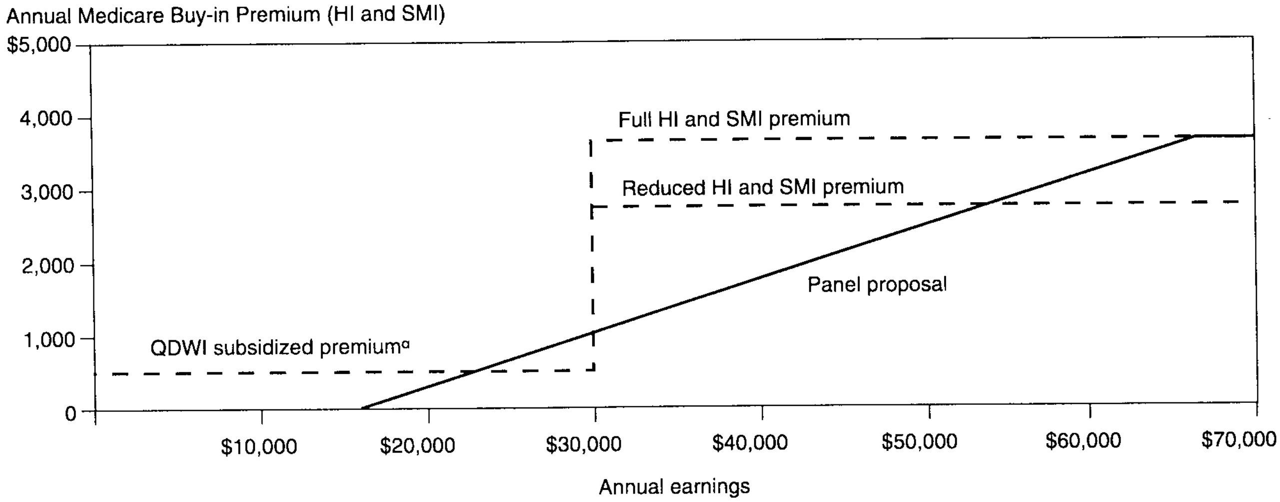
[21] The current SSA pamphlet on working while disabled does not show the cost of the buy-in, which changes every year and is subject to reductions if a beneficiary meets the eligibility criteria. Moreover, SSA staff cannot provide the cost to beneficiaries individually at the start of a work attempt because the time when a beneficiary contemplating work would need to purchase Medicare is at least four years away.

Figure 8-5. Medicare Buy-in Premium — Current Law and Panel Proposal, 1995



Panel Proposal: Medicare buy-in premium is 7 percent of earnings above $15,000, capped at the actuarial value of HI plus the SMI premium.
a. For a one-person family, with all income from earnings, Medicaid is required to pay the HI premium. The working former beneficiary pays the SMI premium.
Abbreviations: HI = Hospital Insurance (Medicare Part A), SMI = Supplementary Medical Insurance (Medicare Part B), QDWI = qualified disabled and working individuals.

need to collect premiums, verify earnings and reconcile payments on a periodic basis.

The Office of the Actuary at HCFA estimates the revised Medicare buy-in would cost $230 million over FY 1996-2000.[22]

TAX CREDIT FOR PERSONAL ASSISTANCE

Some people with disabilities need personal assistance services in order to live independently or to work.[23] Providers of such services can be either paid or unpaid (such as family and friends.) If a paid attendant is used, the services can be quite costly. When services are publicly funded, they are usually means tested.[24] Consequently, persons with disabilities who use them face a dilemma in attempting to work: if they work successfully, their income may disqualify them from receiving publicly-funded services that are subject to a strict means test, yet they may not be able to earn enough to be able to pay for the needed services entirely on their own. Moreover, many public programs do not cover personal assistance services used in the work place.

The Panel recommends a personal assistance tax credit to compensate working people for part of the cost of personal assistance services they need in order to work.

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[22] Health Care Financing Administration, Office of the Actuary, memorandum, January 19, 1996.

[23] About 1.5 million individuals ages 21 to 64 (about 1 percent of the entire noninstitutionalized population of the same age) report needing personal assistance in order to perform activities of daily living (ADLs), such as getting around inside the home, bathing, dressing, eating and toileting. Among employed people, over 260,000 persons (less than 0.2 percent of the total employed population) need personal assistance with at least one ADL. A smaller number of employed people (63,000) report needing assistance with at least three ADLs, the threshold commonly used to define a need for formal assistance from outside the home. U.S. Bureau of the Census, *Americans with Disabilities: 1991-92, Data from the Survey of Income and Program Participation*, P70-33 (Washington, DC: U.S. Government Printing Office, 1993), table 24, pp. 62-63.

[24] Public funding of personal assistance services may come from Medicaid, the Social Services Block Grant program under title XX of the Social Security Act, title II of the Older Americans Act and programs funded entirely at the state or local level. The services and disabilities covered as well as income eligibility standards, cost-sharing formulas and levels of provider reimbursement vary widely from program to program.

The Panel proposes a nonrefundable tax credit to assist disabled persons who need personal assistance services in order to work. The credit would reimburse workers who need such services for part of their extraordinary disability-related expenses when they go to work. It would help to level the playing field between disabled and nondisabled workers. And by making personal assistance services more affordable for working individuals with disabilities, the credit would reduce the dilemma individuals face when their earnings are high enough to disqualify them from publicly-financed services, but too low to afford such services on their own.

Those eligible for the credit would be employed individuals who have a medically determinable physical impairment that has lasted or is expected to last at least 12 months, and who would be unable to engage in substantial gainful activity without personal assistance services. Services covered by the credit would be broadly defined and would not be limited to those costs necessary for work. They would include personal assistance to carry out activities of daily living in or outside the home; homemaker/chore services incidental to personal assistance (such as meal preparation or shopping); assistance with life skills (such as money management) for people with cognitive impairments; communication services; work-related support services; coordination of services; or assistive technology services (including training of family members). The credit would not cover services provided by relatives.

For individuals with adjusted gross income of less than $50,000, the credit would be equal to 50 percent of up to $15,000 in personal assistance expenses, for a maximum credit of $7,500. (The credit would be 50 percent of earned income if the individual's personal assistance expenses exceeded his or her earned income.) The credit would be phased down for individuals with adjusted gross income between $50,000 and $70,000. No credit would be available for individuals with adjusted gross income over $70,000.[25]

The U.S. Department of the Treasury's Office of Tax Analysis projected in 1994 that the total five-year cost of the credit would be $537 million for FY 1996-2000.

MEDICAID

Medicaid is a much more varied program than is Medicare. It pays for preventive and acute care as well as long-term care services for the nation's poor. It is financed jointly by the states and the federal government, with the federal share averaging 58 percent of overall expenditures in FY 1994.[26] States design their own package of covered services and eligible populations, subject to broad federal guidelines. There is great variation among state Medicaid programs in the services covered and the populations who are eligible.

A Diverse Program

Medicaid covers a broad clientele that includes low-income children and their parents, low-income elderly persons in need of long-term care and low-income disabled individuals, whose needs for basic health care and long-term services are extremely diverse.

The diverse purposes of the Medicaid program are shown in the composition of its beneficiaries and in a breakdown of its payments for health care and related services. In 1994, the $108 billion in

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[25] Individuals who are not eligible for the credit because of their income could use the existing income tax deductions which cover personal assistance services. Disabled individuals who itemize deductions can subtract from their income for tax purposes the cost of any unreimbursed impairment-related work expense (IRWE). These include expenses for services at one's place of work and other expenses in connection with one's place of work that are necessary for the individual to be able to work. An individual may also deduct personal assistance services costs from income as a medical expense, but only to the extent that medical expenses exceed a floor of 7.5 percent of gross income. An individual who claimed the credit could not also deduct those expenses from gross income as an unreimbursed IRWE or as a medical expense.

[26] Social Security Administration, op. cit., footnote 7, p. 338.

Medicaid benefits for 35 million recipients were allocated as follows[27]:

- Low-income children and their parents accounted for 71 percent of Medicaid beneficiaries, but accounted for just 29 percent of Medicaid benefit expenditures. Medicaid pays mainly for preventive and acute care services for this relatively healthy population that lacks basic health insurance coverage.

- Low-income elderly persons accounted for 12 percent of Medicaid beneficiaries but represented 31 percent of expenditures, largely for long-term care, medications and other services that are not covered by Medicare.

- Low-income disabled persons under age 65 accounted for 16 percent of Medicaid beneficiaries and 39 percent of Medicaid expenditures, or $42.2 billion in 1994.

Medicaid Covers Acute and Long-Term Care

Medicaid coverage may be sought by low-income and even moderate-income Americans with disabilities for two reasons. First, it covers basic preventive and acute care for those who can't get private insurance. Even when they are employed and have adequate incomes, people with chronic health conditions may not be able to obtain the health insurance they need because of exclusions for pre-existing conditions or very high premiums that make individual purchase of insurance unaffordable.

Second, Medicaid is important to some persons with disabilities because it often covers ongoing services that are not included, or are sharply limited, in private health insurance or Medicare.[28] As such, Medicaid is sometimes sought as a wrap-around package of benefits by DI beneficiaries who are covered by Medicare, or by working people with private insurance that does not cover ongoing supports. Such necessary but costly services include:

- out-patient prescription medications, which are not covered under Medicare, but are essential to control some disabling conditions;

- out-patient mental health services, which are sharply limited under many private insurance plans, and which under Medicare require a 50-percent co-payment, which limits access to these services by those living mainly on DI benefits;

- ongoing personal assistance services that rarely if ever are covered by private insurance and are not covered by Medicare, but are needed by some persons with physical impairments in order live independently; and

- psychosocial rehabilitation, day treatment services and case management services that are essential supports for some persons with severe mental illness or developmental disabilities.

In the majority of states, individuals who qualify for SSI automatically receive Medicaid.[29] Therefore, individuals in these states who need the services that only Medicaid provides are under pressure to qualify for SSI in order to receive Medicaid.

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[27] The expenditures shown do not include disproportionate share hospital (DSH) payments that are paid directly to hospitals that serve a high volume of low-income patients. In 1994, the DSH payments were 12 percent of all Medicaid payments. They also do not include premium payments to health maintenance organizations (HMOs) and Medicare, which accounted for 8 percent of Medicaid expenditures. Social Security Administration, op. cit., footnote 7, table 8.E2, p. 338.

[28] Federal Medicaid guidelines specify both optional and mandatory services covered by state Medicaid programs. They also allow states to limit some of the services covered to specific populations of Medicaid beneficiaries. For example, coverage of prescription drugs is optional, but all states included such coverage in their Medicaid package of benefits as of October 1993. Personal care services are also optional, but 32 states cover such services for at least some of their Medicaid beneficiaries. U.S. House of Representatives, Committee on Ways and Means, *Overview of Entitlement Programs (1994 Green Book),* WMCP: 103-27 (Washington, DC: U.S. Government Printing Office, July 1994), table 18-24, p. 813.

[29] Twelve states have chosen to exercise their option under section 209(b) of title XIX of the Social Security Act to apply at least one more restrictive eligibility standard than those used in SSI. (Only those states who were using more restrictive standards when SSI was implemented in 1972 may use section 209(b).) States may vary from SSI in their definition of disability or in their standards related to income or resources.

Table 8-4. Premium Schedule for the CommonHealth Program

	One-person family, July 1993			
	Full coverage plan		Supplemental coverage plan	
Annual income	Monthly amount[a]	As percent of annual income	Monthly amount	As percent of annual income
$6,000	0	0	0	0
10,000	0	0	0	0
12,000	0	0	0	0
15,000	$12	1.0	$8	0.6
20,000	56	3.4	33	2.0
25,000	92	4.4	55	2.6
30,000	125	5.0	75	3.0
35,000	156	5.3	94	3.2
40,000	187	5.6	112	3.4
45,000	204	5.4	123	3.3
50,000	278	6.7	167	4.0
60,000	364	7.3	218	4.4
70,000	568	9.7	314	5.9
80,000	687	10.3	412	6.2
90,000	960	12.8	576	7.7
100,000	1,034	12.4	620	7.4

a. Eligible applicants with gross incomes greater than 1500 percent of the federal poverty level are charged 15 percent of their annual income.
Source: V.G. Miller, "CommonHealth: A Massachusetts Program for Vulnerable Populations 1988-93," report prepared for The Robert Wood Johnson Foundation, February 1994, pp. 55-58.

The Dilemma of People with Disabilities Who Can Work but Need Medicaid

Some individuals who need the basic health care or long-term supports provided under Medicaid have very limited prospects for working. Others who have quite significant impairments can, with these supports, function in the competitive labor market. Still others may be able to engage in part-time or supported work.

The fundamental dilemma faced by some persons with disabilities is that they need services that are not available under private insurance or Medicare, and which are very expensive to purchase individually. Medicaid provides these services, but generally only to people who are poor. To require that people with disabilities be poor, without savings and unable to work in order to get the ongoing supports they need in order to work, save and escape poverty poses a dilemma for those in need of these services who have no other alternatives than the Medicaid system.

In response to this dilemma, Massachusetts began an experiment that allows people who work despite severe disabilities to purchase a Medicaid-like package of services — either long-term community-based services or a combination of long-term care and acute care. The buy-in does not cover long-term care in institutions.

CommonHealth. Children and working adults in Massachusetts whose impairments meet the level of severity necessary to qualify for SSI can purchase CommonHealth. CommonHealth is a state health insurance plan that offers benefits like the state's Medicaid program, with the exception of institutional long-term care. It covers community-based long-term care, including personal assistance services. Participants can choose between a full coverage plan or a supplemental plan designed as a wraparound to inadequate private insurance or to Medicare if they are working DI beneficiaries.

CommonHealth was designed, in part, to reduce work disincentives for people with disabilities who might otherwise turn to SSI in order to obtain needed health coverage through Medicaid. Adult participants must meet work requirements of at least 40 hours per month (or 240 hours in the six-month period preceding the date of application). Premiums are based on income and family size; 1993 amounts are shown on table 8-4. A private contractor is used to make eligibility determinations and collect premiums.

Gross expenditures for FY 1994 were roughly $21 million, and approximately 3,000 people with disabilities were covered. As of August 1995, about half were adults; more than one-half of the program's expenditures were for disabled children. CommonHealth is a state-funded program with no federal matching funds, although a federal Medicaid waiver was pending action by the state legislature at the time this report was being prepared.

Other states are trying to expand access to the basic, acute-care services covered by Medicaid.

TennCare. Tennessee generally replaced its Medicaid program in 1994 with TennCare, a statewide managed care system that extended acute-care coverage to certain "uninsured" or "uninsurable" groups. Those who meet eligibility criteria for the uninsured or uninsurable categories can buy into TennCare, which includes the services covered by the state's original Medicaid program, with the exception of long-term care services. (Long-term care services are still provided through the original Medicaid program, and individuals must meet Medicaid eligibility criteria to access these services.) People with disabilities who cannot obtain private coverage are eligible under the uninsurable category if at least one private insurer declares them to be uninsurable for a stated medical reason. The uninsured are those lacking access to private health care coverage for nonmedical reasons; they tend to be working poor individuals. They pay premiums based on income, deductibles and cost-sharing. Private contractors make eligibility determinations and collect premiums from those enrolled in the uninsured and uninsurable categories.

Approximately 1.2 million people participated in TennCare in 1994, and 400,000 of these participants were categorized as either uninsured or uninsurable. The program includes enrollment caps in these two categories, and the number of persons enrolled in the uninsured category has reached the cap. TennCare was implemented in January 1994 as a five-year demonstration project under a federal Medicaid waiver.

Medicaid in a Era of Change

The Panel urges states to be mindful of the diverse needs of persons with disabilities as they change their Medicaid programs through the federal waiver process or through possible transformation of the program to a block grant. Persons with disabilities have particular needs, distinct from those of children, pregnant women and elderly persons. Therefore, the breadth of the benefit package is important for some types of disabilities. Managed care has unique implications for persons with disabilities and should be considered carefully in light of their needs. Continuity of treatment is also important, particularly for youth transitioning to the world of work. Finally, states should design their programs for acute care and long-term care in ways aimed at promoting maximum functioning and facilitating work. Secure and accessible health care is important if people are to plan their futures, including work.

The Panel recommends that states design their revised Medicaid programs in ways that promote work and independence while maintaining coverage for vulnerable populations who rely on SSI benefits.

CONCLUSION

The Panel's proposals for improving access to health care for people with disabilities — in terms of both access to insurance mechanisms and the services included in the benefit package — are necessarily limited in scope. They focus on those who are able to work in spite of their impairments. And they have in common that they ask those workers to contribute a reasonable amount toward the cost of their coverage.

