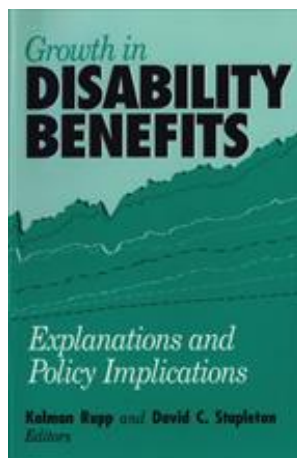




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Unsustainable Growth: Preserving Disability Programs for Americans with Disabilities

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The Social Security disability programs, which constitute the essential safety net for people with disabilities in our country, are growing at an unsustainable rate. If we are truly committed to meeting the needs of people with disabilities, we must make the changes necessary to ensure the long-term viability of these programs. I do not want my following remarks to be misconstrued; while I have no commitment to the status quo, I am deeply committed to developing well-designed disability programs that provide income security while encouraging independence for people with disabilities.

I approach these issues from two different, but mutually reinforcing, perspectives. First, I view them as a policymaker on Capitol Hill who is responding to several national goals: to balance the budget and to get the economy back on track, to make government run more efficiently, and to assist people with disabilities to live productively and independently. Second, I look at them as a person with a disability, who was once a recipient of the Supplemental Security Income (SSI) program,

NOTE: This chapter is based on comments delivered when the author was serving as Legislative Assistant to Senator John McCain. Several significant program changes have occurred since the time of that presentation, particularly with respect to the eligibility of legal aliens and proposals concerning treatment of children with disabilities. The chapter should therefore be read not for current program content, but for conceptual and historical insight into the programs from the perspective of a Senate aide who has a disability and significant experience with the programs. Andrew Batavia is currently associate professor at the School of Policy Management, College of Urban and Public Affairs, Florida International University. The views expressed are solely those of the author, and do not necessarily represent the positions of Senator McCain, or any organization with which Mr. Batavia is or has been affiliated.

and who has some serious concerns about the disability programs and their effect on people with disabilities.

A POLICY PERSPECTIVE

From the perspective of a policymaker, the rapid rate of growth of the disability programs in recent years is alarming. The number of Social Security Disability Insurance (DI) beneficiaries alone increased 27 percent from 1989 to 1993, as compared with a 7 percent increase in retired worker social security beneficiaries (DHHS 1994). Disability benefit payments increased 51 percent over that period. Applications, eligibility awards, and payments for the SSI program are also growing dramatically.

Altogether, the federal government is currently spending about \$70 billion each year for the social security disability programs, almost twice as much as five years ago (Board of Trustees 1995; Committee on Ways and Means 1994). If this upward trend continues, the programs soon will be subject to increasing political scrutiny and criticism. Eventually, public support for them will dissipate. Because these programs are so important, we must get them under control.

There has been a dramatic change over the past thirty years in the way our society perceives people with disabilities (see articles by Ross and by Weaver, this chapter). Previously, when an individual incurred a permanent and significant disability, the general expectation was that he or she would no longer be employable or even potentially employable. In recent years, as a result of the independent living movement, improvements in assistive technology, and enhanced environmental accessibility, there is an increased expectation that even people with very substantial disabilities can work.

This social change is best evidenced by the enactment of the Americans with Disabilities Act of 1990 (ADA), the civil rights law that represents a national consensus on the goals of our nation's disability policy and the legitimate expectations for our citizens with disabilities. Many of our disability laws that were established prior to 1990 are inconsistent with the ADA's basic premise that people with disabilities can be employable and must be given the opportunity to live full and

productive lives. It is incumbent upon policymakers to ensure that all disability policy is consistent with the premises and goals of the ADA (DeJong and Batavia 1990).

A PERSONAL DISABILITY PERSPECTIVE

From my perspective as a person with a disability, I am concerned about the “entitlement mentality” that the social security disability programs impose on their recipients, particularly on young people with disabilities. Beneficiaries, and even potential beneficiaries, are repeatedly given the message that they have a right to benefits as long as they can demonstrate an inability to work by virtue of a disability. Even those raised with a strong work ethic begin to think about how they can demonstrate their absolute inability to work. Once that mind set is internalized, it is very difficult to alter.

