

The Social Security Administration's Efforts to Promote Employment for People with Disabilities

New Solutions for Old Problems



**National Council on Disability
November 30, 2005**

National Council on Disability
1331 F Street, NW, Suite 850
Washington, DC 20004

The Social Security Administration's Efforts to Promote Employment for People with Disabilities: New Solutions for Old Problems

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National Council on Disability

An independent federal agency making recommendations to the President and Congress to enhance the quality of life for all Americans with disabilities and their families.

Letter of Transmittal

November 30, 2005

The President
The White House
Washington, D.C. 20500

Dear Mr. President:

On behalf of the National Council on Disability (NCD), I am pleased to submit this report, entitled *The Social Security Administration's Efforts to Promote Employment for People with Disabilities: New Solutions for Old Problems*. Under its congressional mandate, NCD is charged with the responsibility to gather information on the development and implementation of federal laws, programs, and initiatives that affect people with disabilities.

Our nation's current disability benefit programs are based on a policy principle that assumes that the presence of a significant disability and lack of substantial earnings equate with a complete inability to work. Americans with disabilities remain underemployed, despite the fact that many are willing and able to work. Although the Social Security Administration (SSA) has instituted a number of incentives to reduce the numerous obstacles to employment faced by its Supplemental Security Income (SSI) and Social Security Disability Insurance (DI) beneficiaries, such efforts have had little impact because few beneficiaries are aware of these incentives and how they affect benefits and access to health care.

In recent times there has not been a comprehensive, research-based examination of the practices that are most likely to support the employment of SSI and DI beneficiaries. NCD undertook this study to address that absence and found that the complex obstacles to employment faced by SSA beneficiaries require a comprehensive set of solutions. New approaches must be identified that emphasize beneficiary control of career planning and the ability to access self-selected services and supports. Public and private health care providers must develop new collaborations and new approaches to combining coverage from multiple sources to improve program efficiencies. SSA must continue to work with the Rehabilitation Services Administration and the Department of Labor to improve implementation of the Ticket to Work program and identify new approaches that will overcome the traditional inability of SSA beneficiaries to benefit from services provided by the nation's employment and training programs. Secondary and postsecondary educational institutions must emphasize benefits counseling and financial management training as the foundation for beneficiary self-direction and economic self-sufficiency. Federal agencies and the business community must realize that collaborative approaches to incorporating beneficiaries into the workforce are needed as a way to reduce dependence on federal benefits while simultaneously enhancing the productivity and competitiveness of large and small business.

The recommendations discussed in this report need to be addressed in policy and procedural modifications by both Congress and the Social Security Administration to significantly address the continuing number of SSA beneficiaries who never leave the SSI and DI rolls, and to increase the number of beneficiaries who enter, or reenter, the United States workforce.

Sincerely,

Lex Frieden, Chairperson

(The same letter of transmittal was sent to the President Pro Tempore of the U.S. Senate and the Speaker of the U.S. House of Representatives.)

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Executive Summary

Americans with disabilities remain underemployed, despite the fact that many are willing and able to work. Although the Social Security Administration (SSA) has instituted a number of incentives to reduce the numerous obstacles to employment faced by its Supplemental Security Income (SSI) and Social Security Disability Insurance (DI) beneficiaries, such efforts have had little impact because few beneficiaries are aware of these incentives and how they affect benefits and access to health care.

Introduction to the Problem

Social Security beneficiaries with disabilities must spend months or even years convincing SSA that they are unable to work as a condition of eligibility. Yet, upon their receipt of benefits, SSA begins to communicate to beneficiaries that work is an expectation for them. Congress and SSA have developed a variety of work incentives and special programs designed to encourage beneficiaries to attempt to obtain and sustain employment. Yet SSA's efforts to eliminate work disincentives have often added to the complexity of the entire program, confusing beneficiaries and making them leery of any actions that might unknowingly jeopardize their benefits.