But the Panel's proposals are only part of the solution. The problems in the health care financing system are broader than the special concerns of persons with disabilities who work. The system as a whole is undergoing rapid and unpredictable change, including increased use of managed care plans. These changes have potential for improving quality, but also for constraining access further. While people with disabilities — whether they are able to work or not — have a special stake in health insurance reform because of their risk of high health care expenditures, their problems are not so much one of disability policy but of overall health care financing policy.

The Panel is not attempting to prescribe global reform of public or private health care financing and delivery. It urges policymakers, when considering such changes, to take account of the particular difficulty persons with disabilities face in gaining access to the range of health care and long-term services they need in order to live independently.

Chapter 9 Work Incentives

The Disability Policy Panel conducted extensive field research in the use and implementation of the work incentives in Social Security disability insurance (DI) and Supplemental Security Income (SSI). It finds that the work incentives are inherently complex and that efforts to simplify them by redesigning them are not particularly promising. Moreover, given the large workload and limited resources of the Social Security Administration (SSA), administering the work incentives — a time-consuming process — is often a low priority.

The Panel believes that the most important enhancement needed in existing work incentives in DI and SSI is to improve the way in which they are implemented. Such improvements would involve both service providers who assist beneficiaries and SSA.

The Panel concluded that:

- Because the work incentive provisions are inherently complex, beneficiaries are likely to need assistance with understanding and complying with them when they work. This is particularly true for SSI recipients because their benefits are subject to a monthly means test, where changes in other income or assets affect their benefit amounts.
- Some kinds of assistance could be offered by service providers who assist beneficiaries in returning to work, such as those who accept the return-to-work (RTW) tickets the Panel is recommending. Such service providers would, themselves, need to understand the rules and reporting requirements of the work incentive provisions and consider it part of their job to assist their clients in complying with them.
- Some tasks necessary to make work incentives work can only be performed by SSA or an entity employed by SSA. These tasks include prompt processing of earnings and other reports from beneficiaries so that their benefits can be adjusted promptly as their circumstances change. If return to work is to be a priority, SSA personnel and systems support for these functions are essential.

The Panel recognizes that Social Security and SSI disability benefits are paid to people with very significant work disabilities, only a fraction of whom have prospects for returning to work. As long as the programs continue to have very strict eligibility rules, it is reasonable to expect that only a small proportion of beneficiaries will be able to return to work at a level of earnings that cause them to leave the benefit rolls. The Panel believes its proposal for return to work tickets in chapter 6 can improve the success of beneficiaries' return-to work efforts by encouraging service providers to assist them and to provide on-going supports when needed.

The Panel has heard that fear of losing health care coverage is a significant impediment to returning to work for some beneficiaries. Its recommendation for an affordable and understandable Medicare buy-in option, in chapter 8, is designed to allay these concerns for DI beneficiaries who work. Further, the Panel encourages states, in revising their Medicaid programs, to allocate both acute care coverage and on-going support services in ways that promote work and independence while maintaining coverage for vulnerable populations who rely on SSI benefits.

In this chapter, the Panel proposes several improvements in the DI and SSI work incentives themselves. The Panel considered, but is not recommending, a partial benefit offset in the DI program, similar to the benefit offset that exists in the SSI program. Rather, the Panel believes that one of the most promising ways to support and encourage work among persons with partial work disabilities is through a wage subsidy directly related to earnings. Its recommendation for such a wage subsidy is in chapter 7.

The chapter begins with a description of the DI and SSI work incentives, emphasizes the importance of implementing them effectively and then discusses a series of proposals for legislative changes. The chapter concludes with a discussion of why the Panel is not recommending a partial benefit offset for DI.

WORK INCENTIVES FOR SOCIAL SECURITY DISABILITY BENEFICIARIES

The principal DI[1] work incentives — the trial work period and the extended period of eligibility — are designed to permit beneficiaries to test their capacity for self-supporting work while providing for an uncomplicated return to the rolls if the attempt fails. The other incentives are intended to appropriately value an individual's earnings, in light of any impairment-related work expenses or subsidies. An individual who is found to have medically improved so that he or she is no longer disabled is ineligible for benefits and the work incentives do not apply.

Trial Work Period

Social Security disability beneficiaries are entitled to a nine-month trial work period (TWP) in which full benefits continue regardless of the amount of earnings. The TWP permits beneficiaries to test their ability to work without affecting their benefits. Each month the beneficiary earns above $200 is counted as a trial work month.[2] When the beneficiary has accumulated nine such months (not necessarily consecutively) within a rolling 60-month period, the TWP is completed.

If after the TWP the beneficiary earns at the substantial gainful activity (SGA) level — more than $500 a month — benefits continue for a three-month grace period and then stop. The beneficiary is then in the extended period of eligibility.

Extended Period of Eligibility and Medicare Coverage

After nine months of trial work, beneficiaries who continue to have a disabling impairment enter a 36-month extended period of eligibility (EPE), during which benefits are paid for any month in which earnings are below SGA.[3] If earnings constitute SGA in a month, no benefits are paid for that month. If at the end of the EPE a beneficiary is still earning at the SGA level, DI benefits are terminated, and Medicare is continued for an additional three months.[4] If the beneficiary is not earning at the SGA level at the end of the EPE, benefits are

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[1] The Social Security work incentives apply to disabled-worker beneficiaries, disabled adult children and disabled widows. In discussing work incentives in this chapter, the term "DI beneficiaries" includes all three types of beneficiaries, although technically disabled widows and most disabled adult children are paid from the Old Age and Survivors Insurance (OASI) trust fund.

[2] When the TWP was created by the 1960 amendments to the Social Security Act, the initial threshold was $50 per month. This threshold was revised administratively to $75 in 1979 and to $200 in 1990.

[3] The EPE was created by the 1980 amendments to the Social Security Act. It was originally 15 months, with Medicare paid for a total of 39 months. The EPE was lengthened to 36 months in the Omnibus Reconciliation Act of 1987. Medicare coverage was not further extended.

[4] When Medicare coverage ends, the former DI beneficiary has the option to buy continued Medicare coverage. See chapter 8.

terminated after the first month the individual engages in SGA.

Because benefits can be reinstated during the EPE without a new application or waiting period, the EPE provides a 3-year "safe period" for beneficiaries to test their ability to sustain self-supporting employment. In addition, former DI beneficiaries who cease to earn at the SGA level after the end of their EPE may reapply for benefits without being subject to the 5-month waiting period for DI benefits and the 24-month waiting period for Medicare, as long as reapplication occurs within five years of leaving the rolls.[5]

Impairment-Related Work Expenses

When determining whether a beneficiary's earnings constitute SGA, the costs of certain impairment-related work expenses (IRWEs) are deducted from earnings.[6] IRWEs are deducted from earnings when determining initial eligibility for benefits as well as when evaluating whether a post-entitlement work attempt constitutes SGA.

Subsidies

The value of employer subsidies is deducted from earnings when determining whether the employee is performing SGA. A subsidy is a job support that results in a worker receiving more pay than the actual value of the work he or she produces. Only earnings that represent the real value of the work performed are used to determine if work is SGA.

WORK INCENTIVES FOR SSI RECIPIENTS

The SSI work incentives are generally designed as exceptions to the means test for benefit eligibility, which reduces benefits dollar for dollar by countable income. Under the SSI work incentives, a variety of deductions and exclusions are used when determining countable income. These rules allow for partial benefits to be paid as a beneficiary's earnings rise — even if earnings constitute SGA. If the individual is found to have medically improved and no longer has a disabling impairment, he or she is no longer eligible for SSI benefits and the work incentives do not apply.

General and Earned Income Exclusions

Under the general income exclusion, the first $20 of income from any source is excluded from countable income. Under the earned income exclusion, the first $65 of earned income and half of the remaining earned income is excluded. The monthly benefit is then computed by subtracting the remaining countable income from the federal benefit rate. For example, if an individual earns $100 a month and has no other income, $85 is excluded from countable income and the remaining amount is divided in half, reducing the benefit by $7.50.[7]

About 1 in 12 working-age adults on SSI had some earnings from work in December 1995. The employment rate is higher among younger adults. Of those in their 20s, about 1 in 6 had earnings, as did about 1 in 10 of those in their 30s (table 9-1).

Continued Benefits under Section 1619(a)

Section 1619(a) of the Social Security Act permits working SSI beneficiaries to receive cash benefits after their earning constitute SGA as long as they continue to have a disabling impairment and still meet all other eligibility requirements. Thus, using the general and earned income exclusions, individuals can gradually phase off the SSI benefit rolls as their earnings increase. For individuals eligible for the full 1996 federal benefit of $470, cash benefits are fully phased out when earnings reach $1,025 a month.[8]

Continued Medicaid Coverage under Section 1619(b)

Section 1619(b) of the Social Security Act allows individuals whose cash SSI benefits are phased out due to earnings to retain eligibility for Medicaid

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[5] The elimination of the second waiting period was part of the 1980 amendments to the Social Security Act.

[6] The deduction for IRWE was part of the 1980 amendments to the Social Security Act.

[7] The income exclusions were part of the 1972 amendments to the Social Security Act, which established the federal SSI program.

[8] Section 1619(a) was enacted in the 1980 amendments to the Social Security Act and made permanent in 1986.

Table 9-1. Number and Percent of SSI Recipients Ages 18-64, With Earnings, and in 1619(b) Status by Age, December 1995

Age	Total SSI disabled recipients[a]	With earnings		In 1619(b) status	
		Number	Percent of total	Number	Percent of total
Total number	3,497,177	284,697	8.1	45,557	1.3
18-21	226,912	24,580	10.8	2,232	1.0
22-29	482,418	77,322	16.0	13,648	2.8
30-39	810,471	90,567	11.2	16,091	2.0
40-49	788,986	52,945	6.7	8,416	1.1
50-59	778,930	29,088	3.7	3,920	0.5
60-64	409,460	10,195	2.5	1,250	0.3

a. Includes 1619(b).
Abbreviation: SSI = Supplemental Security Income.
Source: Social Security Administration, *Quarterly Report on SSI Disabled Workers and Work Incentive Provisions,* December 1995, table 6, p. 22.

until their earnings are high enough to compensate for the value of SSI, any state supplements, Medicaid coverage and any publicly-financed personal assistance services they receive. The earnings thresholds range from about $12,000 to $32,000 depending on the state (see table A at the end of this chapter).[9]

About 46,000 individuals or 1.3 percent of persons who have established eligibility for SSI are in 1619(b) status where they continue to have Medicaid eligibility despite earnings that cause their entire SSI benefit to be withheld (table 9-1).

Impairment-Related Work Expenses

As in DI, the cost of impairment-related items and services that the person needs in order to work are excluded during the initial disability determination in assessing whether an applicant's earnings constitute SGA. In addition, these expenses are excluded from countable income. IRWEs are deducted from earnings before the exclusion of one-half of earned income under the earned income exclusion.[10]

In December 1995, 9,940 SSI recipients had their benefits calculated to compensate for part of the cost of IRWEs. Those recipients accounted for 3.5 percent of all SSI recipients with earnings.[11]

Blind Work Expenses

For SSI recipients who are blind, any expense that is attributed to working can be deducted from earnings for purposes of eligibility determination and countable income. These expenses need not be impairment-related and can include payroll taxes, income taxes, union dues, transportation, visual and sensory aids, and translation of material into Braille. In addition, the order in which these expenses are deducted in arriving at countable income is more favorable to the beneficiary than the method for regular IRWEs. Blind work expenses (BWEs) are deducted after the earned income exclusion and its $1 for $2 offset have been applied.[12]

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[9] Section 1619(b) was enacted in the 1980 amendments to the Social Security Act and made permanent in 1986. The earnings thresholds are based on average Medicaid expenditures in the state. The thresholds can be higher if the beneficiary can document that he or she has higher than average expenditures.

[10] The IRWE deduction was created by the 1980 amendments to the Social Security Act.

[11] Social Security Administration, *Quarterly Report on SSI Disabled Workers and Work Incentive Provisions,* December 1995, p. 3.

[12] The BWE deduction was part of the 1972 amendments to the Social Security Act that established the federal SSI program.

In December 1994, 4,380 SSI recipients had their benefits calculated to compensate for BWEs. They account for 73 percent of blind SSI recipients with earnings.[13]

Plan for Achieving Self-Support

Under a Plan for Achieving Self-Support (PASS), an SSI recipient can set aside earned or unearned income and resources for a work goal such as education, vocational training, starting a business or purchasing work-related equipment. The plan must be in writing, have a specific work goal, include a time frame for meeting the goal, and show what funds will be used and how they will be set aside. It must be approved by SSA. Income and resources set aside in a PASS are excluded under the SSI income and resource tests. Like BWEs, PASS expenses are deducted after the earned income exclusion has been applied.[14]

In December 1995, 10,322 SSI recipients had a PASS. The number of recipients with a PASS grew rapidly from about 3,600 at the end of 1991 to about 10,300 at the end of 1994, but grew little in 1995.[15] Those with a PASS include 4,604 persons who had earnings in December 1995 and others whose PASS expenses were deducted from other income, such as Social Security benefits. Those with a PASS who had any earnings accounted for 1.6 percent of SSI disability recipients with earnings.[16]

Income Disregards for Students

A student who is under age 22 and is regularly attending school may exclude up to $400 of earned income a month. The maximum annual exclusion is $1,620. This exclusion is applied before the general and earned income exclusions. In addition, any portion of grant, scholarship or fellowship income that is strictly for use in paying tuition and fees at an educational institution is excluded from countable income. Any remaining portion of the scholarship income is treated as unearned income, which reduces the SSI benefit dollar for dollar.

MAKING THE WORK INCENTIVES WORK

The Panel believes that the most important enhancement needed in existing work incentives is to improve the way in which they are implemented. The work incentive provisions are inherently complex. Proposals to simplify them often add new complexities, significant new costs or both. Consequently, efforts to simplify them by redesigning them are not particularly promising. Beneficiaries, service providers and advocates frequently report that beneficiaries are hesitant to attempt to work, in part because they fear the impact of work on their benefits. Existing work incentives are designed to mitigate these fears. But the provisions can only function as intended if beneficiaries are able to use them and if SSA implements them promptly and accurately.

Beneficiaries considering a transition from benefits to work often need individualized assistance in using and complying with the DI and SSI work incentives. A return to work would also affect other benefits they may receive, such as health care coverage, food stamps, tax credits, housing subsidies or state or local assistance. For some DI beneficiaries, a return to work would affect other private disability benefits they receive. The interaction of work and disability benefits is inherently complex, no less so than the federal income tax system. Just as many Americans employ expert help with their tax returns, disability beneficiaries are likely to need help to understand their options and responsibilities and to comply with reporting requirements when they work.

Individualized assistance in using and complying with work incentives could be offered by service providers who help beneficiaries return to work. For

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[13] Social Security Administration, *Quarterly Report on SSI Disabled Workers and Work Incentive Provisions*, December 1994, p. 3; and Social Security Administration, *Annual Statistical Supplement to the Social Security Bulletin* (Washington, DC: U.S. Government Printing Office, August 1995), table 7.D1, p. 309.

[14] The PASS provision was part of the 1972 amendments to the Social Security Act, which established the federal SSI program.

[15] Social Security Administration, *Quarterly Report on SSI Disabled Workers and Work Incentive Provisions*, December 1991, 1994 and 1995, table 14.

[16] Social Security Administration, op. cit., footnote 11, p. 3 and table 6, p. 22.

example, providers who accept the RTW tickets the Panel is recommending would increase their chances of success by helping their clients comply with the work incentives. Such assistance could also be provided by state vocational rehabilitation (VR) counselors, state or local mental health or developmental disabilities agencies, independent living centers, jobs coaches, providers of supported employment services, or disability managers or rehabilitation professionals who work with recipients of private disability benefits. Service providers would, themselves, need to understand the rules, recordkeeping and reporting requirements of the work incentives and consider it part of their job to assist their clients in complying with them.

Since the mid-1980s, SSA has taken steps to promote understanding and use of the work incentives. It improved its brochures and instructional materials and developed software to help calculate the effect of work on benefits. It also provided "seed money" through research and demonstration program grants to promote use of the work incentives.[17] These projects supported training for beneficiaries, VR agencies, state and local mental health and developmental disabilities agencies, independent living centers, nonprofit and for-profit groups specializing in work incentives, and research, training and technical assistance programs. Increased knowledge of the rules among service providers improves the chances that beneficiaries will get the individualized assistance they need to comply with them when they work.