To avoid this counterproductive self-fulfilling prophecy, people with disabilities must be brought into the mainstream of the community as soon as possible. This is why antidiscrimination laws such as the ADA and the Individuals with Disabilities Education Act (IDEA) are so important. People with disabilities must obtain an expectation of employability before they receive and accept the societal message that they are “too disabled” ever to work.

In 1973, when my spinal cord was injured in an automobile accident at the age of 16, I was confronted with conflicting messages from the people running our nation’s disability programs. I was informed that, because of the “severity” of my disability (C2-3 quadriplegia), I would qualify for SSI and therefore be entitled to cash benefits and Medicaid for the rest of my life. However, if I demonstrated the ability to earn a small amount of money, I would be disqualified and all of these benefits would no longer be available to me. (This was before the various work incentive provisions were enacted in the 1980s.)

I made a decision that was, in a sense, irrational. I decided to take a great risk—to go to college, law school, and graduate school with the support of vocational rehabilitation, and to thereby become employable notwithstanding my disability. To most Americans, this decision may seem neither irrational nor risky. However, by doing so, I was

potentially compromising tens of thousands of dollars of life-sustaining support for the rest of my life. Moreover, I was doing so without any assurance that I would be able to earn comparable benefits through employment. The likelihood of regaining eligibility once I had demonstrated the ability to work seemed remote.

I was fortunate. I have a supportive family and friends who encouraged me to take that risk. I also had a vocational rehabilitation counselor named Joan Brown who believed in me and who provided advocacy in obtaining the educational benefits I needed. Many people with disabilities do not have such supports. As evidenced by program statistics, most make the low-risk decision to stay on the programs permanently. Given the basic structure of the system, even with its current work incentive provisions, this is *not* an irrational economic decision. Many simply do not trust the government to allow them to regain their benefits once they have lost them.

This has convinced me that we need to alter the programs' structures to create strong incentives for people with disabilities to seek gainful employment and ultimately to leave the programs. I come to this conclusion not because it will save the taxpayers money. In fact, it will probably cost somewhat more in the short run to provide the opportunity for people with disabilities to work. I support structural reform of the programs because it will improve the lives of people with disabilities by helping them to achieve their highest potentials.

THE STRUCTURAL PROBLEMS

The 104th Congress recently enacted major welfare reform. Interestingly, in a political climate in which almost all means-tested welfare programs were being considered to be block granted to the states, the disability programs have been largely exempt from the block-granting debate. There appears to be a general consensus that these programs are such an important part of the safety net that they should continue as entitlements. However, that does not mean that they should maintain their current structures and policies. The rapid growth of the disability programs ensures that we will soon be engaged in a debate over what changes should be made.

The causes of the programs' growth is an extremely complex issue and is not well understood (GAO 1994). Among the factors that appear to affect the increase in program applications are economic conditions, the policies of other social programs, state efforts encouraging people to apply, and demographics (Stapleton et al., Chapter 2). However, all of these factors interact with the policy structures of the disability programs. There is a basic conflict between the fundamental premises of these programs and the ADA. I believe that this incongruity explains much of the reason that very few beneficiaries ever leave the disability rolls.

The disability programs are based on an outdated premise equating disability with unemployment. DI was initially structured as an early retirement program, with the foundational notion that if a person had a disability, he or she was basically unemployable; and there was therefore no reason to expend substantial resources in a futile effort to get the individual ready to work. In this stage of our history, we recognize that this is simply not the case. There have been attempts over the years to modify the programs' presumption of unemployment through the various work incentive provisions. However, the programs still maintain their self-defeating historical premise. Until we address this flaw, we are not going to get beneficiaries to work.

Adults with Disabilities

The recent growth in the number of adults in the programs appears to be largely a result of economic recessions and changes in state public assistance programs (Stapleton et al., Chapter 2). In addition, the demographics of our aging population is expected to contribute significantly to future growth, as the large baby boom population becomes more disabled and chronically ill.

