Rethinking Disability Policy: The Role of Income, Health Care, Rehabilitation, and Related Services in Fostering Independence

The Disability Policy Panel of the National Academy of Social Insurance recently issued its *Preliminary Status Report* as a way to invite public comment on its work to date, and, in particular, to invite suggestions for specific policy proposals for the Panel's consideration in the remaining 14 months of its work. The *Social Security Bulletin* is publishing the "Overview" section from the report to help the Panel widen the audience of possible respondents. If you wish to comment, please use the address at the end of this note.

The Panel was convened by the Academy in March 1993 in response to a request from Chairman Dan Rostenkowski of the House Committee on Ways and Means, and Chairman Andy Jacobs, Jr., of its Social Security Subcommittee. They asked the Academy to conduct a comprehensive review of disability income policy with a particular emphasis on ways to enable persons with disabilities to remain in or return to the work force as well as to better serve those who are denied benefits but do not find work. In its first year, the Panel engaged in fact finding and information gathering with regard to disability policy and the broad economic, social, and political environment in which that policy operates. The initial findings of that review are included in the *Preliminary Status Report.*

The National Academy of Social Insurance is a nonprofit, nonpartisan organization whose mission is to promote research and education concerning Social Security, unemployment insurance, workers' compensation, the appropriate role of government in protecting individuals from the costs of personal health care services, and challenges and opportunities facing the world of social insurance. Panel members were selected for their recognized expertise and with consideration for the balance of disciplines appropriate for this project: their names are listed on the page to the right.

The Panel's Perspective

Section I of the *Preliminary Status Report* presents the Panel's perspective on disability policy. The Panel believes: That the primary goal of disability policy is the integration of persons with disabilities into mainstream society; that "disability" is not just an attribute of individuals, but instead represents the interaction between individuals—who may have physical or mental impairments—and the environment in which they live; that there is great diversity among persons with disabilities in terms of their abilities, capacities, needs, and limitations; that the goals of economic self-sufficiency for persons with disabilities are not inconsistent with income security goals of disability income programs; and that integration of and support for persons with disabilities are important to the productive capacity of the Nation and require coordinated responses of the private sector as well as Federal, State, and local governments.

Preliminary Findings

In the final section of its report, the Panel outlines the topics of its future work and describes its current findings on three issues that have repeatedly been raised as problems by persons with disabilities and other experts the Panel has consulted. These issues are health care and disability income policy, the importance of adequate resources to administer the Social Security Disability Insurance (DI) and the Supplemental Security Income (SSI) disability programs, and the importance of long-term research.

Health Care and Disability Income Policy

Health care is important to all Americans. It is particularly important for persons with disabilities because they often have special health care needs, many are at risk of very high health care costs, and they often cannot gain adequate coverage in the private insurance market. The Panel has heard directly from individuals with disabilities that the fear of losing health care and related services is, for many, the major barrier that keeps them from maximizing their earning capacity. Many recipients of DI and SSI disability benefits have said that the risk of losing Medicare or Medicaid coverage that is linked to their cash benefits is a far greater work disincentive than is the loss of cash benefits. Earnings from work can compensate for the loss of cash benefits. But earnings, alone, cannot buy health care coverage when that coverage is simply not available to persons with severe chronic conditions.

The Panel finds that ensuring universal protection against health care costs would present 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:

- Alleviating fear and insecurity among the Nation's citizens with disabilities who now rely on Medicaid and Medicare for the health care they need and who risk losing that coverage if they are found able to work;

- 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; and
- Fostering cash benefit policies that provide security while encouraging work among persons with disabilities who have the capacity to do so.

Universal health care would also foster early intervention to prevent diseases or impairments from becoming permanent work disabilities. Improved access to uniform health care information will also improve the decisionmaking process for cash disability programs.

The Panel also emphasizes that certain health care benefits are particularly important for persons with disabilities, including children. These features include coverage for prescription drugs, durable medical equipment, personal assistance services and devices, and rehabilitation services for congenital or chronic conditions, including mental illness.