Current SSA benefit amounts are quite small and merely allow beneficiaries to live at a basic subsistence level. SSI resource limits make it very difficult to accumulate the financial resources necessary to move toward economic self-sufficiency. Tying eligibility for Medicaid or Medicare to eligibility for SSA benefits forces individuals with high-cost medical needs who could otherwise work to choose between pursuing a career and retaining the medical insurance that sustains their very lives.

The fear of losing benefits and medical insurance through an unsuccessful employment attempt starts well before adulthood with SSI beneficiaries. Many SSI recipients first apply for benefits as children while enrolled in public schools. These individuals often remain on the rolls well into adulthood, with very few transitioning from high school into substantial employment after graduation (GAO, 1996b; GAO, 1998b). Failure to focus on Social Security and other public

benefits during transition is not only a missed opportunity, but harm may be caused when students and family members are not educated or prepared for the effect of earnings on cash benefits and medical insurance (Miller and O'Mara, 2003).

There is also the problem with poor educational attainment of DI beneficiaries who enter the disability system later in life. Efforts to help this population return to work are stymied by their lack of education and marketable job skills — particularly in today's highly competitive information economy. It is now more important than ever that people of all ages have access to higher education and the financial means with which to pay for training and education (Moore, 2003).

Response of Congress and the Social Security Administration to the Problem

Well aware of the enormity and seeming intractability of this problem, Congress and SSA have initiated multiple efforts to promote employment and return to work among SSA beneficiaries. In recent years, a number of work incentives for SSI and DI beneficiaries have been implemented, allowing individuals to keep more of their earnings while retaining their benefits. Work incentives are aimed at reducing the risks and costs associated with the loss of benefit support and medical services as a result of returning to work. Some of the most commonly used incentives are Section 1619(a) and (b) provisions; impairment-related work expenses (IRWE); trial work period (TWP); Plan for Achieving Self-Support (PASS); extended period of eligibility (EPE); and continued payment under a vocational rehabilitation program.

However, despite efforts by SSA and the Federal Government that have led to more favorable conditions for returning to work, most SSI and DI beneficiaries continue to stay on the disability rolls. The work incentives offered by SSA remain largely underutilized; in March 2000, of the total number of eligible working beneficiaries, only 0.3 percent were using PASS, 2.8 percent were using IRWEs, 7.5 percent were receiving Section 1619(a) cash benefits, and 20.4 percent were receiving Section 1619(b) extended Medicare coverage (SSA, 2000). The major reasons cited for the extreme underutilization of these work incentives by beneficiaries were (1) few beneficiaries knew that the work incentives existed, and (2) those who were aware of the

incentives thought they were complex, difficult to understand, and of limited use when entering low-paying employment (GAO, 1999).

The Office of Program Development and Research (OPDR) and the Office of Employment Support Programs (OESP) under the Deputy Commissioner for Disability and Income Security Programs are primarily responsible for the implementation of multiple components of the Ticket to Work and Work Incentives Improvement Act of 1999 (TWWIA). The TWWIA provides a number of new program opportunities and work incentives for both SSI and DI beneficiaries, including the Ticket to Work (TTW) and Self-Sufficiency Program; development of a work-incentives support plan through the creation of national network of Benefits Planning, Assistance, and Outreach (BPAO) programs; and new work incentives, including expedited reinstatement (EXR) of benefits and postponement of continuing disability reviews.

The National Council on Disability's Study of the Problem

It is not known whether the new TWWIA programs will have any more success than past attempts by SSA to impact the employment rate and earnings of beneficiaries. What is clear is that there has not been, in recent times, a comprehensive, research-based examination of the practices that are most likely to support the employment of SSI and DI beneficiaries. This study has been undertaken in response to the need for such a comprehensive analysis. The study was designed to address four research questions:

- (1) What are the evidence-based practices that promote the return to work of working-age beneficiaries of DI and SSI programs?
- (2) What policy changes are needed, given recent trends in program participation and employment?
- (3) Are there proven and documented practices that work better for some populations of people with disabilities and not others?
- (4) Which factors ensure that documented and evidence-based practices could be adapted/adopted by SSA and other entities that seek to ensure the employment of people with disabilities? Which factors prevent adaptation/adoption?