While service providers can help beneficiaries comply with the work incentives, some tasks necessary to make the work incentives work can only be performed by SSA or an entity employed by SSA. These tasks include providing accurate information about the work incentives when inquiries are made by beneficiaries or service providers, and promptly processing earnings and other reports from beneficiaries so that their benefits are adjusted promptly as circumstances change.

For SSI beneficiaries, the partial benefit offset can provide a smooth and secure transition to work only if beneficiaries report changes in earnings timely and if SSA promptly and accurately adjusts benefits as earnings change. If timely adjustments are not made, the beneficiary will be assessed overpayments or be underpaid.[18] Overpayments are common when SSI beneficiaries work: about 6 in 10 SSI recipients with earnings above $65 a month had been charged with overpayments during the 12 months preceding September 1994 (table 9-2).

For DI beneficiaries, the TWP and EPE can effectively serve as a "safe period" to test their capacity for self-supporting employment only if beneficiaries know about the provisions and have confidence that the provisions will work as intended. If benefits are reconciled with earnings only long after the fact, beneficiaries are at risk of being charged with large overpayments, or of being without either earnings or benefits should their work attempt falter.

Over the past decade, SSA field offices have experienced increasing workloads and declining resources. Priority is given to processing initial claims, issuing Social Security cards and performing routine post-entitlement actions, such as changes of address. Disability beneficiaries who might return to work are a small segment of SSA's caseload. Administering the work incentives is often labor intensive and receives low priority.

If disability beneficiaries' return to work is to be a priority, SSA personnel and systems support for implementing existing work incentive provisions are essential. Beneficiaries who work despite disabling

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[17] Among grantees were the Association of Persons in Supported Employment, the United Cerebral Palsy Associations, South Carolina Protection & Advocacy, Easter Seals Society of New Hampshire, Matrix Research Institute and the Arc.

[18] Underpayments are resolved by SSA issuing a check to the beneficiary. Overpayments are, in theory, to be paid back to SSA, either by issuing a payment to SSA or by SSA withholding part of future monthly benefits. However, repayment of the overpayment can be waived if the beneficiary can show he or she is without fault in causing the overpayment and if making the payment would pose undue hardship. If SSA denies waiver of the requirement to repay overpayments, that denial can be appealed. For SSI beneficiaries, who by definition have little income and financial assets, repaying overpayments would often be a hardship.

Table 9-2. Percent of SSI Recipients Charged with Overpayments in the Prior 12 Months, by Earnings Level, in September 1994

Monthy earnings	Total SSI recipients	Percent with any overpayments	Average overpayment amount
Total recipients	**3,025,500**	**14**	**$104**
No earnings	2,776,000	12	69
Up to $65	89,600	16	40
Total — $66 or more	**95,600**	**60**	**332**
$66 to 299	45,700	55	153
$300 to 599	20,800	62	354
$600 to 999	20,800	75	546
$1,000 or more	12,500	58	885

Abbreviation: SSI = Supplemental Security Income.
Source: Social Security Administration, Office of Supplemental Security Income.

impairments take on a number of risks — the risk of failure, of a decline in their health or functional capacity, or of interruptions in accommodations or supports at home, at work or traveling between that are essential to their employment success. For individuals living on very modest budgets, continuity in income is critically important. The added risk of incurring large gaps in income or large overpayments can be mitigated if work incentives are implemented promptly and accurately.

IMPROVING THE WORK INCENTIVES

While the Panel believes that the first priority is to improve the implementation of existing work incentives, it also proposes some changes in the incentive provisions. It is not known how many additional beneficiaries would work if the DI and SSI work incentives were changed. Both theoretical and empirical analysis suggests a modest impact on labor supply.[19] Consequently, the changes are estimated to increase benefit costs. Yet even if the increase in employment is small, modest changes in the work incentives can be justified in terms of making the programs more work friendly.

Proposals

The Panel proposes several changes in DI and SSI to make them more "work friendly":

Update and Index SGA. The Social Security Act does not specify a level of earnings that constitutes SGA (other than for blind individuals[20]). The level is instead set by regulation. Periodic ad hoc adjustments kept the SGA threshold nearly even with wage growth until 1980. It was not raised again until 1990, when it was increased from $300 to $500 a month, its current level.

This proposal would update the SGA threshold level to the amount it would have been had it been indexed to keep pace with wage growth since the beginning of the DI program — $720 in 1996 —

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[19] H.W. Hoynes and R. Moffitt, "The Effectiveness of Financial Work Incentives in DI and SSI: Lessons from Other Transfer Programs," *Disability, Work and Cash Benefits*, J.L. Mashaw, et al., (eds.) (Kalamazoo, MI: W.E. Upjohn Institute for Employment Research, forthcoming); and J.C. Hennessey and L.S. Muller, "The Effect of Vocational Rehabilitation and Work Incentives on Helping the Disabled-Worker Beneficiary Back to Work," *Social Security Bulletin*, Spring 1995, pp. 15-28.

[20] Under section 223(d)(4) of the Social Security Act, SGA for the blind is equal to the monthly earnings test exempt amount for individuals age 65 to 69. This amount is indexed to keep pace with wage growth. In 1995 it was $940.

and would index it by wage growth in the future. These changes provide a more realistic level of earnings for the concept of "substantial gainful activity," which should be a measure of earnings that is relative to overall wage levels in the broader economy. It would give individuals a more realistic threshold to test their earnings capacity before losing their DI benefits.

This proposal is estimated to increase DI expenditures by $700 million over 5 years (FY 1996-2000) and increase SSI expenditures by $265 million over 5 years (FY 1997-2001).[21] It is projected to increase Medicare costs by $70 million over 5 years (FY 1996-2000)[22] and to increase federal Medicaid costs by $1.2 billion over 5 years (FY 1997-2001).[23] The higher SGA threshold would allow more individuals to qualify for benefits and would also allow DI beneficiaries to have higher earnings without losing eligibility.

The Panel considered a less costly variation of the proposal, which would not update the existing SGA threshold for past growth in wages, but would index the current $500 level by wage growth in the future. This version of the proposal is estimated to have no long-range cost over the 75-year projection period because SSA actuaries assume that the SGA threshold would, with ad hoc adjustments, keep pace with wage growth.

Unlimited EPE. The proposal would make the extended period of eligibility of unlimited duration for former DI beneficiaries who work but continue to have a disabling impairment. Benefits would be reinstated in any month that earnings fell below SGA for the rest of the beneficiary's life or until he or she reached age 65. An unlimited EPE would provide an ongoing safe period for individuals whose benefits have stopped because of work. It particularly targets individuals with episodic or progressive conditions who are able to work during "good spells" but need an on-going safe period to return to the benefit rolls during "bad spells" of their conditions. The cost of additional DI benefits paid under an unlimited EPE would be $1.0 billion over 5 years (FY 1996-2000).[24]

The majority of the Panel supports the following changes:

Modify the IRWE Deduction for SSI Recipients. The proposal would change the order in which impairment-related work expenses are deducted from earnings so that they are excluded after, not before, the exclusion of half of earned income under the SSI earned income exclusion.

Under current law for determining countable income, IRWEs are deducted from earnings before the exclusion of half of earned income. Because half of the amount excluded as an IRWE would have been excluded in any event under the earned income exclusion, the effect is a compensating rise in the SSI benefit amount equal to one-half of the amount of the IRWE.

The order in which IRWEs are currently excluded from earnings is less favorable than the method for excluding BWEs and PASS expenditures, which are deducted after the exclusion of half of earned income. Consequently, when BWEs or PASS expenses are incurred, there is a compensating rise in the SSI payment equal to the full value of these expenditures (so long as BWEs and PASS expenses do not exceed countable earnings). Excluding IRWEs from countable income after, rather than before, the exclusion of half of earned income would fully compensate for impairment-related work expenses which do not exceed countable income, and the treatment of this income would be regularized, so that it is more like BWE or PASS. The SSI cost of this change is estimated to be $26.1 million over 5 years (FY 1996-2000).[25]

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[21] Social Security Administration, Office of the Actuary, memoranda, January 25, 1995 and December 7, 1995.

[22] Health Care Financing Administration, Office of the Actuary, memorandum, January 19, 1996.

[23] Health Care Financing Administration, Office of the Actuary.

[24] Social Security Administration, Office of the Actuary, memorandum, February 28, 1995.

[25] Social Security Administration, Office of the Actuary, memorandum, June 19, 1995.

Social Security-SSI Transition. The proposal would allow resource-eligible Social Security disability beneficiaries who lose benefits because of work to use the SSI Section 1619 work incentives. As such it would enable them to qualify for continued Medicaid and personal assistance services in states that use 1619(b) criteria for eligibility.[26]

The transition is likely to be used by certain subsets of working Social Security beneficiaries, including those who need to build up their earnings potential gradually over time, as well as those who can just barely perform SGA but may never be able to become fully self-supporting, such as adults who receive Social Security based on childhood disabilities, most of whom have mental retardation. The transition might also be used by individuals who need medical services that are not covered under Medicare but may be covered under Medicaid, such as prescription drugs or personal assistance services. This proposal is estimated to increase SSI expenditures by $25 million per year by 2005.[27] Federal Medicaid expenditures are estimated to increase $235 million over 5 years (FY 1997-2001).[28]

Scholarship Income of SSI Recipients. SSI rules exclude from countable income any portion of grant, scholarship or fellowship income that is strictly for use in paying tuition and fees at an educational institution. But any portions of grants or scholarships that can be used for discretionary purposes, such as food, clothing and shelter, are treated as unearned income. Because unearned income offsets SSI benefits dollar for dollar, the receipt of such funds can result in a student losing SSI eligibility and therefore eligibility for Medicaid or personal assistance services that are based on SSI eligibility.

The proposal would treat that portion of grant, scholarship or fellowship income which is not already excluded from countable income as earned, rather than unearned, income. One rationale for doing so is that since such awards are often made on the basis of merit, the student, in a sense, has earned them. The change permits young beneficiaries to take advantage of scholarship and fellowships without having to fear the loss of Medicaid and personal assistance services available under Section 1619(b). The SSI cost of this proposal is estimated to be negligible annually over 5 years (FY 1996-2001).[29]

Partial Benefit Offset for DI

The Panel considered, but rejected, a proposal to provide a partial benefit offset for DI beneficiaries, as is currently provided for SSI beneficiaries. Such a proposal would reduce DI benefits by $1 for each $2 of earnings as beneficiaries return to work. The appeal of this approach is that by easing the transition off the DI benefit rolls, it could encourage more DI beneficiaries to return to work. Such a proposal, however, would increase benefit costs because more people would receive benefits. Furthermore, such a proposal would pay partial DI benefits to some individuals who have quite high incomes from work. For example, an individual with monthly DI benefits of $1,100 could earn over $32,000 per year and still collect a partial DI benefit.[30]

A proposal to pay partial DI benefits to disabled beneficiaries who work holds potential to both increase work and decrease work. The net effect, however, is not known.[31] Economic theory suggests that for some beneficiaries, such as those whose earnings are below SGA or who do not work at all, the opportunity to receive partial benefits if their earnings rise above the SGA threshold will provide an incentive to work more than they are currently doing. For other beneficiaries — such as those in the extended period of eligibility, whose benefits are suspended — the availability of a partial benefit may

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[26] SSI Modernization Project, *Final Report of the Experts* (Baltimore, MD: Social Security Administration, August 1992), p. 103.

[27] Social Security Administration, Office of the Actuary, memorandum, December 7, 1995.

[28] Health Care Financing Administration, Office of the Actuary.

[29] "Negligible" is less than $400,000 in each fiscal year. Social Security Administration, Office of the Actuary, memorandum, June 19, 1995.

[30] This assumes the $1 for $2 offset applies to earnings in excess of SGA ($500 per month).

induce them to work less, since they could work less but still receive the same total income (from benefits and earnings combined).[32]

While the net effect on total work effort is not known, both economic theory and actuarial estimates indicate that the net effect on benefit costs is positive and significant.[33] The SSA Office of the Actuary estimates that a proposal to reduce DI benefits by $1 for every $2 of earnings in excess of the SGA threshold, currently $500 per month, would lead to a net increase in DI benefit payments totaling $5.1 billion over 5 years (FY 1996-2000).[34]

This cost derives from three effects: (1) Benefit savings of $300 million would result from paying reduced benefits to about 25,000 current beneficiaries each year who would go to work or work more than they do now in response to the availability of partial benefits. (2) However, increased benefit costs of $1.4 billion would result from paying partial benefits to those who now have benefits totally withheld during the EPE because their earnings are above the SGA threshold. This would affect about 10,000 persons each year. (3) In addition, if partial benefits were available (with no means test, as in SSI), people who can meet the Social Security test of disability may be more likely to file for benefits. That is, there are many individuals with severe impairments who, if they were not working, would meet the Social Security eligibility criteria. The actuaries estimate that, of those who would experience a five-month period when their earnings were less than SGA, some 200,000 would apply for and be awarded benefits in the next 5 years.[35] The additional benefits paid to these individuals are estimated to total $4.0 billion over 5 years.[36]

In addition to the significant cost of the proposal, the Panel has grave doubts about whether SSA has the methods and capacity to administer a monthly, quarterly, or even annual benefit offset for DI in a way that would act as a work incentive.[37] Existing methods used to administer the partial benefit offset in the Social Security retirement program are not particularly promising. They are among the most complex and controversial features of that program. The partial benefit offset in the SSI program frequently results in overpayments or underpayments because benefits are not adjusted promptly as earnings change.

The Panel believes instead that SSA should focus on implementing the existing partial benefit offset for SSI, as well as the other work incentive provisions. Moreover, it believes that its proposal for a disabled worker tax credit that is a wage subsidy for low-income workers with partial work disabilities is a more effective and equitable way to encourage work when impairments limit, but do not preclude, work.

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[31] H.W. Hoynes and R. Moffitt, op. cit., footnote 19.

[32] For example, under a partial benefit offset of $1 for every $2 by which earnings exceed $500, a beneficiary now in the EPE who earns $1,300, and whose DI benefit was $700, could maintain the same total annual income if his or her earnings dropped to $700, allowing a benefit of $600 to be paid.

[33] H.W. Hoynes and R. Moffitt, op. cit., footnote 19.

[34] Social Security Administration, Office of the Actuary, memorandum, June 13, 1994.

[35] These are only a subset of the relatively large population of people with severe impairments who work, estimated to be 2 to 10 million people.

[36] Social Security Administration, Office of the Actuary, memorandum, June 13, 1994.

[37] That is, explaining how the offset works to interested beneficiaries, processing reports of earnings received by beneficiaries timely and adjusting benefits promptly.

Table A. State 1619(b) Thresholds for Disabled SSI Recipients, 1995[a]

State	Twice supplement	Base amount	Medicaid	Threshold
Alabama	$0	$12,012	$3,592	$15,604
Alaska	8,688	20,700	11,804	32,504
Arizona	0	12,012	0	12,012
Arkansas	0	12,012	6,046	18,058
California	5,386	17,380	4,717	22,115
Colorado	0	12,012	9,296	21,308
Connecticut	6,936	18,948	3,474	22,422
Delaware	0	12,012	10,293	22,305
District of Columbia	360	12,372	7,954	20,326
Florida	0	12,012	5,669	17,681
Georgia	0	12,012	5,215	17,227
Hawaii	118	12,130	4,588	16,718
Idaho	888	12,900	7,516	20,416
Illinois	0	12,012	7,978	19,990
Indiana	0	12,012	11,536	23,548
Iowa	0	12,012	7,079	19,091
Kansas	0	12,012	7,822	19,834
Kentucky	0	12,012	5,048	17,060
Louisiana	0	12,012	5,048	17,060
Maine	240	12,912	8,303	21,215
Maryland	0	12,012	9,481	21,493
Massachusetts	2,745	14,757	8,000	22,757
Michigan	0	12,012	6,859	18,871
Minnesota	1,944	13,956	12,867	26,823
Mississippi	0	12,012	3,447	15,459
Missouri	0	12,012	6,543	18,555
Montana	0	12,012	6,665	18,677
Nebraska	456	12,468	8,900	21,368
Nevada	0	12,012	3,244	15,256
New Hampshire	648	12,660	12,615	25,275
New Jersey	750	12,762	9,630	22,392
New Mexico	0	12,012	6,035	18,047
New York	2,064	14,076	13,114	27,190
North Carolina	0	12,012	7,837	19,849
North Dakota	0	12,012	10,979	22,991
Ohio	0	12,012	4,431	16,443
Oklahoma	1,320	13,332	4,093	17,425
Oregon	41	12,053	6,776	18,829
Pennsylvania	778	12,790	5,647	18,437

Table A. State 1619(b) Thresholds for Disabled SSI Recipients, 1995[a] (continued)

State	Twice supplement	Base amount	Medicaid	Threshold
Rhode Island	$1,544	$13,556	$6,281	$19,837
South Carolina	0	12,012	5,732	17,744
South Dakota	360	12,372	6,933	19,305
Tennessee	0	12,012	3,929	15,941
Texas	0	12,012	6,303	18,315
Utah	0	12,012	8,157	20,169
Vermont	1,426	13,438	8,488	21,926
Virginia	0	12,012	5,783	17,795
Washington	672	12,684	5,092	17,776
West Virginia	0	12,012	5,937	17,949
Wisconsin	2,011	14,023	5,830	19,853
Wyoming	233	12,245	9,013	21,258
Northern Mariana Island	0	12,012	0	12,012
State Thresholds for the Blind				
California	$5,074	$17,086	$4,717	$21,803
Iowa	528	12,540	7,079	19,619
Massachusetts	3,594	15,606	8,000	23,606
Nevada	2,623	14,635	3,244	17,879
Oregon	778	12,790	6,776	19,566

a. Under section 1619(b), Medicaid continues until an SSI beneficiary's earnings are high enough to compensate for SSI, state supplements, Medicaid and the value of any publicly-financed personal assistance services. This table is used as a reference guide by Social Security Administration district office staff and is based on the average expenditure per Medicaid beneficiary in the state. However, in applying the 1619(b) provisions, if an individual can document that he or she has higher than average medical needs, the threshold is calculated based on the individual's circumstances.