The Panel is not prepared to take a position on the merits of particular health care reform proposals. There are many factors to be considered as that debate proceeds and they are not our primary focus. Nor do we, as a Panel, take the position that only a universal health care scheme can address the particular concerns that are the subject of our work. Rather, our purpose is to highlight that secure, appropriate health care for persons with disabilities is an important underpinning for developing sound disability benefit policies that facilitate entry or return to paid employment for those with the capacity to do so.

Importance of Adequate Resources to Administer DI and SSI

In its review of the history of the DI and SSI programs over the past 25 years, the Panel has been struck by the volatility of disability benefit claims, allowances, and terminations. Major factors in this volatility are cyclical changes in the economy and radical shifts in administrative and legislative policy. From this review of the tumultuous history of the disability programs over the past 25 years, the Panel sees several important lessons.

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First, stable administration of DI and SSI is critically important to the economic security of the persons with severe disabilities who rely on these benefits as well as for public support and the fiscal integrity of the programs.

Second, cutbacks in administrative resources in the 1980's were accompanied by growing concerns that vulnerable populations are not being well-served. Problems were reported about provisions for assigning and monitoring representative payees for beneficiaries who need them, difficulties beneficiaries have in getting information about how particular changes in their work would affect their benefits, the need for outreach to enroll eligible persons in SSI, difficulties beneficiaries face in receiving prompt answers to their questions, and prompt adjustments in benefits as a beneficiary's circumstances change in order to minimize underpayments or overpayments.

Third, adequate staff and other resources to administer the programs are essential. The investment in making correct, timely initial disability decisions and documenting them fully should shorten delays in getting correct benefits to applicants, reduce appeals, and avoid the cost of paying any incorrect allowances. If the required medical improvement standard for conducting continuing disability reviews is to be implemented properly, allowances must be sufficiently documented to support an assessment of whether there has been a change in the beneficiary's condition between the allowance and the review. And to be fair to the beneficiary, there must be adequate staff to assure that the record is fully developed at the time of review. For program integrity and public confidence in the programs, resources must be adequate both to decide and document initial claims promptly and correctly, and to conduct appropriate quality reviews and continuing disability reviews.

Fourth, changes in regulations that were called for in legislation and court decisions in the 1980's require greater emphasis on assessing claimants' functional capacity in conjunction with medical evidence. If properly conducted, these functional assessments are likely to be more time consuming than determinations based solely on medical evidence. This shift needs to be taken into account in resource allocations.

Finally, it is reasonable to expect some volatility in disability claims with cyclical changes in the economy. Disability claims have risen during every economic recession since the late 1960's—with the one exception of the early 1980's, when unprecedented retrenchment policies offset those effects. The majority of working-age persons with disabilities do, in fact, work. They have much better prospects for finding and keeping their jobs when jobs are plentiful. When they lose their jobs during recessions and exhaust other sources of support, it is reasonable to expect that they will apply for disability benefits. Flexibility in administrative resources is needed to accommodate cyclical changes in disability claims.

The Social Security Administration is now engaged in rethinking and reengineering its disability adjudication processes to ensure that available resources are used as efficiently as possible. At the same time, in the wake of reduced staff resources in the 1980's, the recent rapid growth in initial claims and backlogs, the growth in pending appeals, the fact that continuing disability reviews are not being done as called for in the law, and ongoing concerns that vulnerable populations have difficulty gaining the service they seek, the Panel finds that staff and related resources are not now adequate to administer the DI and SSI programs. It believes that such resources must be set at a level that ensures stable, effective management of the disability programs. Specifically, resources must be adequate to: Provide fair, accurate, and prompt decisions on disability claims; provide the individualized service to disability beneficiaries that are contemplated under current law, including clear and accurate answers to individuals' questions about how changes in their work effort will affect their benefits; and conduct timely and predictable reviews of the continuing eligibility of those receiving disability benefits.

Importance of Long-Term Research

Long-term research is needed to better understand the size and attributes of the underlying population of persons with disabilities who could meet the program definition of disability if they were not working, as well as to make valid and reliable decisions of eligibility. Such research is needed in order to anticipate the consequences for disability claims and allowances of cyclical changes in the economy, of outreach efforts to enroll eligible persons, or of other changes such as appropriate updates of the medical and other criteria for making disability determinations. Such research would also provide information about the circumstances that distinguish persons with disabilities who are successfully integrated into the work force from those who become unable to work because of their impairments. That information could help develop ways to expand opportunities for successful integration of beneficiaries into the world of work.