While such factors have important implications and represent a challenge to finite federal and state budgets, they should not be the primary focus of program policy. Such growth could be constrained through more restrictive eligibility criteria. However, to the extent that this would disqualify individuals with significant disabilities that, at least temporarily, preclude employment, it would ultimately increase their vulnerability and interfere with their employment objectives. By far, the more important policy considerations for addressing the growth

of the adult beneficiary population are appropriate vocational rehabilitation, education, and return to work.

Certainly, we should be developing better criteria and mechanisms (e.g., functional assessment measures) to determine who should be eligible (Batavia 1992). The current eligibility system is based primarily on a medical model of disability that equates impairment with the inability to work. The Listing of Impairments used by the Social Security Administration (SSA) is a poor proxy for determining functional deficits and inability to work. SSA's system of ongoing medical reviews in which beneficiaries are categorized and reviewed periodically according to expected medical improvement is also largely irrelevant. Capacity to work is not necessarily associated with medical condition or improvement in medical condition; the relationship is far more complex, with the more important variables being functional capacity and social (e.g., family) support.

Return to work is currently impeded by program policies that discourage beneficiary efforts to become rehabilitated and employed and that do not encourage maintenance of any existing relationships with former employers (Mashaw et al. 1996; Burkhauser and Haveman 1982). These policies range from the medical model definition of disability (assuming a causal relationship between an impairment and the ability to work), to a waiting period for eligibility that discourages early rehabilitation, to a benefit structure that creates an enormous disincentive to work.

As suggested above, in response to a general consensus that these disability programs impose substantial disincentives to work, several laws were enacted by Congress in the 1980s to encourage SSI and DI beneficiaries to seek gainful employment and leave the disability rolls (NARF 1988). Yet, despite this legislation and indications that many disability beneficiaries wish to work, few ever leave the programs voluntarily (Muller 1989). In December 1993, only 35,299 of the 5.98 million disabled SSI recipients participated in the Section 1619 work incentive program (DHHS 1994, Tables 7.F5 and 7.A3).

The unabated growth of the programs and the failure of the work incentive provisions to curtail such growth have demonstrated that incremental changes are not sufficient. We need substantial structural reform to ensure the long-term viability of the disability programs. In 1991, when Susan Parker was Associate Commissioner for Disability

of SSA and I was associate director of the White House Domestic Policy Council in the Bush administration, we and our staffs developed a proposal to fundamentally alter the premises of the disability programs. It would maintain the entitlement status of the programs but make them time-limited, thus creating a presumption and expectation of employability (Batavia and Parker 1995).

Our proposal would create four categories of disability:

1. A Permanent Disability Pension, which would apply to individuals with no capacity to work (e.g., people with severe brain injury)
2. A Temporary Disability Benefit, which would apply to the vast majority of beneficiaries, whose benefits would be limited to three years but would be potentially expandable for education, training, and other activities to become employable
3. An Early Retirement Benefit, which would allow people with disabilities 55 years of age and over to opt out of the job market and accept early social security retirement
4. Provision Benefits, including personal assistance services, assistive technology, and training that would be provided to Temporary Disability beneficiaries to become employable

In addition, the proposal includes several other provisions that are geared to enhance administrative efficiency and encourage beneficiaries to work. These include elimination of the current five-month waiting period for DI, expediting the paperwork, determining the appropriate course of action through increased beneficiary and physician responsibilities, using case management techniques to capitalize on the beneficiary's functional capacity and relationship with former employers, creating positive incentives to work, and establishing a contract between the SSA and the beneficiary in which both would have responsibility to ensure that the beneficiary may become employed as soon as feasible.

The overarching goal of the proposal is to alter the culture of the programs by changing the expectations of all parties. However, the proposal will only work if there is adequate funding for rehabilitation, training and provision benefits, and if positive incentives to work are

built in. Fear of losing health insurance and personal assistance services creates among the greatest disincentives to work for people with disabilities (Friedland and Evans 1996; Batavia, DeJong, and McKnew 1993; Burns, Batavia, and DeJong 1991). An array of policy options, including reform of our in-kind benefit programs, are available to reduce these disincentives (Batavia 1993, 1996).