A four-step approach was taken to implement the study. First, a comprehensive literature synthesis was completed through a review of published and unpublished literature. Second, detailed structured interviews were conducted with key stakeholders, including SSA beneficiaries, federal SSA officials, representatives of other federal agencies, consumer and advocacy organizations, service organizations, community service providers, and business representatives. Third, a preliminary list of findings, evidence-based practices, and recommendations based on the literature review and structured interviews was used to develop seven topic papers. These papers were used to facilitate discussion and obtain reaction from participants who were invited to a consensus-building conference at the end of January 2005. Individuals with disabilities (including current and former SSI and DI beneficiaries), advocacy organizations, service providers, and policymakers who attended the conference had the opportunity to further develop the recommendations that appear throughout the report.

Major Findings of the Study

Purpose and Mission of SSA's Disability Benefit Programs

Our nation's current disability benefit programs are based on a policy principle that assumes that the presence of a significant disability and lack of substantial earnings equates to a complete inability to work. The current SSA eligibility determination process thwarts return-to-work efforts, because applicants are required to demonstrate a complete inability to engage in substantial gainful activity (SGA) in order to qualify for benefits. The definition fails to recognize that, for many consumers, disability is a dynamic condition. The length of the application process in our current programs actually contributes to the ineffectiveness of our return-to-work efforts and our inability to intervene early in the disability process.

For DI individuals, lack of a gradual reduction in benefits as earnings increase and lack of attachment to the DI and Medicare programs after an individual has maintained employment for an extended period of time make return to work unfeasible. For SSI beneficiaries, the program's stringent asset limitations thwart efforts toward asset development and economic self-sufficiency. Inconsistencies in program provisions lead to confusion and inequities for beneficiaries of both programs.

Beneficiary Perspective and Self-Direction

To receive benefits, applicants must characterize their situation as an inability to work long-term. They must demonstrate that they are unable to work in any significant way. Once they are determined to be eligible for disability benefits, beneficiaries face a host of complex program rules and policies related to continuing eligibility for cash benefits and access to health care. Many beneficiaries are confused or uninformed about the impact of return to work on their life situation and have shied away from opportunities to become self-sufficient through work.

Beneficiaries report that their experience with SSA is often unfavorable. Insufficient staffing has led to long lines and poor services. Misinformation is frequent, and mistrust common. Local SSA field office staff members are overburdened with accurate and timely processing of post-entitlement earnings reporting, which often leads to overpayments to beneficiaries. Beneficiaries do not trust SSA to make appropriate and timely decisions. There is prevalent fear that work attempts would result in either a determination that the disability had ended or the need to repay benefits.

SSA has implemented many legislative changes, program modifications, training initiatives, and automation efforts in the past 15 years to improve its customer service. Although efforts to streamline processing and improve customer service should be lauded, they have not significantly improved beneficiaries' ability to direct and control their own careers.

Income Issues and Incentives

A multitude of rules regarding employment income, continued eligibility for disability benefits, waiting periods, earnings reporting, management of benefit payments, and management of assets (among many others) come into play once an individual is determined to be eligible for DI or SSI. SSA rules regarding employment and income are such that many beneficiaries will actually be worse off financially if they work full time. Disincentives to employment in the current benefits programs include a sudden loss of cash benefits as a result of earnings above the SGA level for DI beneficiaries. Despite a number of programs that are designed to encourage asset building among SSI beneficiaries, it remains very difficult for beneficiaries to save and

accumulate resources under SSI, which contributes to long-term impoverishment and dependence on public benefits.

Over the past decade, SSA has devoted considerable resources to promoting employment and return to work among SSI and DI beneficiaries. The agency has aggressively implemented a number of new initiatives authorized under the TWWIA, such as the Ticket to Work and Self-Sufficiency Program, the BPAO program, area work incentive coordinators, and Protection and Advocacy for Beneficiaries of Social Security. It has modified program rules to provide increased work incentives to beneficiaries, such as the EXR and protection from continuing disability review provisions of TWWIA, indexing the SGA threshold, and increasing the level of earnings allowed during the Trial Work Period (TWP). The agency has also launched or is planning to initiate a number of demonstrations that will test the efficacy of new modifications to work incentives within the DI program and services targeted toward youth with disabilities. Yet, while SSA has taken steps to improve its return-to-work services through the provision of work incentives, these efforts are hampered by the underlying program rules that were designed for individuals assumed to be permanently retired from the workforce and individuals who were viewed as unable or unlikely to work in the future.