There has been a dearth of rigorous research on the disability benefit programs over the past 10–15 years. In the 1960's and 1970's, the Social Security Administration conducted periodic comprehensive surveys to measure the prevalence of work disability in the general population and to assess the role of the disability income programs in meeting the needs of persons with work disabilities. No comparable data have been collected since 1978.

A comprehensive program of long-range research is needed in order to provide basic information about the populations being served and the changing environment in which disability programs operate. The Panel is encouraged to find that thoughtful new research initiatives are planned and underway to rectify major gaps in information that is needed to evaluate and forecast disability income programs. Multiyear funding commitments are essential for long-range research. The Panel strongly supports the continued investment in such research initiatives.

The Panel's Future Work

In its remaining work, the Panel is focusing on specific issues concerning disability policy, which it has divided into nine necessarily overlapping categories:

- The definition of disability for DI and SSI eligibility, and its assessment in functional, medical, and vocational terms;
- Work and other incentives and disincentives for DI and SSI applicants and beneficiaries;
- Prospects for vocational rehabilitation and job placement for persons with significant disabilities;
- The coordination of health care and cash benefits for persons with disabilities;
- Provisions for personal assistance services and assistive devices for persons with significant functional limitations;
- The coordination of short-term and long-term disability income protection;
- Implementing and administering cash benefits and services for persons with disabilities;
- The relationship of disability and retirement policy, particularly in light of scheduled increases in the Social Security normal retirement age; and
- The special concerns of subgroups of persons with disabilities, including children and persons with severe mental illness.

In each area, we propose to develop what we believe to be the appropriate objectives of disability policy, to analyze the degree to which current public and private programs and processes accomplish those objectives, and to make recommendations for policy and administration that are consistent with the objectives as defined. As our work proceeds, we may decide that some of these categories require further disaggregation or that others are so interconnected that separate recommendations on those topics are unnecessary or unwarranted.

The Environment of Disability Income Policy

Sections II, III, and IV of the *Preliminary Status Report* describe various aspects of the environment of disability income policy.

Review of Selected Disability Income Programs

Section II provides an overview of major employment-based public and private programs and means-tested public programs that provide monthly cash disability benefits. It begins with a review of Social Security Disability Insurance (DI) and Supplemental Security Income (SSI) disability provisions, which are the focus of the Panel's work. It also reviews coverage and provisions of compensation programs for workers who are injured on the job or veterans who are injured while on active duty in the Armed Forces. State temporary disability insurance and private sector short-term and long-term disability income plans also are covered. It finds that among private sector employees:

- Almost all are covered by Social Security DI, which provides earnings replacement benefits after a 5-month waiting period for workers with severe long-term disabilities;
- About 30 percent of private sector employees have no short-term disability income protection. Another 26 percent have sick leave only, which typically replaces 100 percent of earnings for only a few weeks, rarely long enough to cover the full period until DI benefits begin. About 44 percent of private sector employees have some type of short-term disability insurance (SDI), which usually replaces about 50-67 percent of the worker's earnings for up to 6 months. This SDI includes mandatory social insurance programs in five States and union-negotiated and employer-provided benefits in other States.
- Employer-provided long-term disability insurance (LTDI), which is supplemental to Social Security Disability Insurance, covers about 25 percent of private sector employees, with upper status white-collar workers much more likely than blue-collar workers to be covered. These benefits typically replace about 60 percent of prior earnings and are offset $1 for $1 by Social Security. About another 17 percent of private sector employees are in defined-benefit pension plans that provide immediate disability pensions if the worker meets the age and service requirements of the plan.

Attributes of Persons with Disabilities

Section III provides information about the population of persons with disabilities, including estimates of the prevalence of disabilities in the total population, the attributes of DI and SSI beneficiaries, and what is known about outcomes for persons who have been denied DI benefits in the past.

Prevalence of disability.—There is great diversity among persons with chronic health conditions, or disabilities. For example, as many as half the total population (including children, the elderly, and working-age adults) have some type of chronic health condition, but for most, the condition does not limit their ability to work, attend school, or engage in other daily activities.