Abbreviation: SSI = Supplemental Security Income.

Source: Social Security Administration, Office of Supplemental Security Income.

Chapter

10

The Fit Between Disability and Retirement Policy

Retirement age policy in the Social Security program has been a topic of some debate and that debate has implications for the disability program. Issues of concern are: should the age at which full retirement benefits are paid be raised? If so, should the early retirement age be raised? Or should early retirement benefits be further reduced? In either case, for people facing the decision to claim early retirement benefits, what should be the relationship between disability benefit amounts and early retirement benefits?

RETIREMENT AGE POLICY

Today

The Social Security normal retirement age (NRA) — the age at which full Social Security retirement benefits are payable — is 65. Early retirement benefits are first available at age 62, the so-called earliest eligibility age (EEA). Early retirement benefits, however, are actuarially reduced to take account of the longer period over which they will be paid.[1] Benefits claimed at age 62 are reduced by 20 percent.[2] The rationale for the reduction in early retirement benefits when it was first implemented was that the choice to retire early is voluntary. The general idea was neither to penalize nor reward early retirement.

Disability benefits can be claimed at any time up to age 65 and are calculated by the same formula used for retirement benefits that are first received at the NRA. For those who claim benefits between age 62 and age 65, retirement benefits are reduced, while disability benefits are not. This has led to questions about whether the difference in amounts between the two kinds of benefits creates an undue incentive for older workers to claim disability benefits instead of early retirement benefits.

In the Future

The 1983 amendments to the Social Security Act scheduled increases in the age at which full benefits are paid. The NRA is scheduled to rise gradually from age 65 to 66 in the years 2000 through 2005, and then to rise again from age 66 to 67 in the years 2017 through 2022.[3]

The EEA remains age 62, but the reduction in benefits at that age will be larger. When the age-66 NRA is fully phased in, the reduction in benefits at age 62 will be 25 percent. When the age-67 NRA is fully phased in, the benefit at age 62 will be reduced by 30 percent.

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[1] That is, when the early retirement option was first made available under Social Security, the reduction in early retirement benefits was set so that a retiree of average life expectancy would receive the same in lifetime benefits whether the benefits were claimed early or at the NRA.

[2] Retirement benefits are reduced by five-ninths of 1 percent for each month they are received before age 65, or about 6.7 percent per year.

[3] The NRA is scheduled to rise by two months per year for those reaching age 62 in the years 2000 through 2005. It then remains at age 66 until it rises again by two months per year for those reaching age 62 in the years 2017 through 2022.

In 1983, the rationale for raising the NRA was twofold. First, it lowered future benefit costs and was part of a package to restore long-range solvency to the Social Security trust funds. Second, part of the increased future cost of retirement benefits was attributed to increased life expectancy of persons after age 65. Because retirees are living longer, aggregate retirement benefits cost more. Raising the age at which full benefits would be paid was viewed as a way to allocate some of that increased life expectancy to a longer work life, as well as to a longer retirement. If future retirees delayed their retirement by a year or two, their monthly benefit would be equivalent to what it would have been without the policy change.

At the time, the question was considered whether to raise the EEA from age 62 to 63 or 64 along with the NRA. The choice between raising the EEA or keeping it at age 62 and increasing the early retirement reduction had roughly the same effect on long-range costs. The choice was made to keep benefits available at age 62 with the larger benefit reduction.

A second question is whether the scheduled 25-percent or 30-percent differential between disability and early retirement benefits will pose too great an incentive for future workers at age 62 or older to claim disability benefits instead of retirement benefits.

If in the future large numbers of early retirees are awarded disability benefits, the policy of raising the NRA will not yield its expected savings in long-range Social Security costs. This concern has led some to suggest that disability insurance (DI) benefits should be lowered so as to reduce the disparity between early retirement benefits and disability benefits.

Proposed Changes

Because the Social Security trust funds are not now in long-range balance, proposals have been made to further increase the NRA. This again raises the question of what the EEA should be and how early retirement benefits should fit with disability benefits claimed at or after the early retirement age.

It is not the Disability Policy Panel's charge to recommend changes in retirement-age policy. The Panel does, however, have a disability policy perspective on questions about how disability benefits should fit with retirement-age provisions in current law and with proposals to change retirement-age policy.

DISABILITY AND EARLY RETIREMENT

Today

The Panel first examined whether the 20-percent reduction in early retirement benefits in effect today poses a powerful incentive for workers to claim disability rather than retirement benefits between ages 62 and 65.

Current experience with the 20-percent differential suggests it does not appear to. There is no clustering of disability benefit awards around early retirement age; in fact, the number of individuals awarded disability benefits actually declines after early retirement benefits are available (table 10-1). Further, the number of disability awards is small relative to the number of early retirees. For every 100 early retirement benefits awarded at ages 62 to 64, there were four disabled-worker benefits awarded at those ages.

Some of those awarded disability benefits at ages 62 or older had actuarial reductions in their disability benefits. This reduction would occur if they received early retirement benefits before their disability claim was processed and allowed.[4]

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[4] Under current law, individuals between ages 62 and 65 can file for both early retirement benefits and disability benefits. They can receive reduced early retirement benefits while their disability claims are being processed. If the DI claim is allowed and the effective date for the disability benefits is before the date they began to receive early retirement benefits, they qualify for full benefits. If the effective date for DI is after they began receiving early retirement benefits, their benefit is actuarially reduced for the number of months they received early retirement benefits before the effective date of their disability benefits.

Table 10-1. Social Security Benefit Awards by Single Years of Age, 1994

Number of benefit awards
(in thousands)

		Disabled workers		
Age in month of award	Retired	Total	Reduced	Full
55	—	23.2	—	23.2
56	—	21.8	—	21.8
57	—	24.0	—	24.0
58	—	25.1	—	25.1
59	—	27.9	—	27.9
60	—	25.9	—	25.9
61	—	25.3	—	25.3
62	850.3	21.3	10.9	10.4
63	114.0	12.9	9.3	3.6
64	175.2	9.4	7.6	1.8
65	395.3	0.9	0.8	0.1
DI conversions	169.0	—	—	—
New	226.3	0.9	0.8	0.1

Abbreviation: DI = Social Security disability insurance.
Source: Social Security Administration, *Annual Statistical Supplement to the Social Security Bulletin* (Washington, DC: U.S. Government Printing Office, August 1995), tables 6.A4 and 6.A5, pp. 268 and 269.

The most striking findings in the trends in disability and early retirement benefit awards by single year of age are:

- There appears to be a pent-up demand for early retirement benefits at the EEA. By far, the largest number of benefit awards are for retirement benefits at age 62.
- At age 62 and thereafter, the number of persons awarded disability benefits declines quite sharply. Thus, the early retirement reduction does not seem to pose a powerful incentive for older workers to seek and receive disability rather than early retirement benefits.

There are a number of reasons why disability benefits are less attractive than early retirement benefits, despite the fact that early retirement benefits are actuarially reduced. The incentives and deterrents to claiming benefits are summarized in figure 10-1. Deterrents to claiming disability benefits include:

- A more difficult application process, including the need to provide medical and vocational evidence of disability. Applicants must provide up-to-date medical evidence from their own doctor or undergo an exam by a physician paid by the Social Security Administration (SSA).
- The outcome of the disability claim is uncertain.
- There is a five-month waiting period after earnings stop for disability benefits, but not for retirement benefits.
- Disability benefits are subject to a stricter limit on earnings. DI benefits are fully withheld if earnings exceed $500 per month, and such earnings may

Figure 10-1. Incentives and Deterrents to Claiming Disability Benefits After Early Retirement Age

	Disability	Early retirement
	Incentives to claiming disability benefits	
Benefit level (percent of full benefit)	100 percent	80 percent today (at age 62); 70 percent for those reaching age 62 in the year 2022 and after.
Medicare coverage	Begins two years after benefits start (29 months after onset of disability); if benefits begin at age 63 or later, Medicare is available no sooner under DI than it is for retirees (i.e. age 65).	Begins at age 65.
	Deterrents to claiming disability benefits	
Ease of application process	Lengthy and complicated. Outcome uncertain. Must provide all medical evidence of record and/or undergo a medical exam by a physician employed by SSA.	Fast, simple, outcome is certain. Based solely on age and earnings record.
Waiting period	Five months after the onset of the disability and after last earnings that constitute SGA ($500 per month).	None.
Effect of further earnings on benefits	Earnings in excess of SGA after a trial work period cause full benefits to be withheld.	Benefits are not withheld if under-65 retirees earn up to $8,280 per year, after which benefits are reduced by $1 for every $2 over that amount (the monthly amount, in the first year of retirement is $690[a]).
Maximum family benefit	Capped at 85 percent of average pre-disability earnings, but not less than the benefit amount nor more than 150 percent of the benefit amount.	Higher than for DI benefits (formula is complex).
Benefit reduction for workers' compensation	If DI benefits plus worker's compensation exceeds 80 percent of the beneficiary's recent average earnings, DI benefits are reduced.	No offset for worker's compensation.

a. In the first year of receiving benefits, retirees may use a monthly earnings test rather than an annual earnings test if it results in more benefits being paid. Under the monthly test, benefits are paid for any month in which earnings are less than 1/12 the annual amount -- $690 in 1996 -- but no benefits are paid for any month in which earnings exceed the monthly limit.

Abbreviations: DI = Social Security disability insurance, SSA = Social Security Administration, SGA = substantial gainful activity.

lead to a finding that the person is no longer disabled. Early retirement benefits are subject to partial withholding, and only if earnings exceed $690 a month in 1996.

- Disability benefits are subject to a lower cap on family benefits.
- Disability benefits are subject to a workers' compensation offset, while retirement benefits are not.

In brief, the 20-percent reduction in early retirement benefits does not appear to pose a powerful incentive for workers to claim and receive disability benefits at age 62. Deterrents to claiming disability benefits appear to have a stronger effect.

In the Future

The Panel then examined whether the scheduled 25- or 30-percent differential between disability and retirement benefits may pose too great an incentive for future older workers to claim disability benefits.

The early retirement reduction is scheduled to increase gradually from 20 to 25 percent for those reaching age 62 in the year 2000 through 2005. It will gradually rise again from 25 to 30 percent for those reaching age 62 in the years 2017 through 2022. Current experience with the 20-percent reduction suggests that deterrents tend to outweigh incentives to claim disability benefits among early retirees. It is not known whether or how much this might change as the reduction in early retirement benefits is increased. Given that the increase is scheduled to phase in gradually, a policy of watchful waiting seems warranted. The Panel sees no evidence of a compelling need at this time to modify disability benefits for future disability beneficiaries of early retirement age.

If retirement-age policy, itself, is to be changed, there are strong arguments for scheduling the change well in advance so that future retirees can plan for the change in what they can expect from Social Security. Since disability is not planned, changes in disability benefit levels do not need lengthy phase-in periods. If, in the future, large numbers of early retirees do claim disability benefits, policy changes could be implemented at that time.

POLICY OPTIONS IF THE RETIREMENT AGE RISES FURTHER

Proposals to further increase the NRA raise again the issues considered in 1983 about whether the EEA should also be raised, how great should the early retirement reduction be at the EEA and whether the differential between disability benefits and early retirement benefits is a problem.

These proposals are generally evaluated in terms of their impact on retirement behavior, the adequacy of retirement income and long-range Social Security costs. The Panel offers a disability policy perspective on elements of these proposals that affect disability benefits.

Raise the Early Retirement Age

Some proposals would raise the EEA along with the NRA (for example, raising the NRA to age 68 and the EEA to age 65). Such a proposal would maintain the 20-percent reduction in benefits at the EEA that applies today.

As such, the differential between early retirement and disability benefits would be no greater than it is today. It does not appear to pose a problem now. Deterrents to claiming disability benefits seem to outweigh an incentive to avoid up to a 20-percent reduction in retirement benefits.

Lower Disability Benefits

Some have proposed to reduce the differential between early retirement and disability benefits by lowering DI benefits across the board to disabled workers of all ages.

The Panel believes this is not sound disability policy. The rationale for an actuarial reduction in early retirement benefits is that early retirement is, by and large, voluntary. It is meant to offer the retiree a choice of retirement ages without unduly encourag-

Table 10-2. Persons Awarded Disabled-Worker Benefits, by Age at Award, and Average Benefit Amounts
Disabled and Retired Workers Under Age 65, 1994

		Average monthly benefit			
		Men		Women	
Age	Percent of disabled worker awards	Disabled	Retired	Disabled	Retired
Number of persons awarded benefits (thousands)	613.3	379.3	923.4	234.0	690.1
Total percent	**100.0**				
Under age 45 (subtotal)	**35.7**		—		—
Under age 25	2.5	$397	—	$403	—
25-29	4.5	496	—	454	—
30-34	7.5	590	—	533	—
35-39	10.3	645	—	550	—
40-44	10.9	729	—	536	—
Age 45-54 (subtotal)	**28.8**		—		—
45-49	12.8	797	—	564	—
50-54	16.0	821	—	521	—
Age 55-65 (subtotal)	**35.5**		$754		$475
55-59	19.9	842	—	547	—
60-64	15.6	863	—	542	—
60-61	8.3	876	—	546	—
62-64	7.3	847	754	538	475

Source: Social Security Administration, *Annual Statistical Supplement to the Social Security Bulletin* (Washington, DC: U.S. Government Printing Office, August 1995), table 6.A4, p. 268.

ing or discouraging retirement at any age between the EEA and the NRA. Disability, in contrast, is not voluntary. People expect to retire and can plan and save for early retirement; disability at any age is unpredictable.

Further, when the rationale for raising the NRA is based on the fact that older people are living longer, it is not clear how that applies to young disabled workers. In the case of retirement benefits, the idea is that increased life expectancy should be shared between longer work lives and longer retirement. If future workers delay their retirement by the amount that the NRA is increased, their monthly benefits would be equivalent to what they would have been without the change in policy and behavior. But workers who become disabled do not have the option to delay their disability onset in order to avoid the benefit reduction.

Young disabled workers are considerably worse off financially than retirees. Men disabled at younger ages have lower Social Security benefits than new retirees.[5] Because disabled workers have truncated work lives, the earnings on which their benefits are based are less than what they would have been had they achieved their full earnings potential. This is reflected in their benefit levels. Average benefits awarded to individuals under 45 are considerably

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[5] For women, average disability benefits are higher than early retirement benefits. This occurs because the work history needed to qualify for retirement benefits is less than that needed to qualify for disability benefits. Some women who receive retirement benefits haven't worked for many years. To qualify for disability benefits, an individual must have a recent work history.