Coordination and Collaboration Among Systems

Expansion of the disability programs and the poor employment rates of adults with disabilities have become major concerns for SSA and disability policymakers across the country. Too often, the alarming growth of the Social Security disability rolls has been represented and perceived as SSA's problem to solve in isolation, when in fact it is a larger societal problem with myriad complex causes. Receipt of Social Security disability benefits is merely the last stop on a long journey that many people with disabilities make from the point of disability onset to the point at which disability is so severe that work is not possible. All along this journey, individuals encounter the policies and practices of the other systems involved in disability and employment issues. When these systems fail to stem the progression of disability or work at cross-purposes with one another to prevent successful employment retention or return to work, it is the Social Security disability system that bears the eventual brunt of this failure. Any meaningful effort to slow down or reverse this relentless march toward federal disability benefits will require

significant and sustained collaboration and coordination among SSA and the other federal agencies with a stake in developing disability and employment policy.

The complex obstacles to employment faced by SSA beneficiaries require a comprehensive set of solutions. New approaches must be identified that emphasize beneficiary control of career planning and the ability to access self-selected services and supports. Public and private health care providers must develop new collaborations and new approaches to combining coverage from multiple sources to improve program efficiencies. SSA must continue to work with the Rehabilitation Services Administration (RSA) and the Department of Labor (DOL) to improve implementation of the TTW program and identify new approaches that will overcome the traditional inability of SSA beneficiaries to benefit from services provided by the nation's employment and training programs. Secondary and postsecondary educational institutions must emphasize benefits counseling and financial management training as the foundation for beneficiary self-direction and economic self-sufficiency. Federal agencies and the business community must realize that collaborative approaches to incorporating beneficiaries into the workforce are needed as a way to reduce dependence on federal benefits while simultaneously enhancing the productivity and competitiveness of large and small business.

Recommendations

A total of 38 specific recommendations have been developed in the areas of Beneficiary Perspective and Self-Direction, Income Issues and Incentives, and Coordination and Collaboration Among Multiple Public and Private Systems. The recommendations are presented and justified in Chapters III, IV, and V of the report, and a complete list is provided in Chapter VI. The key recommendations resulting from the study are summarized below.

Beneficiary Perspective and Self-Direction

Customer Service – SSA should take immediate steps to improve the services provided to beneficiaries by improving the accessibility of SSA field offices and Web sites; redesigning field office personnel roles, staffing patterns and work assignments; continuing efforts to automate work reporting procedures; and enhancing outreach efforts to beneficiaries.

Ticket to Work Program – Congress and SSA should address current shortcomings in the TTW program by (1) expanding Ticket eligibility to include beneficiaries whose conditions are expected to improve and who have not had at least one continuing disability review (CDR), childhood SSI beneficiaries who have attained age 18 but who have not had a redetermination under the adult disability standard, and beneficiaries who have not attained age 18; (2) modifying the TTW regulations to ensure that Ticket assignment practices do not violate the voluntary nature of the program and beneficiary rights to grant informed consent; and (3) implementing a strong national marketing program to inform beneficiaries about TTW and other SSA programs.

Facilitate Beneficiary Choice – Congress should authorize and direct SSA, the Rehabilitation Services Administration (RSA), the Centers for Medicare and Medicaid Services (CMS), the Department of Housing and Urban Development (HUD), and the Department of Labor Employment and Training Administration (DOLETA) to develop and implement an integrated benefits planning and assistance program that coordinates resources and oversight across several agencies that enables beneficiaries to access benefit planning services within multiple federal systems. Congress should also authorize and direct these agencies to consider changes to the existing BPAO initiative to improve the accuracy and quality of services provided to individual beneficiaries.