Chronic health conditions can limit activities in a variety of ways. Among working-age persons in 1990, 19.4 million people (12.8 percent) said they were limited in some way because of a chronic health condition, including: 6.7 million (4.4 percent) who reported they were unable to work; 7.4 million (4.9 percent) who were limited only in the kind or amount of work they could do; and 5.3 million (3.5 percent) who were limited only in nonwork activities. A small portion of the working-age population report such significant functional limitations that they require assistance with activities of daily living. They include some individuals who report they are able to work, despite the need for assistance.

DI and SSI beneficiaries.—At the end of 1993, a total 6.7 million adults under age 65 were receiving Social Security or SSI benefits based on disability. To receive benefits, individuals must meet a strict test of work disability due to a medically determinable physical or mental condition. In addition, children under age 18 receive SSI based on a definition of disability for children comparable to that for adults.

There is great diversity among DI and SSI recipients. Those who receive DI as disabled workers must have had recent covered work in order to be insured for benefits. They tend to be older—most are in their fifties or early sixties—and their impairments frequently are associated with aging—such as musculoskeletal impairments, including arthritis, or circulatory or respiratory diseases. Mental illness is a growing cause of disability among disabled-worker beneficiaries, however, particularly those under age 50. It is the primary diagnosis for about 1 in 4 persons receiving disabled-worker benefits.

SSI recipients tend to be much younger. Many have developmental disabilities and enter the rolls as children (if they live in low-income families) or when they reach adulthood, when their eligibility based on income and resources is considered independent of the financial status of their parents. For about 1 in 4 adult SSI recipients, the primary diagnosis is mental retardation; for another 1 in 4 adults, it is mental illness.

Although adults who receive DI or SSI based on disability have severe work limitations, most beneficiaries are capable of managing their own affairs. When beneficiaries are not capable of managing or directing the management of their benefits, representative payees are assigned to manage the payments for the beneficiary's use and benefit. About 1 in 8 disabled-worker beneficiaries and about 3 in 10 SSI recipients aged 18–64 have representative payees to help them manage their benefits.

The SSI criteria for determining disability for children were modified following a 1990 Supreme Court decision in *Sullivan* v. *Zebley*. The number of children receiving SSI has grown rapidly since 1989 and was 770,000 at the end of 1993. Among children on the rolls at the end of 1992, mental retardation was the primary diagnosis for about 40 percent. Other mental disorders—including autism, Down's syndrome, organic mental disorders, schizophrenia, mood disorders, attention deficit disorders, personality disorders, and developmental and emotional disorders for infants—together accounted for 16 percent. Another 16 percent of children on the SSI rolls had impairments of the nervous system or sensory system, such as vision or hearing impairments, as their primary diagnosis.

Outcomes for denied DI applicants.—Five different studies over the years have examined outcomes for people who applied for but were denied DI benefits. These five studies, conducted between the mid-1960's and the late 1980's show many similarities in outcomes for persons who were denied benefits and who were still alive and not on the disability or retirement benefit rolls 3–5 years later.

- In each study, fewer than half the surviving denied applicants were working. Lower employment rates among denied applicants were associated with higher nationwide unemployment rates.
- The economic status of denied applicants who are not working is poor. Their main sources of income are earnings of other family members or assistance. Denied applicants who were working generally were better off.
- The self-reported health status of denied applicants who were not working is not much better than that of those who were allowed DI benefits. Denied applicants who were working generally reported fewer health problems.

Trends in DI and SSI—Policy and Administrative Changes

Sections IV and V describe the trends in DI and SSI benefit awards and terminations over the past 20–25 years and review how cyclical changes in the economy, new legislation, and administrative policy affected the likelihood of disability benefit receipt. The tumultuous history of the disability programs supports the Panel's finding that adequate staff resources and stable administration are critical for protecting both the rights of individuals as well as public support for and the fiscal integrity of the disability programs.

The early 1970's: growth in the disability rolls.—The early 1970's were characterized by rapid growth in the number of people awarded DI benefits as well as the large influx of SSI recipients when that program began in 1974. Economic recessions and high unemployment in 1969–70 and in 1973–75 and legislative expansions in DI before and during this period contributed to the growth. Under pressure to process new claims in an era of government-wide restrictions on personnel, staff resources were diverted from reviewing the accuracy of disability decisions and conducting continuing disability reviews of those on the rolls to processing new claims.