Table 10-3. Shares of Aggregate Income of New Beneficiaries from Various Sources, by Age, 1982

	Disabled					Retired		
Type of income	Total	Under 45	45-54	55-59	60-64	Total	62-64	65 & over
Married men and their wives								
Total number of beneficiaries (thousands)	111.1	17.1	29.4	35.7	28.9	573.7	433.9	139.9
Total percent	100	100	100	100	100	100	100	100
Percent of aggregate income from:								
Social Security	45	50	44	44	45	34	34	35
Earnings	24	30	28	22	18	20	19	23
Pensions	11	5	11	16	16	19	21	14
Asset income	10	4	10	11	14	23	23	25
Other income	6	11	8	7	7	5	5	4
Unmarried men								
Total number of beneficiaries (thousands)	39.5	16.9	8.1	8.7	5.8	111.3	87.2	24.1
Total percent	100	100	100	100	100	100	100	100
Percent of aggregate income from:								
Social Security	65	63	66	67	67	40	41	37
Earnings	4	8	3	2	1	15	10	26
Pensions	11	2	12	17	19	20	24	14
Asset income	6	3	9	8	7	20	19	22
Other income	12	23	10	6	8	7	7	4
Unmarried women								
Total number of beneficiaries (thousands)	32.2	8.3	7.8	9.7	6.4	182.4	128.5	53.9
Total percent	100	100	100	100	100	100	100	100
Percent of aggregate income from:								
Social Security	62	62	65	58	63	42	44	40
Earnings	3	7	3	1	2	14	12	19
Pensions	11	3	13	13	12	16	18	14
Asset income	11	3	7	19	13	21	21	22
Other income	14	25	12	9	10	7	6	8

Source: Social Security Administration, *SSA's 1982 New Beneficiary Survey: Compilation of Reports* (Washington, DC: U.S. Government Printing Office, September 1993), table C, p. 9-149; table 12, p. 14-205; and table B, p. 14-212.

Table 10-4. Median Monthly Income of New Beneficiaries, 1982 Dollars

Beneficiary type	Disabled	Retired
Married men and their wives	$1,230	$1,500
Married women and their husbands	1,360	1,470
Unmarried men	490	780
Unmarried women	460	760

Source: Social Security Administration, *SSA's 1982 New Beneficiary Survey: Compilation of Reports* (Washington, DC: U.S. Government Printing Office, September 1993), table 11, p. 14-204; and table 11, p. 9-141.

lower than those of older disabled workers (table 10-2). At the same time, data from SSA's New Beneficiary Survey[6] shows that newly-awarded DI beneficiaries depend on Social Security for a greater share of their income than do new retirees (table 10-3). Such disabled workers have lower median income than retirees; are less likely to have supplemental sources of income from pensions, insurance or savings; and have vastly smaller asset holdings, including home equity (tables 10-4, 10-5, 10-6).

It is well known that Social Security benefits are not meant, by themselves, to provide an adequate level of living. Throughout their work lives, workers are encouraged to acquire pensions and set aside savings for their retirement. Often workers do much of their retirement saving relatively late in their work careers. Disability at younger ages, however, interrupts both earnings and opportunities to save.

In brief, making an across-the-board cut in disability benefits, as a way to avoid incentives for early retirees to claim disability benefits, is not sound disability policy. Other more targeted options are available.

Change Disability Benefits Claimed After Early Retirement Age

If retirement-age policies are adopted that are believed to pose too great an incentive for early retirees to claim disability benefits, then a number of targeted approaches have been suggested to address that concern. One type of proposal would set the maximum age at which disability benefits could be claimed at some age between the EEA and the NRA. For example, if the NRA were raised to age 68 and the EEA remained at age 62, such a proposal might keep the maximum age for disability benefits at age 65.

Another type of proposal would pay a blended early retirement/disability benefit to persons who qualify for disability benefits after the EEA. For example, when the NRA rises to 67 and age-62 early retirement benefits are 70 percent of the full benefit, full disability benefits could be paid when claimed before the EEA, but disability benefits claimed after the EEA would be gradually reduced, such that benefits claimed at age 63 would be reduced to 90 percent of the full benefit and disability benefits claimed at age 64 would be reduced to 80 percent of the full benefit (the same amount that would be paid to those claiming retirement benefits at that age). Benefits claimed after age 64 would be the same amount as the early retirement benefit available at that age. Such a blended benefit would dilute the incentive to file for DI rather than accept early retirement. It would also limit the protection against loss of income due to a disability that began at older ages without abolishing it entirely.

The New Beneficiary Survey shows that those who claim disabled-worker benefits at ages 60 to 64 (or even at ages 55 to 59) are almost as likely as retired workers to have income from pensions, insurance or annuities, although their median income is still lower than that of new retirees (table 10-5). But despite their similarities in age, they have far smaller asset holdings than retirees and their income from those assets is a smaller share of their aggregate income (table 10-6). Whether this is due to smaller asset accumulation during their work lives, or

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[6] Information on the sources of income or total incomes of disabled workers is very limited. Although SSA's New Beneficiary Survey dates back to 1982, it is the only available comparison of income of newly disabled beneficiaries and new retirees.

Table 10-5. Percent of New Beneficiaries Receiving Income from Various Sources and Median Monthly Income, by Age, 1982

	Disabled					Retired		
Sources of income	Total	Under 45	45-54	55-59	60-64	Total	62-64	65 & over
				Married men and their wives				
Total number of beneficiaries (thousands)	111.1	17.1	29.4	35.7	28.9	580.1	438.7	141.3
Percent receiving:								
Pensions	41	17	38	50	53	56	57	53
Insurance, annuities	8	6	11	8	8	3	3	3
Asset income	60	39	56	64	73	83	81	90
Earnings - total	44	50	49	42	36	44	42	48
Disabled or retired worker	3	5	3	2	4	27	24	35
Wife only	40	45	46	40	32	17	18	13
Median monthly income	$1,230	$1,160	$1,250	$1,240	$1,240	$1,500	$1,410	$1,820
				Unmarried men				
Total number of beneficiaries (thousands)	39.5	16.9	8.1	8.7	5.8	112.5	87.9	24.6
Percent receiving:								
Pensions	18	5	19	32	37	41	41	41
Insurance, annuities	2	2	2	4	4	2	2	3
Asset income	29	21	30	30	47	63	58	78
Earnings	7	17	4	4	4	22	18	35
Median monthly income	$490	$430	$520	$560	$600	$780	$700	$1,070
				Unmarried women				
Total number of beneficiaries (thousands)	32.2	8.3	7.8	9.7	6.4	183.4	129.3	54.1
Percent receiving:								
Pensions	23	6	24	30	34	30	43	45
Insurance, annuities	4	1	4	6	3	3	3	4
Asset income	39	28	37	45	47	43	70	77
Earnings	6	13	5	1	3	30	29	34
Median monthly income	$460	$460	$450	$470	$500	$760	$710	$930

Source: Social Security Administration, *SSA's 1982 New Beneficiary Survey: Compilation of Reports* (Washington, DC: U.S. Government Printing Office, September 1993), table A, p. 9-144; table A, p. 14-208; table B, p. 14-212; and table B, p. 9-147.

Table 10-6. Rates of Home Ownership and Value of Total Assets of New Beneficiaries, 1982

Assets	Disabled by age		Retired
	Under 55	55-64	
Married men and their wives			
Percent who own homes	75	83	87
No mortgage	20	44	60
With mortgage	55	39	27
Median value of all assets			
Excluding home	$300	$3,600	$20,000
Including home	23,000	41,000	68,300
Unmarried men			
Percent who own home	16	30	48
No mortgage	7	20	35
With mortgage	9	10	13
Median value of assets			
Excluding home	$0	$0	$3,500
Including home	0	200	1,700
Unmarried women			
Percent who own home	31	48	58
No mortgage	12	29	43
With mortgage	18	20	15
Median value of assets			
Excluding home	$0	$200	$5,100
Including home	200	6,300	30,000

Source: Social Security Administration, *SSA's 1982 New Beneficiary Survey: Compilation of Reports* (Washington, DC: U.S. Government Printing Office, September 1993), table 7, p. 12-188.

depletion of assets due to unanticipated expenses associated with the onset of disability, is not clear from the data, but the latter is certainly plausible. It is also consistent with the Panel's findings from focus groups with older DI beneficiaries, ages 50 to 61. The focus group members regretted the loss not only of their health but also of their savings on the threshold of retirement.

CONCLUSION

The Panel finds that the existing 20-percent reduction in early retirement benefits does not appear to pose a powerful incentive for workers to claim and receive disability benefits at ages 62 to 64. Deterrents to claiming disability benefits are numerous and they appear to have a stronger effect. Between the earliest eligibility age and the normal retirement age, there are just four disabled-worker benefits awarded for every 100 early retirement benefit awards.

It remains an open question whether scheduled increases in the early retirement benefit reduction from 20 to 25 percent and then to 30 percent will pose too great an incentive for older workers to claim disability benefits in the future. The Panel recommends a course of watchful waiting. If a problem emerges as the differential between early retirement and disability benefits increases, DI benefits claimed at or after the EEA could be adjusted at that time. Unlike retirement benefits, changes in future disability benefits do not need to be scheduled in advance, because disability is not planned.

If further changes in retirement-age policy are contemplated, there are two kinds of options to address concerns about incentives to claim disability rather than early retirement benefits: raise the early retirement age, to preserve the existing relationship between disability and early retirement benefit levels; or change disability benefits for those who claim them between the EEA and the NRA.

The Panel believes it is not sound policy to reduce DI benefits across the board in order to address a problem that emanates from changes in retirement-age policy. It would reduce the incomes of all disabled beneficiaries. Disability is neither expected nor voluntary. Young disabled workers have lower Social Security benefits, less in supplemental income from pensions, insurance or savings and vastly smaller asset holdings than retirees. For these reasons, they depend on Social Security for a greater share of their income than do retirees.

Appendix

Profiles of Disability Beneficiaries

To get beneficiaries' perspectives on their disabilities, benefits and prospects for work, the Disability Policy Project conducted focus group and telephone interviews with over 60 Social Security disability insurance (DI) and Supplemental Security Income (SSI) beneficiaries or parents of young adult beneficiaries. A pilot focus group was held in Virginia in August 1994. Eight other focus groups were conducted in three sites — Iowa, New York and Oregon — in October 1994. The Project collaborated with the U.S. General Accounting Office to obtain from the Social Security Administration (SSA) lists of beneficiaries' names. Beneficiaries were contacted by phone and invited to participate in the focus groups. All of the beneficiaries contacted had filed for disability benefits within the last five years. Beneficiaries gave permission for the information to be used for the research project. Interviews were conducted by LaScola Qualitative Research and covered the beneficiaries' perspectives on their quality of life, their experience with disability and work, their prospects for returning to work and their experience with the Social Security Administration. Focus groups consisted of three age groups of beneficiaries — those ages 50 to 61, 25 to 49 and 18 to 24 — and parents of beneficiaries ages 18 to 24. Participants within each age group were selected to include a mix by gender, ethnicity and three broad categories of impairments. The categories were musculoskeletal impairments, common among those ages 25 to 61; mental impairments, most common among young adult beneficiaries but present in all age groups; and cardiovascular, respiratory and other impairments, also common among those ages 25 to 61.

Excerpts from the focus groups convey both common themes and the diversity of beneficiaries' experiences. The first sections of this appendix present profiles of participants ages 25 to 49 and 50 to 61, grouped by the three general impairment categories by which they were selected. These age groups are combined because they reported common experiences. Those ages 25 to 49 included many beneficiaries in their mid to late 40s, as is the case with the beneficiary population in general. Many in the age 50 and older group were in their early 50s and had been in their late 40s at the onset of their conditions. The final section of the appendix profiles young adult beneficiaries and parents of young beneficiaries.

Cardiac, Respiratory and Other Impairments

These beneficiaries often were very ill or had life-threatening health conditions. Many had remained on their jobs months or even years after the onset of their conditions, determined to "beat the odds" of their diagnosis. By the time they turned to Social Security, they had experienced the loss of their health, their livelihood and their hopes for ending their work lives with a comfortable retirement. Returning to work usually was not an option. Most had exhausted efforts to remain at work before turning to disability benefits. Their emphasis was on preserving their health, and often their lives, and finding meaning in activities without the psychological and monetary rewards of paid employment. Some were more serene about this than others, being grateful for their "good days" and finding meaning in family or other relationships. Many said that their claims were processed promptly by Social Security. They often had clearly diagnosed and documented medical conditions that probably met SSA's medical listings.

Accountant. Age 53, she is an accountant who worked her way up from being a bookkeeper. She has five sons and a daughter and now lives in Oregon near her daughter. She has chronic respiratory failure and wore oxygen during the focus group. Her condition was diagnosed in 1990 when she lived in Las Vegas. She applied and received Social Security without difficulty. She is very worried about paying for her medication.

In 1990, I'd just arrived in Las Vegas. I was trying to apply for work, and I just didn't feel well. I kept going into emergency. I thought maybe it was the atmosphere there, and then the doctor said "Your lungs are gone. You should be on total disability." I had no health insurance in Las Vegas. I had worked in California, and had Kaiser insurance there. So I went back to San Diego and stayed with my son.

When I applied for Social Security, the paperwork went through and everything. I had no problem. I just couldn't believe that I was totally disabled. I still can't believe it. I'm getting more oxygen to my brain and I'm getting more aware. But I don't have the energy. Even walking a block, I'm out of breath — and it isn't getting better.

I thought at this time of my life I'd be comfortable. Not wealthy or anything, but all right. But with the increases in drugs, you can't make it. It's going to get worse. It's not going to get better. The longer I live, the more medication I have to take. The bills just keep mounting. I don't want to worry about it, because it just makes it worse. I pay $81 a month for my insurance, and I have to pay 70 percent of my prescriptions. At this point, I've been charging my prescriptions, because they've been running over $100 a month. I applied for family services, senior disabled services. I should know today whether I'll get assistance or not. If I don't, he says to keep trying. I may be able to get them to pick up the prescriptions.

Management Secretary. In her 40s, she had been a management secretary in a hospital in Iowa. She has cancer and worked after her first surgery. After her second surgery she applied for Social Security and qualified quickly. She also receives a disability benefit from the hospital where she worked.

I probably look pretty good, but I have a tumorous cancer that could not be removed by surgery. So I have gone the chemo/radiation route. It's in remission now.

I had cancer before and was able to work through my first surgery. Then when it occurred again, I was working and I tried to go back to work after surgery, and could only maintain about two weeks and I couldn't because of the pain, and so forth.

The hospital gave me options to come back to work. But you have to look at it long-term. They've seen you when you've been able to perform 100 percent. Now with your illness, maybe you can only perform 50 percent one day, maybe 30 the next. Maybe one day you just can't make it to work. So eventually, you're not going to have a job because you cannot fulfill that obligation.

My first disability benefit was through the hospital. Then I called the Social Security office. Mine went right through without any problem.

With cancer, they say a lot of times most of your therapy is your attitude. I don't plan to go back to work. I don't know how long I have. I haven't been told yet — it could be any time. So I try to take a very positive attitude so I don't make myself worse than I am. There may be a chance maybe later on, to find something in therapy or medication to live longer. We take a day at a time.

Financial Services Representative. In his 40s, he lives in Virginia. He was diagnosed with multiple sclerosis (MS) two and a half years ago. He worked 20 years for an insurance company selling financial services. He kept working until his vision declined to the point where he was no longer able to read or drive. His motor coordination is faltering. He was initially denied Social Security before being allowed on appeal.

For me, a good life would be just being able to be mobile. To be able to walk more than 3 blocks without falling down. To be able to see so I can drive and get myself around.

I was originally diagnosed as having MS in August of '91. And I went through approximately two years with no major problems. Around June of '93 my vision got to the point I was having problems seeing street lights. Finally, my wife insisted I stop driving. I had to stop working in August '93.

I have a good relationship with the executives of my company. I've been working with them for 20 years. And they have been very fair and very nice to me. They have tried to come up with alternative things I could possibly do while I am on disability. But because of not being able to read properly, that has created problems. But one of the things we've talking about is my giving little speeches, motivational things, you know, for prospective agents.

I try to stay active. For example, my daughter's in college and my wife works, so I do the cooking. I can't see what I'm cooking, but I can still try to cook it. I do things around the house, so I feel like I still have some self-worth. Your body and your attitude can adjust. I mean, I fall down all the time now. So I just get up. I just keep getting up.

Private School Teacher. A widow in her 50s, she has lived in New York City all her life and had taught 12 years at a private girls school. She had heart surgery nine years ago and returned to her job after being out for six months on temporary disability. In January 1994, she again had heart surgery and found that her condition was more serious than she had expected.