Reduce SSA Overpayments to Beneficiaries – Congress and SSA should implement a series of procedural reforms to reduce overpayment to beneficiaries by increasing the use of electronic quarterly earnings data and automated improvements to expedite the processing of work activity and earnings; piloting the creation of centralized work CDR processing in cadres similar to PASS and Special Disability Workload Cadres; and enhancing efforts to educate beneficiaries on reporting requirements, the impact of wages on benefits, and available work incentives.

Eliminate the Marriage Penalty – Congress and SSA should undertake a complete review of the SSI program and make program modifications that eliminate the financial disincentive to marriage inherent in the present program, including amending the current Title XVI disability legislation to modify the manner in which 1619(b) eligibility is applied to eligible couples.

Income Issues and Incentives

Ease the SGA Cash Cliff for DI Beneficiaries – Congress should modify the current Title II disability legislation to eliminate SGA as a post-entitlement consideration for continued eligibility for Title II disability benefits and provide for a gradual reduction in DI cash benefits based on increases in earned income.

Reduce Restrictions on Assets for SSI Beneficiaries – Congress should direct SSA to (1) develop and test program additions and regulatory modifications that will enable SSI beneficiaries to accumulate assets beyond existing limits through protected accounts and other savings programs, and (2) change current program rules and work with other federal agencies to modify and expand the value of individual development account (IDA) programs to SSA beneficiaries.

Decrease the Complexity of the DI/SSI Program Rules Governing Income and Resources – Congress should direct SSA to (1) simplify regulatory earnings definitions and wage verification processes so that they are consistent across the SSI and DI programs, and (2) direct SSA to modify regulations related to the treatment of earnings in the DI program by applying the same rules currently applied in the SSI program.

Coordination and Collaboration Among Multiple Public and Private Systems

Health Care Systems – Centers for Medicare and Medicaid Services (CMS) and SSA should work together closely to (1) modify existing program regulations in order to uncouple Medicare and Medicaid coverage from DI/SSI cash payments; (2) identify and eliminate the many employment disincentives currently built into the Medicaid waiver, Medicaid buy-in, and Health Insurance Premium Payment (HIPP) programs; (3) expand benefits counseling services to include the full range of financial education and advisement services; and (4) work collaboratively with public and private insurance providers and business representatives to design public-private insurance partnerships that will expand access to health care for individuals with disabilities.

Vocational Rehabilitation (VR) System – SSA should modify TTW program regulations to allow the SSA’s traditional VR cost reimbursement program to carry on as a parallel program to the Employment Network (EN) outcome or outcome-milestone payment mechanisms, and ensure that an EN is able to accept Ticket assignment from a beneficiary, refer that individual to the VR agency for needed services, and not be required to reimburse the VR agency for those services.

Federal Employment and Training System – Congress, SSA, and the Department of Labor should undertake an analysis of the impact of allowing DOL One-Stop Career Centers to receive cost reimbursement payments for successfully serving beneficiaries under the TTW program, evaluate the impact of the Workforce Investment Act (WIA) performance standards on beneficiary participation in WIA programs, and design and test a set of waivers that will assist beneficiaries in accessing and benefiting from WIA core and intensive services, as well as individual training accounts.

Educational System – Congress should direct SSA to work with the Department of Education (ED) to (1) ensure that benefits planning and financial management services are available to the transition-aged population; (2) expand the current student earned income exclusion (SEIE) and the Plan for Achieving Self-Support (PASS) to encourage involvement of SSA beneficiaries in postsecondary education and training; and (3) implement a policy change that would disregard all earned income and asset accumulation limits for beneficiaries who are transitioning from secondary education to postsecondary education or employment for at least one year after education or training is completed.

Employers, Business Community, and Private Insurance Industry – Congress should direct SSA and the Department of the Treasury to (1) evaluate the possible effects of a disabled person tax credit as a means of increasing the use of disability management programs in business to prevent progression of injured and disabled workers onto the public disability rolls, and (2) collaborate with Department of Labor’s Employment and Training Administration (DOLETA), the Small Business Administration (SBA), and the Rehabilitation Services Administration (RSA) to develop and implement an employer outreach program targeted toward small and mid-size businesses.