Children with Disabilities

Much attention has been focused on the rapid growth in the number of children in the disability programs after the *Zebly* Supreme Court decision. That decision dealt with the legal standard for children's eligibility. At this time in the history of the programs, we should reexamine the policy rationale underlying that eligibility standard. With respect to adults with disabilities, a cash benefit is clearly justified as income replacement for individuals who, as a result of their disabilities, cannot work. This rationale applies to adults, at least for the period of time that they are incapable of employment. It does not apply to children with disabilities, who are not breadwinners and who therefore have not forgone income as a result of their disabilities.

Consequently, some other rationale is needed for a cash payment to children. Typically, the justification offered is that the child's disability requires the parents to work less and earn less than they otherwise would or to hire outside help to assist in addressing the child's disability-related needs. The needs of a child with a disability are often much greater than those of a nondisabled child, and the costs of meeting those needs are correspondingly higher for children with disabilities.

Because the policy rationale for a cash benefit is stronger with respect to adults than children with disabilities, further policy consideration should be given as to which children justify a cash payment. It may be that the needs of many children with disabilities can be addressed entirely through in-kind benefits, including health care, assistive technology, and personal assistance services. Alternatively, a cash benefit may be warranted in certain cases to allow one of the parents to stay home and take care of the child. Analysis may reveal that some children warrant higher payments than they are currently receiving.

Assuming that it is determined that a cash payment continues to be justified for certain children, substantial research will be needed in

assessing the appropriate eligibility criteria for identifying such children and in determining the appropriate amount of the payment.

Legal Aliens

Another issue that has received increasing attention lately is the large increase in the number of individuals from other countries who have entered the United States legally and who have become recipients of the disability programs. It has been reported to Congress that approximately 738,000 legal aliens currently receive SSI, up from 127,000 in 1982 (Rector and Lauber 1995; Matloff 1994). This constitutes a growth rate of 580 percent in just twelve years. The vast majority are elderly, and most apply for benefits within five years of entry into the United States. This disturbing trend should not be occurring under long-standing federal immigration policy, which precludes aliens who may become a "public charge" from entering our country.

There is a tendency to scapegoat noncitizens for the problems of our country. In fact, legal aliens have always played an important role in our economy and have contributed significantly to the growth of our nation. To the extent that they pay into social programs over an extensive period of time, they should be entitled to benefits, proportionate to their contribution. However, there is evidence that many are attracted to our country primarily by its generous social programs (Rector and Lauber 1995). To the extent that this is occurring, policy changes are needed. One approach might be to preclude benefits for a stated period of time (e.g., three, five, or ten years) after the individual legally enters the country.

CONCLUSIONS

There are those committed to the status quo who would argue that the policy changes being suggested here, such as time-limiting disability benefits, lack compassion. They are wrong. What lacks compassion is a system that convinces people with disabilities, and particularly children with disabilities, that they are too disabled ever to work. Our disability programs currently are fundamentally flawed. While incre-

mental reforms have improved the programs, they have not corrected the basic problems. We must fix the programs to ensure that the people who rely on them will receive the benefits that they need, but in a manner that encourages and empowers them to be more independent and productive.

Most important, for all people with disabilities, we must raise the expectations of our disability programs. As much as any other factor, including the work disincentives built into the current system, the presumption that an impairment necessarily limits the ability to work has handicapped generations of program beneficiaries. The experience of hundreds of thousands of people with disabilities who are now working, despite significant functional limitations, proves that this presumption is false. People with disabilities can become gainfully employed if we expect them to become gainfully employed, and if they expect themselves to become gainfully employed.

Adults with disabilities must be given the expectations, opportunities, and incentives to seek and obtain gainful employment. Children with disabilities must receive the education and training that they need, alongside children without disabilities to the extent possible, to offer them full opportunities throughout their lives. The programs should be reformed to ensure that every dollar spent is invested efficiently in the future of their beneficiaries. People with disabilities in our country must be encouraged to seek employment to improve their personal situations and to remove themselves from the dependency of the disability programs. Such dependency is neither in their interest nor that of our country.

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