The period 1975–80: controlling expansion.—The period after 1974 was characterized by growing concern about the rapid rise in the number of people receiving DI benefits, the escalating cost of benefits, and the projected insolvency of the DI Trust Fund. Legislation in 1977 and in 1980 reduced future disability benefits, and in 1980 legislation required that more quality reviews and continuing disability reviews (CDR's) be done. During the late 1970's, administrative initiatives tightened adjudicative standards, placing new emphasis on "medical" as opposed to "functional" criteria for assessing disability. Also, the review standards for CDR's were changed to permit benefit terminations without a finding that the beneficiary's condition had medically improved.

The period 1981–84: retrenchment and reaction.—With administrative tightening that began in the late 1970's, and the 1980 legislative mandate in place, the new administration, which had promised to reduce the size and cost of government, sought through administrative initiatives to significantly reduce the cost of disability benefits. In the midst of a deep economic recession with unemployment rising to record levels in 1982–83, administrative initiatives to review the rolls and terminate benefits were implemented abruptly without adequate staff or training. In response to widespread dismay at the human suffering caused by the abrupt retrenchment, the courts, the States, the Administration, and the Congress all acted to rectify the situation.

By June of 1983, after two district courts had declared SSA's restrictive policy for assessing mental impairment claims to be illegal, the Secretary of Health and Human Services issued a moratorium on denying disability claims based on mental impairments until new guidelines were developed. In April 1984, the Secretary announced a nationwide moratorium on continuing disability reviews and pledged to work with Congress on reform. By that time nine States were operating under a court-ordered medical improvement standard for continuing reviews, and nine other States had suspended reviews pending implementation of a court-ordered medical improvement standard, or pending action by the circuit court. In 1984, Congress responded with reform legislation.

The period 1985–89: economic expansion, agency downsizing.—As the Nation enjoyed sustained economic growth and unemployment rates fell, disability claims leveled off. New adjudicative criteria called for in the 1984 legislation were put in place. It was generally agreed that deciding claims based on the new criteria for assessing disability based on mental impairments and for conducting disability reviews would be more labor intensive than the approaches that had been invalidated by the courts.

A major administrative initiative during this period was a decision to significantly reduce the number of SSA staff—from about 80,000 employees in fiscal year 1985, to about 63,000 in 1989. Along with the agency downsizing, SSA leadership sought ways to streamline operations. In the process, fewer field office personnel were available to provide individualized attention to vulnerable populations—such as SSI recipients. Meanwhile, Congress called for improvements in service to the public, including outreach to enroll eligible persons in SSI, more responsive representative payee services, and improved responses to individuals' questions and needs. Legislation also extended work incentives for SSI recipients and incremental changes improved access to SSI for persons with severe mental illness.

The early 1990's: growth in the rolls.—The early 1990's, like the early 1970's, were characterized by rapid growth in the disability rolls, with particular growth in SSI claims. The growth coincided with an economic recession in 1990–91. It also followed legislative, administrative, and judicial actions that enhanced access to SSI—through SSI outreach activities and new standards for determining childhood disability. In the wake of agency downsizing during the 1980's, and increased workloads in the 1990's, agency resources were not allocated to conducting continuing disability reviews in order to process new claims. The agency is currently engaged in reassessing and reengineering its disability processes to ensure that available resources are used as efficiently as possible.

The Broader Environment

Section VI explores some of the broader environmental factors beyond the DI and SSI programs that influence the context in which disability benefits are claimed and decisions are made to allow or deny benefits. While these environmental factors affect the context of disability benefit programs, no attempt is made to precisely associate these factors with past or future trends in the disability benefit programs.

Structural Shifts in the Labor Market

Structural changes in the labor market have long-term effects on employment opportunities for particular subgroups of workers, including those with disabilities. On one hand, analysis of earnings level trends show a declining demand for workers with limited educations and job skills. To the extent that such workers have disabilities, they are likely to be doubly disadvantaged in the labor market. On the other hand, the shift from manufacturing to service sector jobs is projected to increase jobs for well-educated workers, which would mean that highly skilled workers with physical disabilities will have better opportunities to find work. At the same time, workers with cognitive limitations or mental illness may still have difficulty finding work.