When I had surgery the first time nine years ago, it was great to get back to work. In January I went to have surgery again to get a new valve. I have a leaky aortic valve. But when they went in they found out I had a silent heart attack. So instead of doing the two operations — they did it with the balloon. The doctor said, no, I should not go back to work this time. It would be too much.

I had 52 weeks of disability benefits from the school. After that I went on Social Security disability. I'm a widow, so I got more on my husband's than I did on mine.

I had no problems with Social Security. It went through the first time. The business office in the school helped me file. She filled out certain things and the doctor had the information. I waited the six months. But I had no problems. I get a pension from the school, too. They'd only started it maybe nine years ago. So I get something from them too. And then from my husband's job, too. Thank goodness.

Clerk, Nurse's Aide. In her 40s, she has been a file clerk, a singer and a nurse's aide. She lived in Detroit and Dallas before moving to Iowa. She stopped working 4-5 years ago because of severe headaches. She was diagnosed with brain tumors, one of which has been removed. Two were inoperable.

I stopped working because I was having real bad headaches. My cousin told me to go get my head checked out. When they cut my brain — opened me up — they saw three tumors in my brain. The doctor said he's going to remove one, but he couldn't touch the other two. They were right in the middle of my brain. I could have died or lost my speech forever. I didn't used to talk this way. But the doctor told me, he said, "Baby, you're getting up fast!" I said, "Yes, I want to get on." And three days later I had another stroke. I couldn't talk. I couldn't walk. I couldn't do anything. That's why I thank God for every day that he gives me.

The state of Iowa told me to go on disability. They put me on Social Security straight out of the hospital. They just automatically put me on. I did not know it then.

A good life? A good life would be if I could quit hurting. Every morning I take Phenobarbital, aspirin, I take a nerve pill. I take them all. And if I really want to do something, I do it. I just put my mind to it. There's a higher power in me to feel better. Every day when I wake up, I sit up and look at the sky and say, "Thank you, Jesus, for another day."

Switchboard Operator. Age 41, he had been a switchboard operator at a hotel for years. While hospitalized with pneumonia, he was diagnosed with emphysema. After his health insurance with the hotel ran out, he went on welfare and received Medicaid. The welfare office referred him to Social Security.

A good life? Being able to create something, like write a book or make a movie, just doing something positive. Leaving a mark that you did something with your life, or being able to help someone else. I like to go shopping with my roommate, to help her carry the packages. Even though it takes a lot out of me, it feels like I'm accomplishing something. It helps my peace of mind.

I had a lung operation in 1991 because I had a complication with pneumonia. I have severe emphysema. For a while I didn't know I could collect disability. I was on welfare. They told me to go to Social Security.

I was on Medicaid. Before that I was on the hotel's insurance. But, they only give you a certain amount of time after you're out of work, then they don't pay your health benefits.

Just getting to a job would be hard. I could only work two hours at a time. Maybe being able to rest would help, but that wouldn't be very productive. Who would put up with that? My doctor said I shouldn't.

Day Care Center Worker. In her 50s, she had worked in a day care center. Both she and her partner were diagnosed with HIV. He has since died. She was referred to Social Security by public assistance and had no problem qualifying for SSI. Her illness came as a great shock. She is determined to keep a positive attitude to fight her illness.

About five and a half years ago I was starting to feel kind of sick. At that time, I was living with this guy, and he started getting sick. I wanted him to go and have himself checked because there was a lot of things going wrong with him. I felt that I didn't need to for the simple reason that I was never into drugs, I was not running around. Before that I was a housewife with my children and my husband. It turned out that he had the HIV virus. I was hysterical. I went into a depression. It was hard for me to deal with the idea that he had HIV.

I went to have myself checked. And it turned out that I came down with HIV myself. So I started crying, "What do I do now?" I never thought of myself as being in that situation. I loved to work in the day care with the children. I could never go back. That was my first reaction, "I can never be around anybody now." I felt like I was contagious. But anyway, about four and a half years ago is when I did find out, and I went to Social Security and they started giving me SSI.

I was on public assistance at the time. Public assistance sent me down to Social Security. They approved the SSI, and I've been on SSI right now for four and a half years. But it's a struggle. Living from one month to the other. Food, rent, and everything. All I get is $10 of food stamps. I go to the store once and they are gone. That's it.

Lately, I've been very sick. I try to keep my attitude positive — going to church. And I have gone to groups with people with HIV. It's the only thing that keeps me going. The guy that I was with, he passed away last year. It has been some rough times. But I am a survivor. I won't let it get me down.

Nurse Manager. Age 50, she has lived in the Portland area for 25 years. She had been a nurse manager in charge of eight departments in a hospital. She was diagnosed with lupus in 1986. Despite her doctor's prognosis, she kept working for 18 months after her diagnosis. But she ultimately had to leave her job and claim disability benefits from the hospital and Social Security.

A good life? Just to be able to do the things that I had thought I would be able to do when I reached this point in my life.

I have lupus, and I've had it most of my life. In 1986, I thought I had a heart attack. And they found out it was an infection around my heart. There are very few reasons why it should happen, and one of them is lupus. And we went back over all my records and did more tests. When I was first diagnosed, my physician said, "You won't be able to work any longer." And I laughed at him, because I wanted to prove him wrong.

I didn't want anybody to know that I was not well, and finally it became evident that I could no longer function. It took me a half hour to walk half a block from my car into the hospital, and when I got there I had to rest for an hour. I just didn't have the energy to get upstairs to my office. My staff members carried a lot of my load for me. When I found that in an eight hour day, I was spending four and five hours just trying to gear up the energy to do something — it was time to leave. After 18 months, I decided on my own that I needed to leave, because I couldn't carry on any longer.

All my medical records were documented for about five years. And there was never any question about whether I would get Social Security. I turned it in and I got it. I got a letter in about two months, saying your disability will start — once they settled it with the disability insurance from the hospital.

Musculoskeletal Impairments

Beneficiaries with musculoskeletal impairments included many who had back injuries and chronic pain. They reported difficulty with a broad range of physical functions — walking, standing, stooping, lifting, sitting, even sleeping — and some had difficulty with concentration due to the pain or their medications to ease it. They shared a common experience that employers, insurers and doctors often were not sympathetic to their conditions, particularly when workers' compensation was involved. Perhaps because pain is difficult to diagnose, measure and treat, many felt accused of malingering, often being told, "You should be better by now" or "There's nothing wrong with you." They had typically remained on their jobs for a time after the onset of their injuries. Some had aggressively sought other work and were still looking. Some found that both their age and medical history reduced their appeal to prospective employers. They typically qualified for Social Security disability benefits only after lengthy appeals. The long hiatus between earnings and benefits had often wiped out their savings. While they expressed frustrations with the Social Security claims process, their feelings about workers' compensation were even more negative.

Custodian. Age 53, she lives in Oregon and is a mother and grandmother. She has worked as a hairdresser, a sales person in cosmetics, and most recently as a custodian, where she has worked for six years before she was injured on the job about five years ago. She uses a scooter. She is very angry about her experience with workers' compensation. In Oregon, workers' compensation is administered by the State Accident Insurance Fund (SAIF). After receiving compensation for about four years, she had a heart attack. When her workers' compensation ended, Social Security determined she was disabled. But she had lost her insured status for DI and qualified only for SSI. Social Security, apparently, set the onset of her disability after her heart attack, rather than at the time of her back injury.

I was injured on the job and that was a disaster. I feel that somebody should do an investigation of the SAIF. I went through hell.

Well, I weighed 110 pounds. I was strong as a horse. I could outwork anybody. I was a custodian. I fell down the stairs and injured by back, sacroiliac and my hips some. I just couldn't work any more. I was in pain. They kept telling me there wasn't anything they could do to stop the pain.

I went through four years of misery with the state workers' compensation. They were giving me my money — but they wouldn't train me. They kept saying, "You apply for Social Security." I applied for my Social Security. Social Security said, "You can't apply for Social Security when you're on workers' compensation." We went through this for four years.

The doctor said I couldn't do the work I was doing. I tried to find other work. I went back to the drug store. I thought maybe I could at least clerk for a while. No way. They wouldn't hire me. Number one, they said my age. Number two, they said I'd been on disability for a year. I was now a risk.

I begged the insurance company to help me get other work. My doctor said, "She can't do that physical labor anymore. Train her." I went through a year of aptitude testing. They got me all set to go into a program. It was a medical records certification course. I really was excited about doing that. It was two years and you're certified. That would have been fantastic. At the last minute they said, "Sorry, we can't send you to a two-year program. That's too long. You'll have to find something else. We're going to send you to Goodwill." I keep trying to think of the straw that broke my back. That was a big one.

I think that's why my health deteriorated. If you're fighting all the time just to survive — with an insurance company that you've paid for — then the rest of your health goes. That happened to me. I had a stroke. I had a heart attack. Then Social Security finally says, "Yes, you're disabled all right!"

SAIF then dropped me and I was in the middle of fighting them. The thing that hurts is, after five years of this misery and my health goes down, and Social Security finally accepted me as disabled, they told me, "Well, you can't get Social Security because you don't have the earnings credits." I didn't have enough credits because I didn't work for the last four years. So because of that job injury and that insurance company, I lost all my Social Security income. So then they put me on SSI, which in the long run turns out to be better for me. Because now I'm on Medicaid. My medical costs are like $1,200 a month. But, it's still not right. I'm just so angry.

I've been downing everything, Let me say one good thing. It if wasn't for Medicaid from the State of Oregon, I would be decayed in the ground because I had no other insurance. I have $1,200 a month worth of pills and medicines and treatment. And if they hadn't helped me, I'd be dead. And maybe it would have been just as well. I've certainly felt that way. But my children and grandchildren don't. So, I want to say that I do appreciate Medicaid.

Nobody wants to be disabled. Nobody wants to live off the state. I'd love to play with my grandkids and start hiking and bowling again. It's a great loss.

Contractor and Carpenter. In his 40s, he has been a carpenter and contractor for a number of years. He moved to Iowa from Illinois, where he had been injured on the job. He had back surgery, and after the surgery, developed deep venous thrombosis in his lower left leg, which he described as 2 1/2 inches bigger than the other due to the thrombosis. He walks with a cane. He received no cash benefits from the company where he was injured. He qualified for Social Security without difficulty. In Illinois, workers' compensation is administered by private insurers or self-insured employers. It is a state where employees have a choice of their doctor. He has worked with a professional job locator and put out over 300 job applications, but has not yet succeeded in finding other work he can do with his disability.

I was hurt on the job. They had a fire, and this man turned the fire hose on and it blew him off a four foot platform. I tried to catch him. The fire hose hit me and he landed on me and knocked me down. Immediately, I was suffering a lot of pain. So they sent me to the doctor, and he confirmed I had something wrong. Then they brought me back to work. I never missed a day of work. The doctor put me on light duty. They put me on a stool that was three feet off the ground, and they had me bending over pulling trays of nuts and bolts out of the bottom to separate them. And I just couldn't *do it. I told them I'd get on my knees and do it and they said, "Well, you should be getting better by now." It was just intimidation on their part.*

I went 10 months at my company after the injury and did not receive a dime in benefits. Never have received any money. I was hurt there. I was automatically alienated from any benefits. I never received them, and to this date have never received them.

When I applied for Social Security, I went to a Social Security doctor, and he said, "You're really messed up." He wrote a letter and they just took me right through and it was all said and done.

I had a professional job locator I worked with for quite a few months. I put in over 300 applications. I didn't even get a call. That's pretty discouraging. I made phone calls. I did everything I could. It's like me and her starting out. She's 18 years old and I'm over 40. I've got some serious problems going on, and this kid here is right out of high school. They are going to hire her. They wouldn't even look at me. They haven't looked at me.

Technically, they are not allowed to ask if you have a disability. But they have asked me how come there's a lapse between this time and that time on my resume. I said, you know by law you're not allowed to ask. He said, "Well, if you want a job, I've got to ask you."

I can understand how people don't understand pain. I know what I used to think. I had an uncle that was built like a gorilla, a muscle man. He had a back that was absolutely shot. To look at that guy, his chest and arms, you'd think, "He could lift a tank!" But the poor guy could hardly walk. If I didn't know him, I'd think — what's your problem?

I'm six two, and I weigh over 200 pounds. People are looking at me like, "Look at this big strong guy. What's the problem?" I was the second highest on medication in St. Anthony's Hospital. I've never been a drug addict. I've got a real high tolerance to medication. I do not take medication now. Because I'd have to take it by the handfuls — and I'm not going to do it. I'm in pain right now. You learn to live with it.

In the time before my benefits went through, we went through all our savings. I own my house. That was fortunate. I didn't have to pay rent. We went almost a year between my last pay and when Social Security came in. So we were down to our last $500. It just wiped us out.

Hospital Transcriber. In her 40s, she worked at a hospital doing surgical transcriptions. She had also been a school teacher and a church organist. Before college she sold encyclopedias, waited tables and tended bar. She has multiple back problems and is very bitter about her experience with workers' compensation. In Iowa, workers compensation is administered through private insurers or self-insured employers. Iowa is one of the states where insurance carriers select the physicians that treat injured workers.

I've had a four level fusion which was not successful, and a rhizotomy which also was not successful. I have a cervical spine problem that I am reluctant to have surgery for because the other surgery has not been successful.

I was working in a hospital when I was injured. The big shock for me was that other people did not have any grasp of what was happening to me physically. They do not understand pain. It's always a surprise to tell somebody you worked side by side with, that you're in tremendous pain and that you can't do something.

When you're injured in a work comp setting, you find that people change their attitudes toward you. There was a little indictment. You can see yourself losing respect in their eyes, because you've been injured on comp. So you try to not show the injury. In physical therapy, I can look back on doctor's reports and see a difference. I think they think we are malingering. Faking it. Even though you're not, there's a judgment. "Well, you should be better by now."

I think people who are injured on comp are discouraged from connecting with other people. I used to go to chronic pain support group meetings at Mercy Hospital. About 50 of us showed up. And it was the most reinforcing, affirming thing I'd experienced. But I *think what happened, too many of the comp people were expressing their true feelings about the way they've been treated, and for some strange reason the group was disbanded. It was not for lack of participants.*

I went to the insurance company doctor to see if he could help me. He said, "Did your attorney send you here, or did the insurance company send you here?" And I said "The insurance company." He closed my file and said "Well, I don't think anything else can be done for you." And I said "What am I supposed to do?" And he said "Go into business for yourself." I said, "If I can't work for somebody else, how am I going to go into business for myself?" And he said that maybe I should go on disability. That's when I applied for Social Security.

Meatpacker. In his 40s, he lives in Iowa. Married with two teenage children, he has been a laborer all his life. He sustained a back injury on his last job at a meat packing company. He has had back surgery twice and lives with chronic pain.

He apparently received no workers' compensation income, although he did attend a workers' compensation seminar. It took three years for his Social Security to be approved on appeal, during which time his family depleted their savings and turned to relatives for help.

You asked, "What is a good day?" A good day for me is to wake up once without pain. To go one hour without pain. It doesn't happen.

When it [back pain] first happened to me, I was told I had a muscle spasm. They sent me back to work. I pulled between 75 and 100 pounds of meat every two and a half seconds. I did not miss a day of work. They told me I was faking the pain.

My co-workers told me you have to pull your number, so I did. When you work in a packing house on a line, there's four of you. You might be number one, two, three or four. One coming up, that's your number to pull off the line. They were telling me I couldn't pull my number. I was determined to prove that I could still do it. I'd trained them. I knew this job. But it took half an hour for me to get on the line, find a comfortable position to pull my load. It went on for a month, month and a half. And it got to the place where I couldn't do it. But then they said I was goldbricking.

When I went to the company doctor, he told me there was nothing wrong with me. They said, "Here, go into the back room and they'll give you a treatment with infrared. You can be back to work in no time."

I went to a seminar probably two years ago. They call it "Workforce." It was through the workman's comp. And I was told by them repeatedly there is nothing wrong with you. We want you to go out and get a job. I put out applications and didn't get a call back.

At home, my wife got tired of me laying in bed crying because my back hurt. You can't lay down. You can't sit down. You can't stand up. You can't do anything.

It took me three years to get Social Security. And I had to go to court to get it. I went to court on a Friday, and I had surgery on the Tuesday. The judge says, "When did you have your last surgery?" I said, "Three days ago." He said, "This case is closed." Because when I was there I told him that I could not sit down — and I couldn't. I was there merely five minutes.

In the three years before I got any kind of disability money, we used our savings, which are long gone. In the last year and a half, my family helped us out.