Chapter I: Introduction

Overview of the SSDI and SSI Programs

The long-debated concept of social insurance for persons with disabilities was first set into action by the Social Security Amendments of 1956, with the establishment of the Social Security Disability Insurance (SSDI) program. Since its original enactment, SSDI (referred to in this report as DI) has been examined and modified repeatedly over the decades. In the beginning, monthly disability benefits were provided only for disability-insured workers between the ages of 50 and 65 who had an “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 to be of long-continued and indefinite duration” and for children of retired or deceased insured workers who developed a disability before the age of 18. There was a six-month waiting period from the end of work until the beginning of DI benefit payments (SSA, 1986).

Over the course of the next few years, legislation was enacted to make various amendments to the DI program, many of which increased both eligibility for disability benefits and benefit levels. The 1957 regulations added the consideration of nonmedical factors to the evaluation of disability, including education, training, and work experience. The Social Security Amendments of 1958 expanded DI to include benefits for the dependents of workers with disabilities. In 1960, the minimum age requirement of 50 years was removed for DI beneficiaries. That same year, a nine-month trial work period was established, allowing beneficiaries to test their ability to gain employment without losing their benefits. The Social Security Amendments of 1965 replaced the requirement that the impairment be of “long-continued and indefinite duration” with the condition that it was “expected to last for a continuous period of not less than 12 months” (SSA, 1986).

Such changes led to an increasing public awareness of DI, along with significant growth in both the size and complexity of the program. As a result, the Social Security Amendments of 1967 were passed to clarify that a claimant may only be found to have a disability “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.” The Social Security Amendments of 1972 brought additional changes to DI, including a reduction in the waiting period to begin benefit payments from six to five months, and an extension of the definition of adult children with disabilities to those whose condition developed before age 22 (SSA, 1986).

The most momentous aspect of the 1972 Amendments was the creation of the Supplemental Security Income (SSI) program, which replaced various state programs of public assistance effective January 1, 1974. In contrast to DI, eligibility for SSI payments was needs-based and was available to individuals who had attained age 65 or who had a disability with little income and few resources, regardless of their work history, to ensure that they were afforded a minimum level of monthly income to meet expenses. SSI operated under the same definition of disability used for DI benefits, with a modification for SSI claimants under age 18. Other provisions applicable to DI were incorporated into the new program as well, including the nine-month trial work period and the suspension of benefit payments upon refusal to accept rehabilitation services. Medicare and Medicaid protection for Social Security disability recipients were also provided for the first time as a result of the 1972 Amendments (SSA, 1986).

The number of people on the disability rolls and the costs of both the DI and SSI programs increased substantially during the 1970s. Between 1970 and 1978, the number of workers on the DI rolls nearly doubled, and expenditures quadrupled. It was widely believed that factors such as high unemployment rates, changing attitudes toward disability, high benefit levels for beneficiaries who did not work, and inadequate administrative control were collectively responsible for such unprecedented growth. Consequently, a number of proposals for disability reform legislation were introduced in Congress in the latter half of the decade with the intent of removing the work disincentives that were purportedly built into the disability program, as well as improving program administration (SSA, 1986).

To that end, the Social Security Disability Amendments of 1980 included changes to the DI benefit structure and procedures for strengthening incentives for rehabilitation and return to work. A cap was placed on the benefits that could be paid to DI beneficiaries and their families, to prevent excessive replacement rates from discouraging employment. In addition, work incentives were augmented in both DI and SSI, and those who completed the nine-month trial work period were now provided with an additional 15-month period during which they could test their ability to maintain employment while retaining disability status, with benefits automatically reinstated in the event that the work attempt failed. Furthermore, impairment-related work expenses incurred by the individual were no longer counted when determining whether earnings could be counted as substantial gainful activity (SGA) (SSA, 1986).