Other Components of the Public and Private Safety Net

All Western European countries as well as the United States face the problem that large numbers of persons lose their connection with the labor force before retirement age. It happens particularly during economic recessions, but occurs in normal times as well. The social welfare responses to this problem can be grouped as follows: *Work-based interventions*, which provide rehabilitation or training or expand job opportunities; *unemployment benefits*, which provide income continuity to those actively seeking work; *disability benefits*, which provide income security to those severely limited in their ability to work; and *assistance*, which provides universal income guarantees or means-tested benefits for the poor.

The comparative research suggests that differences in the size of disability rolls across countries depend much more on the relative strength of these four social welfare responses than on differences in the underlying health of the population. The United States, in contrast with many other Western countries, has relatively weak support systems other than for disability. For example, job creation, rehabilitation, and training programs serve small numbers of persons relative to the numbers receiving disability benefits; unemployment benefits are paid to only about half of those seeking work and are limited in duration; Federal funding for assistance, other than that based on disability, is available only to certain low-income families with children and those benefits have declined in value over the past two decades. The same analysis suggests that policies that seek to reduce reliance on one or more of these sources of support are likely to increase reliance on others.

Availability of Health Insurance

In the absence of universal health care coverage, persons with disabilities face particular problems in gaining the coverage they need. If they are employed, they may be covered by employer-sponsored health insurance. But standard employment-based plans may not cover the services needed by persons with chronic conditions. Furthermore, coverage under employment-based insurance has been declining. Between 1988 and 1992, the number of persons under age 65 in the United States without any private or public health care coverage rose by nearly 5 million. The growth in the number without any coverage occurred despite significant growth in the proportion of that population who were covered by Medicaid. In the absence of universal health care protection, individuals who lack the coverage they need may turn to DI and SSI to gain coverage under Medicare or Medicaid that accompanies entitlement to cash disability benefits.

Changing Treatment for Persons with Severe Mental Illness

An important change in DI and SSI that occurred in the 1980's was an increase in the number of persons with severe mental illness who qualified for benefits. Contributing to this growth were changes in DI and SSI adjudicative policy in the early and mid-1980's, a longer-term trend away from State mental institutions to community-based care for persons with severe mental illness, and incremental changes during the later 1980's that were designed to increase access to SSI for persons with severe mental illness.

Although changes in treatment of mental illness represent advances in the integration of persons with severe mental illness into the community, they also bring a shift in sources of support. Medicaid and SSI, as well as Medicare and DI, are important underpinnings of the community-based system. Effective treatment in the community still requires coordinated services that replicate what had previously been the responsibility of State mental hospitals—housing, some supervision, medical and psychiatric care, and psychosocial rehabilitation. Because of the importance of SSI and Medicaid for their clients, many mental health practitioners now consider it part of their job to help their clients qualify for these programs.

Increased Claimant Representation and Third-Party Interest

Over the past 15–20 years, there has been a significant increase in the number of Social Security claims that are appealed after initially being denied, as well as an increase in the likelihood that benefits will be allowed on appeal. There has also been a significant increase in the size and sophistication of organizations of claimants' representatives and a growing interest of third parties in helping individuals gain access to DI or SSI disability benefits. Recent legislation also expedited the process for approving fees that representatives may charge their clients when their appeals of denied benefits are successful.

Third-party interests include groups other than the claimant, or the claimant's representative, who have a direct interest in having DI or SSI claims allowed to certain individuals. They include State and local governments with State financed assistance programs which seek to ensure that SSI is first payor for low-income persons with disabilities. Employers and insurers that provide private disability insurance calculate premium and replacement rates based on Social Security DI being first payor of benefits to disabled workers. Consequently, they often encourage or require those claiming private benefits to also claim DI. In addition, hospitals, rehabilitation facilities, or other providers of services may have a direct interest in helping patients qualify for SSI and therefore Medicaid so that they can be reimbursed for their services. Without Medicaid coverage for their patients, the care they provide is likely to be uncompensated.

The Panel invites comments of interested individuals and organizations about the issues for its future work, the appropriate objectives of policy in each area, and specific suggestions for policy proposals the Panel should consider. Comments and suggestions should be directed to:

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