I'm a laborer. I've been a laborer all my life. I worked in factories. And I would rather go back to the job that I got hurt on. Because that, to me, is the hardest job I ever had in my life — but to me it was the best job. But I don't think it is possible for me to pull 50 pounds of meat off the line every couple of seconds. And there's nothing they can do. There's no such thing as light duty in a packing house.

Salesperson. Age 57, he lives in Oregon. He sustained back and leg injuries in an automobile accident 2 1/2 years ago. He worked in sales and sales management and had been a coach in the past. He believes that he should have qualified for the company's disability benefits, but did not learn about them until after he was laid off because he was no longer meeting his sales quota. It took him two years to be allowed Social Security on appeal. While waiting for his Social Security, they relied on his wife's earnings until she had a heart attack. Her Social Security disability claim is now on appeal.

I was injured in this car accident. I was rear ended. But it wasn't during work, so it wasn't covered by comp.

I tried to continue working for about three months after the injury, because I'd just started with this company. But during this time I was spending most of my time at the doctor's office or getting therapy. I was in outside sales. And my numbers were going down. My supervisors were constantly on me to produce. But the people I was working with couldn't understand how I was up and around. It finally got to the point where I was asked to leave. I couldn't maintain a quota. They couldn't afford to keep me on.

Little did I know at the time that I should have gone on the company's disability. I could have drawn benefits — 70 percent of my salary until I got better — if I got better. I found out about that after they let me go. Then I read the policy. But it was too late to go back and say, "Wait a minute!"

When I was out of work, people were saying "Well, there must be some kind of work that you can find." I can't stand for long periods of time, I'm not supposed to sit for long periods of time, I'm constantly up and down. The only position I'm comfortable in is laying down. I'm on pain medication, I take it every three hours. So I finally gave up. I tried, but I couldn't do it.

Then it was fighting the Social Security system. It's about a two-year scenario. They tell you right there in the Social Security office. You get denied, then you ask for a reconsideration, and then you appeal.

My wife was working and we had a small amount of income from her — but my income went from about $2,000 a month down to zero. We squeaked by with her income, and fell further and further in debt. My Social Security was finally approved in June of this year, and it went back to August of the year that I had the accident. However, I lost the first six months. And I paid $4,000 out of my back benefits for the lawyer.

In December of last year, my wife had a heart attack. All the doctors she has seen have told her she cannot go back to work, now or ever. She filed for Social Security and has been denied. Here she is with all these medical records. What do you have to be, in a body bag? I mean, mine wasn't as definite as hers, because mine was pain and suffering, and tissue problems in my lower back and legs. Hers, it's right there, heart attack, insulin dependent diabetic, asthma and high blood pressure. Yet she's denied and has to appeal.

Until my wife gets her Social Security, we're not going to make it. I always thought when I was younger, growing up and working, that when I reached a certain age and level, retirement time, things would start being a little easier. Well, it's turning around the other way. It's getting harder and worse, and there's just nowhere to turn, no help available.

Restaurant Manager. In his late 40s, he has a history of back problems that goes back 20 years. He has had five back surgeries and reported he has two steel plates and six screws in his spine. He lived in Michigan, where he had managed a restaurant, before moving to Omaha, where he had his most recent back surgery. He recently moved to Iowa. Before he was a restaurant manager he had been a personnel manager in retail sales. Having been in management, he understood employers' concerns about employing and paying benefits for high-risk employees. Because of his chronic back problems, he has had experience with medical care financed by workers' compensation. He was covered by private long-term disability insurance on his last job. The insurer helped him appeal his denial of Social Security benefits and offered to help him find other work. He is still looking.

A good life? To live without pain. If we rate pain on a scale of one to ten, a five is a good day. Eight or nine is a bad day. So, you learn to live with what you've got left and go from there.

All the comp carriers I have dealt with have certain doctors they send you to. The doctor in Michigan, all he wanted to do was give me pills. He had me on so many pills I hardly knew day from night. They want to push you back into the work force. In my type of *business, there is no light duty. Everyone has to carry their own weight. I was in management, but don't let that fool you. I used to go out there and load trucks when that had to be done.*

To get the medical treatment you need, you have to keep pushing until you get somebody that could possibly help you. When they finally sent me to the orthopedic surgeon, who was not a comp doctor, you get the feeling that because you're on comp, you're some kind of a drag on the earth. Comp, you know, pays doctors less than they get from private insurance. After a period of time, the comp carriers were not paying the medical bills on time. Then the doctor wants you to settle up. You've got enough to worry about making a living and making ends meet without having to worry about making comp pay your doctor bills.

My back history goes back about 20 years. I've learned to work through pain. And I've had some good years, too. The restaurant that I worked for took a chance on me, quite frankly, by hiring me knowing my history of back problems. That has to be on their minds because the employer pays the premiums for workers' comp claims. I can appreciate what they go through. I was a personnel manager in retail for about 5 years, and then being in the restaurant business — I know what they feel. I have to have this person in this position 38 hours a week, and get this much production out of them — or I don't need them.

It got to the place where my back just finally gave all the way out. The long-term disability carrier is willing to train you to go back into another position. My problem is I can't stand for a long period of time. I can't sit for a long period of time. And I can't be on my feet, as far as walking, for a long period of time. Driving is the same way. So I'm trying to find something else. I've been thinking about real estate. If there's something out there, I'm going to find it. It's just that right now the pain is too debilitating. And I have another minor surgery scheduled in November.

After I was rejected for Social Security in Michigan, the long-term disability carrier said they would pay the legal cost for an attorney. So, in the Iowa branch of Social Security, it went right through. When I got on Social Security, my LTDI went down. They pay the balance up to your "reasonable wage." But they don't count your bonus pay. That's where you really get killed, when you work on bonus programs. I'm drawing one-third to one-quarter of what I was drawing in management.

We're all nervous about whether you can handle another job or not. Can you do it? Or will we go back through this whole thing over again — surgeries, rehabilitation. It's scary. We can laugh on the exterior, but you cry on the inside. You don't know what tomorrow will bring. Yesterday it brought pain.

Information Analyst. In her 50s, she was an information analyst at a New York hospital for 29 years, where she dealt with third-party insurance claims. She also was a violinist and did volunteer advocacy work assisting elderly nursing home patients. She has arthritis, sciatica and spinal stenosis that was exacerbated by a fall at the hospital where she worked. She has dealt with bouts of depression in the past. Her mental health declined after her injury. Her Social Security disability benefit is reduced by the amount of workers' compensation payments she is entitled to but is not receiving.

I have worked with my health problems for 30 years. Stenosis, arthritis and sciatica. I was happy, my work kept me going. But then I had an awful fall, and with stenosis, it's all you need, for things to break. I had a serious problem with my spine, lower and upper, and I went into such a depression.

After the first fall, I was off for a while. When I went back to work, I was severely depressed. And they knew, unfortunately. The hospital had to pay for my psychiatrist. Before my fall, I felt as an analyst I was never second-guessed. But now I was, and by people I had trained and promoted.

There is a terrible misconception of depression and being able to perform. I have worked with depression for many years. I was able to go along with it. But *when they know that there's something wrong, then they kind of belittle you. That's how I felt. I tried desperately to work. I had my second fall. It's been an incredible nightmare. It does not even allow me to play the violin, which I love, or clean my house, or do anything.*

When I fell I was sent to the workmen's compensation doctor. He would not even give me an x-ray. I had to sue workmen's compensation in order to get an x-ray. That's how bad it was. And I worked in the hospital.

Comp is the most humiliating thing that you can deal with. My problem is not with Social Security. But I was assigned a very small amount of Social Security based upon what workmen's compensation should give me on full disability. But the insurance company who carries workmen's comp refuses to pay me. I'm going to court with the insurance company. In the meantime, Social Security is just sending me a very small amount — thinking that I'm getting the payment from workmen's compensation. So I have to cash my IRA and cut my expenses in order to survive. I was making a decent salary. It's so frustrating.

When I found myself on Social Security, struggling for myself this time, I could not believe that it was I who was asking. I was very upset because I felt I'm supposed to be doing this for others. For years I've helped other people get the benefits they are entitled to. Here I am myself. When you're sick, it is hard to be your own advocate.

Mental Disorders

Participants in the focus groups who had mental disorders were also a diverse group. Many were taking concrete steps to get treatment and improve their situations. Some were working, others looked forward to returning to work, although with some trepidation. Like those with back injuries, they felt a stigma attached to their impairments. Having an advocate — whether a son, mother, therapist or community mental health clinic — was a key link in getting connected with supports in their communities. Those with mental illness were generally being treated with costly prescription medications, often financed by Medicaid. Medicare does not cover outpatient medications. If they were able to earn enough to leave the benefit rolls, continued coverage of their medication would be essential.

Musician. In his 40s, he is a musician. During the years when his schizophrenia was in remission he taught piano. A Virginia resident, when his mental illness returned he enrolled in a research program at the National Institute of Mental Health (NIMH) to test a new drug to treat schizophrenia. It has helped him. It is very expensive and he is grateful that Medicaid covers it. He hopes to work again.

A good life? I'm sure that every one of us would answer that question by saying, "If I didn't have my disability..." In my case, my good life would be totally free of mental illness. I had been schizophrenic, but I had achieved 15 golden years of remission, during which time I was teaching piano. I'm a musician, even a composer in the past, and a pianist. So during those years I was doing great. I was in remission. And then the voices came back. I got sick again. I got so that I couldn't put a sentence together. And I was totally out of it. Schizophrenic, you know. I just couldn't work any more.

My mother heard about the NIMH program, because she's always looking around for new things for me. Basically, the reason I went to NIMH is to try Clozapine, which is a new drug. It worked on me. After I entered the NIMH research project, I was able to get Medicaid and Medicare. Before that, Blue Cross wouldn't pay my bills because they didn't cover mental illness. My family's paid most of my expenses, the shrink and whatnot. But when I went to NIMH, I guess that cinched the fact that I was schizophrenic, or I wouldn't have been there, right? As a result, I think, that's how I got Medicaid and Medicare. They take care of most of my expenses. Medicaid and Medicare really does help a lot with Clozapine. I pay $1 a week for my medicine. That's really a bargain. I wish everyone could have that.

The people that I like to hang around with are the people that are caring and concerned about you and you can do the same thing for them. My family for instance. I found that when I was diagnosed with my mental disorder, all of a sudden I was a loony. I was crazy. People didn't have anything to do with me. So being in recovery as I am, I've got friends now. People who I can call and talk to.

As a recovering mental patient — I'm pretty close to being recovered now — they have a great thing, a social rehab center. And I go every morning and that helps me, too. It's a structured environment, sort of a mixture of work and play. In the afternoons, I work on my music.

Sheltered Employment Worker. Age 57, she has three grown children and has lived in Portland for 22 years. She has chronic depression, and had been receiving SSI until she recently began receiving Social Security benefits on her deceased husband's record as a disabled widow. She has worked as a microfilm reader. Currently she works part-time in a vocational rehabilitation program where she is paid $1.86 per hour.

Well, I'm in good health physically, and I feel very grateful to God for giving me good physical health, but I've been going through depression for about 30 years, pretty severe depression.

I worked at a credit union as a microfilmer for about six years, working about eight hours day. If I hadn't had my religion, I don't think I could have kept working on that job, because I was in a room all by myself working on this computer. And it wasn't working half the time. The work wasn't coming out right. I don't know how I stuck it out.

I've had depression most of my life. I'm still depressed, but I'm doing better now due to the fact that they've got me on the right medicines now. I'm very grateful for that. But it has taken years of trying to find the right one that would at least ease the depression. Maybe not completely take it away, but at least ease it some. But through the help of my friends and family I have been able to keep going.

I was getting regular SSI before. Now I'm getting the widow's disability pension from Social Security. They are two separate payments. My son helped me. I don't know how he managed to do that — but he made inquiries after my husband died. Now I'm getting quite a bit more than what I was receiving before. I get my medicines through the spend-down program from adult and family services.

Now I'm working part-time. It's with vocational rehab at the Network. I heard about it through the mental health clinic where I go as a patient. They do bulk mailing. They do it part-time and I've been there going on six years. You only get paid $1.86 an hour. But I realized even though I wasn't getting paid much for what I was doing, it's the sociability. Just being with others and knowing you're extending yourself toward others.

Home Shopping Club Worker. In her 30s, she has lived in Iowa three years. She has severe diabetes and major depression. In the past she worked at the Home Shopping Club. She was turned down for Social Security six years ago. When she reapplied three years ago, her application went right through. She now receives DI and Medicare.

A good life? I think waking up in the morning and feeling good about things. I take 30 pills a day. Depression gets hold of me pretty easily. I'd like to just be able to get up and say, "Gee, it's a new day." But it doesn't work like that.

My problem is everything overwhelms me. The simplest thing, like doing the dishes or making the bed. It just overwhelms me and I can't handle it. So I just try to figure out why I can't do these things any more.

Mine started when I was really young. I was sexually abused by four members of my family. For years I just didn't think about it, until it got to the point you just can't not... People don't understand mental problems. They don't understand at all. It's, "Well, you should be able to just put that behind you and go on." Even my in-laws are like that. "Just forget it and go on." Well, how do you just forget it and go on? People treat you like you've got the plague or something. They think if you've got major depression, you're crazy.

I applied to Social Security six years ago and they turned me down. I applied the last time three years ago and it went right through. Before that I'd had 17 jobs in three months.

I'm going to start school here. The newspaper sponsors a 16-week course in computers and they try to get you into a job you can handle. I learned about it through my therapist. I'm nervous about the training. Whether I can do it or not. The last time I held a job I had a nervous breakdown.

I'm kind of in a mess right now because Medicare doesn't cover any of your prescriptions. And my prescriptions run $800 to $3,000 a month.

Graphics Illustrator. Age 52, she lives in Oregon. She has held numerous jobs in the past including one as a graphics illustrator. She describes herself as slow. She has difficulty keeping jobs and finds that employers expect more from her than she is able to perform. She has tried to find other types of work, but has been unsuccessful.

I've been disabled all my life with dyslexia and learning disabilities. I never realized I was disabled, I just thought I was a slow person. I held jobs where speed wasn't important for about 20 of my years in the advertising business. Leaning over the drawing board started bothering my back.

I started other types of work, and found out speed was more important than quality. I didn't have trouble getting a job, but I had a hard time keeping a job, because they expected my speed to improve after the probationary period, but it never did. So I've had 33 jobs in my life. The state job service had difficulty finding the right niche for me. They recommended that I go to vocational rehabilitation. They were the ones that advised me to go to Social Security.

Young Adult Beneficiaries and Their Parents

The young adult beneficiaries were a highly diverse group. For some, SSI benefits were a temporary source of support while they attended college in preparation for professional careers. Students with vision impairments reported they had received support from public agencies such as state commissions for the blind and had good experiences in elementary and high school. Some beneficiaries with cognitive impairments were working part time at low pay and were connected with social workers or skills trainers who helped them manage their affairs. Others reported excellent support from their families. Some young beneficiaries had impairments with sudden onset, including head injuries and physical trauma from automobile accidents, and were still recuperating. Parent interviews included some whose adult children had very significant impairments that precluded work. The parents wanted their children to be treated with dignity and respect and to live with as much independence as possible.

College Student, Special Education Major. He is in his 20s and lives in Oregon. He was born with ocular albinism and is legally blind. He was informed about SSI when he turned 18 and qualified without difficulty. The State Commission for the Blind pays his college tuition, where he is studying special education.

As far as effects of my disability on my life, I can't drive. I have to commute. That affects job searches. I read very slowly and need to pay for a reader. It will take me five years to complete a four-year degree. It seems that manual jobs, for those who don't have degrees, rely on ability to see well. This limits what jobs I can do. In my hometown, which is real small, I had a special education room and teacher available any time. And I had a note-taker in math class. Sometimes people don't know about my disability just by looking at me (if I'm not reading). It was important in high school that people didn't know about it. But now it has shaped who I am — I like the way I write — people think I write funny because I couldn't see how the teacher formed the letter on the board. So I think that your mindframe is just as important as the physical disability.

I've had several jobs. Managed a Subway in high school, KFC cook, cleaned motel rooms and now manage an apartment building on campus, in return for my rent.

I'm studying special ed and plan to teach as a "Handicapped Learning Specialist." I do drama workshops in the summer — the kids love me. It will take me three more years to get my masters degree.

Quality of life? Fantastic! I'm getting married in three months. We've been together for six years and this is a good time for us. I can't see me not having a regular job. I'm going to have a real nice career and SSI has gotten me through college.