In passing the 1980 legislation, Congress also aimed to strengthen federal management of the state disability determination process, eliminating the current system of individual state agreements in order to ensure more efficient and consistent administration of the disability programs throughout the nation. Furthermore, in an effort to maintain the integrity of the disability programs, Congress approved a requirement that the status of all disability beneficiaries be reviewed at least once every three years to assess their continuing eligibility for benefits. Prior to this highly contested change, such continuing disability reviews (CDRs) were only conducted in selected cases where the individual's condition was expected to improve, or where the individual had returned to work. Consequently, the Social Security Administration (SSA) found nearly one in two people reviewed ineligible for benefits, and for many of these people, benefits were terminated. Shortly thereafter, numerous hearings were held regarding the effect the controversial CDRs and subsequent terminations were having on beneficiaries, as well as concerns regarding the standards applied in evaluating disability (SSA, 1986).

In response, the Social Security Disability Benefits Reform Act of 1984 set forth a new standard of review for the termination of disability benefits, making it more difficult to terminate a beneficiary by requiring substantial evidence that an individual's impairments had medically improved to the point where he or she could now perform substantial gainful activity. Furthermore, the Act specified that in determining eligibility, the collective effect of all of an individual's impairments must now be taken into account, even if no single impairment qualified

as “severe.” In addition to providing explicit standards of disability review, the 1984 legislation had the goals of improving the accuracy and the nationwide uniformity of decisions in disability programs, and returning disability policymaking to federal legislators. Thus, this Act was viewed as corrective or remedial rather than driven by reform.

In the past two decades, continued progress has gradually been made toward increasing the availability of work incentives and return-to-work services for disability recipients, carried out within the context of the broader disability policy climate aimed at expanding the vocational and social prospects of persons with disabilities. Given the contradictions inherent in providing vocational services to a population of individuals who have already been required to demonstrate an inability to work in order to qualify for disability insurance, the ultimate effectiveness of such employment-focused endeavors within the current Social Security system is frequently regarded with skepticism.

Determining Eligibility for DI and SSI

Under both the Social Security (Title II) and SSI (Title XVI) programs, there are two sets of requirements that must be satisfied before entitlement: (1) does the individual meet the eligibility criteria other than disability, and (2) does the person meet the disability standard? When applying for benefits, potential beneficiaries must prove the former to SSA. Applicants must prove their age, relationship to the person who paid into the Social Security system, marital status, work history, and, for SSI, their income and resources.

The other determination, that of disability status, is made by contracted state agencies (20 CFR 404.1503). The disability determination process is complex and lengthy. There is inconsistency from state agency to state agency (GAO, 2004a), and determinations that an individual is not disabled are often appealed, leading to lengthy waits before final resolution. For example, a table from the SSA Annual Statistical Report for 2003 (SSA, 2004a) offers data on the outcomes of applications filed between 1992 and 2003. According to that data, 22,062 applications from 2000 were still pending in mid-2003.

Successful applicants for benefits receive one of four types of disability payments administered by SSA. The largest program, DI, is authorized by Title II of the Social Security Act. It is paid to former workers who contributed Social Security taxes on work income. The other two disability programs under Title II of the Social Security Act are Disabled Widow(er)s Benefits (DWB) and Childhood Disability Benefits (CDB). These are paid to the survivors or dependents of workers who paid Social Security taxes and then died, became disabled, or retired from the workforce. The fourth disability program, SSI, is a federal poverty program for individuals who are over age 65, blind, or disabled; it is authorized by Title XVI of the Social Security Act. All four programs use the same definition of disability, which follows:

(a) the law defines disability as the inability to do 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. To meet this definition, you must have a severe impairment(s) that makes you unable to do your past relevant work (see §404.1560(b)) or any other substantial gainful work that exists in the national economy (20 CFR 404.1503).

Currently, substantial gainful activity is work effort valued above \$1,380 per month for blind individuals, and valued above \$830 per month for beneficiaries who are not blind (2005 limits). The word “valued” refers to a host of complex work incentives that are used to trim the amount of gross wages earned in a month down to the amount considered to be “countable earnings.” The countable earnings are then compared to the financial guidelines for substantial gainful activity (SGA) stated above.