College Student, Visual Arts Major. She is in her 20s and lives in Iowa. She works in an art supply store and attends college. Legally blind, she receives funds from the state department for the blind that helps her pay for a reader service, books and supplies. She has a scholarship from her college.

My sisters and I were born with cataracts that were removed at an early age. We all learned braille as a precautionary step. In school we used tapes and cassettes and large print books. But I did not attend any special education classes.

I had a very high GPA in high school and receive a merit scholarship to attend college. I'm a visual arts major and want to write and illustrate children's books.

Because of my disability, I don't drive. I commute by bus to get a job or have to pay a driver. I also have a reader for classwork. The state service with rehab helps pay for that.

A counselor from the department for the blind set up a work and school plan with me. I love my job at the art supply store. They knew me because I shopped there frequently. I know a lot about the supplies. But I can't read the cash register. SSI is a great help. It is still difficult to pay for everything.

Grocery Bagger. In his 20s, he lives in Oregon. He described himself as having learning disabilities, or "slow." He lives in a semi-independent living center and his skills trainer helped him apply for SSI. He works part-time in a grocery store.

I've always had learning disability. I got older and learned to appreciate what the teachers were trying to do to help me. My speech therapy when I was little is an example. I got to appreciate those more as I grew up and went to junior high and high school.

I'm in the semi-independent living program and my skill trainer who helps me budget my money and stuff, she helped me get on Social Security.

I like my job. When somebody wants to know where something is in the store, it's nice to know that I'm able to take them to it and show them. And just to help the little old ladies, help taking their groceries out to the car. The satisfaction for me is knowing that I did that and they're happy with that.

Stock Clerk. Age 18, he lives in Iowa. He has mental retardation and works part-time at a store. He had difficulty early on, but is proud that he has everything under control. He can hold down a part-time job.

I'm mentally retarded. And I'm basically . . . now I have a job. I work at Bonanza. I work about maybe 20 hours per week.

Before I had a temper problem, a violence problem. And every time someone says a word to me, I kind of like hit every person I see. So basically they wouldn't let me work. And so now I can control it. Basically no one wouldn't want to hire me because I'm slow . . . slow about learning things. But now I've gotten a chance to work. 'Cause I work at Bonanza. I used to work at Domino's as a delivery person. I used to work at McDonald's. So I've gotten chances and I've proved that I can work. And I can be a . . . that I can do it fast.

Busser. He is 21 and lives in Oregon. His disability began when he had seizures at age four. Now he has regular shaking. He appeared also to have a cognitive impairment. His family has given him a lot of encouragement and he feels well prepared to work. He completed high school and has taken a special "transition class" at a local college, which helped him find a job in the community. He received an award at the college for leadership. He works part-time as a busser at a restaurant. His quality of life is "pretty good — I have a job, I have family that cares."

Job Applicant, File Clerk. She is in her early 20s and lives in Iowa. She has been receiving SSI since she was five years old. She has multiple health conditions, including kidney and bladder problems, scoliosis, which causes pain and limits her movement (climbing stairs and lifting), and a weak immune system which makes her susceptible to illnesses and infections. She recently began receiving DI as a disabled adult child on the record of her father.

She has difficulty retaining what she reads and received special education help to improve her retention. Because of her difficulty climbing stairs, she quit high school and got her GED instead. She has attended college. Her reading difficulties were not a significant problem during college because most of the courses were lecture classes. She reported she has "no problem working with computers."

She has had difficulty finding a job. She has looked on her own and is registered with the Job Service, which she noted is for everyone, not just the disabled. But without work experience, she does not feel very well prepared for work. Also, "I'm not saying it's discrimination, but it seems they don't want me once I tell them I have a disability." Because she has two young children, it has been difficult to go to vocational rehabilitation to get help finding work. They said she would have to come in for a whole day at a time and make phone calls. They do not offer daycare and her family and friends can only help during part of the day. She can only afford to pay for child care if she is working.

For the past three weeks, she had been working temporarily at a job that requires sitting all day with just arm movement. She is used to moving around and walking when she needs to. Now she is experiencing more back pain. She recently applied for a filing clerk position at a hospital. She is hopeful they will call her for an interview because they told her the disability was not a problem. Also, the job would not require her to sit all day.

She is currently living with her mother because she can't afford a home of her own. "To afford a half ways decent house I would have to be on ADC and I don't want to rely on that. My mother was on ADC and I want to fare better than her." She was generally happy with her life, noting it has its ups and downs, "but that's life."

Parent Interview (cook and student). The mother of a student, age 18, said her daughter has a learning disability and wants to become a cook. She received something in the mail explaining about vocational rehabilitation (VR) and about the availability of apartments with supervision, and how to find jobs. Her daughter went to VR, which sent her to Goodwill. She has a part-time job bussing tables.

Well, when she first was diagnosed, you know, for her learning disability — she felt like she was unequal with the other kids. Kids used to tease her, and call her, like, a doofus, and all that. But she didn't mind it.

When they're in LD classes, they're kind of separated from all the rest of the kids. So they probably have a stigma with that. Well, they stuck her in a BD [behavioral dysfunctions] room, but she doesn't have a behavior problem.

At VR, they had her counting screws, and putting screws and things together — stuff like that. She went out there because she wanted to cook, and they put her on everything else but what she wanted to do. Finally, she got put where she wanted — and she did real well. They didn't want her to go back to school. They told her to stay out there and not go back to school, but she wanted to go back to school. She does have a part-time job. She's bussing tables.

GED Student. Age 18, he lives in Iowa. He was injured in an accident when he was in the ninth grade, about five years ago, and lost some of his vision. He missed school while undergoing repeated operations and treatment. He applied for SSI benefits to help pay the hospital bills. He is working toward his GED, but still has severe headaches and difficulty with reading his assignments. He believes he can work.

I was in the hospital 3-1/2 weeks to a month. I don't know. I was in surgery most of the time. But I overcame it. I lost my eye. I missed a lot of schooling 'cause I had to go back and forth for surgery and all kinds of things.

I was trying to find somebody that could help us. Worrying about if my mom was going to be able to pay the bills. Doctor bills.

It's hard. Sometimes I have headaches a lot. I don't get to read all my assignments. And all of that. It's been hard on me. But I make it sometimes. I have headaches sometimes.

My appearance might be different from other people, but in my mind I'm the same as you or her or anybody else. And I can do the job.

Young Mother. She is in her 20s and lives in Oregon. She reported her disability as "retarded," or being a "slow learner." She left high school midway through 11th grade. She did not know how long she had been receiving disability benefits; her father had helped her to qualify. She has a toddler.

Her main source of help and support is her boyfriend. She has been to a "skills center" which taught her how to apply for a job, but has had no other contact with vocational rehabilitation or supported employment. She believes she is too slow for a regular job. She would like to be a cashier, but believes she is too slow with numbers. She would also like to work in a bakery or in a day care center. She has done babysitting in the past. "I love kids and catch on real fast with kids." "It would help if there were people to help find a job."

Mother Interview. Her son, age 22, has severe mental retardation and lives in Iowa. He attended special schools until he was 21. He continues to live at home. A case manager from the Department of Human Services advises the family about benefits and services available to him now that he is an adult.

My son couldn't be here. The happiest thing in his life is love. He really doesn't know much else. He's 22, but he's got a mentality of about six months. So that's all he really knows. He seemed to be normal until he was about 14 months old, and then he started having seizures. Grand mals about six times a day for about six months. It just destroyed his brain.

He's been in school since he was four, which has been a blessing. First going to Easter Seal. When he outgrew that then he went to a school for handicapped children, for the kids when they are over 12 — until they are 21. They graduate — which he just did last May. It's been wonderful for both of us. It got him out and gave me a little time to be without him. It was a break that I needed too. Because he's completely dependent.

The people at these schools were very, very dedicated to him. I loved him being in that atmosphere. He was around other kids a lot like him, and some that weren't nearly as bad. Some that are just retarded, or maybe a physical disability.

Thank God I had him in that school. Because the school social worker told me to go through the Department of Human Services to get a case worker for him. And they have them for the rest of their life. And they let you know about the benefits that are available. The case worker explained that I needed to go before a judge to be appointed his guardian, now that he is an adult. If something came up, mostly medical for him, where he couldn't sign for himself, I had to become a guardian.

We always had to have him omitted from family health insurance plans. Thank God, I don't have to worry about that anymore, with title XIX [Medicaid] now that he's of age.

Father Interview. Her father reported that she just turned 20 years old. She had medulla blastoma, a form of brain cancer, when she was two years old and was not expected to survive. She is three foot three inches tall, weighs 54 pounds and needs 24-

hour care. She attends school. He wants her to be treated with respect and encourages her fighting spirit.

We weren't told how to take care of her because nobody expected her to live at all. We were just told to try and make her as comfortable as possible before she died. And I don't want to make her comfortable. I want to irritate her. Because I think the only way she's going to keep going is fighting.

About her experience in school? Well, she's not what you'd call a sweet little handicapped person. She's as mean as a rattlesnake. If things bother her she tells people quickly. The problem that I have with schools is that she seems to have been stuck in a program that's very inflexible. And they insist on trying to teach the entire class the same way and it doesn't work.

She's a natural leader. She actually runs her class most of time. Because she tells people where they have to go — where they have to be. She knows where everybody else has to be but she doesn't know where she's supposed to be all the time. And I don't understand it. She's kind of unique because they cut her brain in half and so there's no connection between the two halves. And at times, either half seems fairly intelligent. But it's kind of a wild connection all the time.

A couple of years ago they had some program where the kids at her school were stuffing envelopes for the DMV. She felt very accomplished because she had one piece of paper to fold and put in an envelope. She could deal with that. But if she had two she couldn't have handled it. She can't ... the concept of two different things just doesn't fit.

She's not supposed to be able to walk. Supposed to be paralyzed. She walks on bones brittle as the devil. She breaks bones all the time.

My idea of what a good life for her would be that my wife and I outlive her. That's all. When you have a person that needs 24 hour-a-day care — thank God there are two parents in my house — because one of us can stay home all the time. I'll work six months. My wife will work six months. Because I would go crazy if I don't work some.

My hopes for her? When they said she was going to die — I prayed just to let her live. That's all I want. I want her to be able to live. You know, if she sits around and is mad at the world and everything else, she's still alive and I can hold her and squeeze her and tickle her and poke at her to make her mad. Make her do something.

Mother Interview. Her daughter is 19. She was born with a visual impairment. She had a stroke in the womb and she had a stroke when she was three. She is now totally blind and nonverbal. She is small. She weighs 68 pounds and is 4 feet tall. Her mother applied for SSI for her when she turned 18.

We withheld her from school for a while because she was coming home soiled. Yet she had learned toileting skills at home. She had already accomplished many things at home that they were trying to teach her at school. So we gave them a list of things that we wanted her to learn to do in a school setting — very basic things that she was doing at home. She needs to know the touching, the feeling, the sound around other people. And she wasn't experiencing that.

She used to go into frustration of anger and she would pull and dig at her body. They labeled her autistic. I said no, she's frustrated. She doesn't have enough to occupy her time.

Now they are listening to us and following through. And she has become happy. Her bus ride to school is happy. Her bus ride home is happy. Her whole day at school is a positive. And we know this because we have a notebook that we send back and forth as our communication tablet. The teacher writes information and I write information.

I question whether she will ever get a paid job. She would need someone like a shadow reminding her everywhere she went. She follows through with very simple commands, but she wouldn't be able to do it on her own. Even though you would like that to happen. My aspirations for her? I want her to be a happy individual that feels adjusted enough in society and people will be accepting of her.

Disability Policy Panel Biographies

Jerry L. Mashaw, Chair, is Sterling Professor of Law at Yale Law School and a Professor at the Institute of Social Policy Studies at Yale University. He is a leading scholar in administrative law and has written widely on social insurance and social welfare issues, including disability policy. His works related to disability policy include: *Social Security Hearings and Appeals* (1978); *Bureaucratic Justice: Managing Social Security Disability Claims* (1983); *Social Security: Beyond the Rhetoric of Crisis* (1988); and *America's Misunderstood Welfare State* (1990). He received his LL.B. from Tulane University and his Ph.D. in European governmental studies from the University of Edinburgh.

Monroe Berkowitz is Professor of Economics, Emeritus at Rutgers University and Director of Disability and Health Economics in the Bureau of Economic Research. He is also the Director of Research at Rehabilitation International. He is a leading authority on the economics of disability and rehabilitation in both public programs (Social Security disability insurance and workers' compensation), private disability insurance and public and private rehabilitation systems. Professor Berkowitz has also conducted extensive comparative analyses of foreign systems. His publications include: *Disability and the Labor Market* (1986), winner of the Book of the Year Award from the President's Committee on the Employment of People with Disabilities; and *Measuring the Efficiency of Public Programs,* (1988). He received his Ph.D. in economics from Columbia University.

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Eileen P. Sweeney is Director of Government Affairs at the Children's Defense Fund. Previously, she was a staff attorney with the National Senior Citizens Law Center, where she specialized in Social Security and SSI, and at the Legal Assistance Foundation of Chicago. She is a recognized expert in the field of administrative law, particularly the Social Security programs where she served as co-counsel on several cases. She is an effective advocate for children, the elderly, people with disabilities, and those in poverty. She also served as a member of the SSI Modernization Panel (1992), which was charged to examine the fundamental structure and purpose of the SSI program. Ms. Sweeney received her J.D. from Northwestern University.

Jerry Thomas is the President of the National Council of Disability Determination Directors. He is also the Director of Adjudicative Services for the state of Georgia. He has spent over 20 years in the state disability adjudication agency in various positions. He is a member of the Social Security Administration's Disability Redesign Advisory Council, a member of SSA's National Disability Issues Group, and has represented state disability agencies on many national panels and work-groups. He received his M.S. in political science from Florida State University. Mr. Thomas replaced Charles Jones on the Panel in July of 1994.

List of Abbreviations

ADA	Americans With Disabilities Act of 1990
ADL	activities of daily living
AFDC	Aid to Families with Dependent Children
AGI	adjusted gross income
AIDS	acquired immune deficiency syndrome
ASPE	Assistant Secretary for Planning and Evaluation, DHHS
AIME	average indexed monthly earnings
ALJ	administrative law judge
BRP	Beneficiary Rehabilitation Program
BWE	blind work expense
CDR	continuing disability review
CPS	Current Population Survey
D/ART	Depression: Awareness, Recognition and Treatment Campaign, NIMH
DDS	disability determination service
DHHS	U.S. Department of Health and Human Services
DI	Social Security disability insurance
DSH	disproportionate share hospital
DWTC	disabled worker tax credit
ECA	Epidemiological Catchment Area, NIMH
EEA	earliest eligibility age
EITC	Earned Income Tax Credit
EPE	extended period of eligibility
FICA	Federal Insurance Contributions Act
FY	fiscal year
GAO	U.S. General Accounting Office
GDP	gross domestic product
GED	general equivalency diploma
HCFA	Health Care Financing Administration
HI	Hospital Insurance; Medicare Part A
HIAA	Health Insurance Association of America
HIV	human immunodeficiency virus
HMO	health maintenance organization
IADL	instrumental activities of daily living
ICFs/MR	intermediate care facilities for the mentally retarded
IOM	Institute of Medicine
IRWE	impairment-related work expense
IWRP	individualized written rehabilitation program
LTDI	long-term disability insurance
MR	mental retardation
MR/DD	mentally retarded/developmentally disabled
MS	multiple sclerosis
NASI	National Academy of Social Insurance
NIDRR	National Institute of Disability and Rehabilitation Research
NIMH	National Institute of Mental Health
NRA	normal retirement age
OASDI	Old-Age, Survivors and Disability Insurance
OASI	Old-Age and Survivors Insurance
OBRA	Omnibus Budget Reconciliation Act
PASS	Plan for Achieving Self-Support
P.L.	Public Law
QDWI	qualified disabled and working individual
RFC	residual functional capacity
RSA	Rehabilitation Services Administration
RTW	return to work
SAIF	State Accident Insurance Fund (Oregon)
SCI	spinal cord injury
SGA	substantial gainful activity; currently $500 per month for nonblind disability beneficiaries
SIPP	Survey of Income and Program Participation
SMI	Supplementary Medical Insurance; Medicare Part B
SSA	Social Security Administration
SSI	Supplemental Security Income
STDI	short-term disability insurance
TWP	trial work period
TDI	temporary disability insurance
U.S.C.	United States Code
VC	Veterans' Compensation
VR	vocational rehabilitation
WC	workers' compensation