SSI and the Social Security disability programs authorized under Title II of the Social Security Act (DI, CDB, and DWB) are currently the largest federal programs providing cash payments to people with disabilities. In 2002, about 6.5 million persons received Social Security benefits based on disability. This represented an increase from 6.2 million beneficiaries in 2001. In addition, nearly 4.8 million adults and children received SSI due to blindness or disability. The number of blind or disabled adults ages 18 to 64 rose by 1.7 percent between December 2001 and December 2002, while the number under age 18 increased by 3.7 percent. Benefit payments from the DI trust fund increased by 10.2 percent, from \$59.6 billion in 2001 to \$65.7 billion in 2002. Total SSI payments were \$34.6 billion in 2002, up 4.6 percent from 2001 (SSA, 2004b).

The steady growth pattern of the DI and SSI rolls seen in the past few years is not a new phenomenon. As early as 1994, the Government Accounting Office (GAO), now called the Government Accountability Office, was investigating the growth in Social Security's disability programs. In a study released in February 1994, the GAO reported that in the three years between 1989 and 1992, DI applications rose by a third, and almost half the applicants in 1992 succeeded in obtaining benefits. The GAO also found that, once on the rolls, beneficiaries were staying longer. Between 1985 and 1992, the number of beneficiaries who had been on the rolls more than 15 years grew by an alarming 93 percent. In addition, while the total number of DI terminations continues to increase as the rolls swell, termination rates as a percentage of those on the rolls have steadily declined. Terminations from the DI program averaged approximately 12 percent during the 1988–1989 period, but stood at only 9.5 percent by 1994. SSA research concluded that termination rates were declining for three main reasons. First, the younger average age of beneficiaries over the past 10–15 years has led to a lower number of conversions to retirement and terminations due to death. Second, the decline in the number and rate of medical CDRs has been a significant problem (SSA, 1996). Finally, terminations from the disability programs due to employment are almost nonexistent. SSA statistics cited in a 1998 GAO report estimate that fewer than 1 in every 500 DI beneficiaries left the rolls by returning to work (GAO, 1998).

Considering the prevalence of poverty among beneficiaries of DI and SSI benefits, it was not surprising that, according to a 1994 Harris poll conducted for the National Organization on Disability, 79 percent of individuals who had a disability stated that they wanted to work. Although the criteria defining disability were far less stringent than those used by SSA, the poll still strongly indicated that people with disabilities wanted to work. Unfortunately, a very small number of individuals receiving benefits, consistently less than one-half of 1 percent, successfully left the benefit roles through work (SSA, 1999).

Overview of the Problem

Americans with disabilities remain underemployed, despite the fact that many are willing and able to work. Although SSA has instituted a number of incentives to reduce the numerous obstacles to employment faced by its beneficiaries, such efforts have had little impact because few beneficiaries

are aware of these incentives and how they affect eligibility and benefits. The variety of complex issues surrounding disability policy and the provision of long-term disability benefits has been documented repeatedly. Such issues highlight the need to find adequate solutions that will allow Americans with disabilities to recognize their unfulfilled potential in the workforce.

Very few beneficiaries ever leave SSA rolls (SSA, 1999; GAO, 1996a; GAO, 1996b; GAO, 1996c). There is a lack of temporary options for cash support, health care, and rehabilitation within SSA programs, making it very difficult for beneficiaries to gain financial independence. Ironically, the employment supports that could potentially enable a beneficiary to remain off the disability rolls by returning to work or entering the workforce are not available until after a lengthy determination procedure has been completed, at which point the individual has essentially proved that he or she is unable to work. Indeed, less than one-half of 1 percent of SSI and DI beneficiaries leave the rolls to obtain employment (SSA, 1999; GAO, 1996c).

The problems are well-known and thoroughly documented. Medical advances save lives but increase the number of individuals with functional limitations to a degree that it makes it difficult for them to obtain and maintain employment. Societal and employer attitudes, cyclical fluctuations in the economy, and rapidly changing workplace demands in our information age economy lead to discriminatory practices that arbitrarily, unnecessarily, and sometimes illegally exclude individuals from the workforce. Employers and insurance companies frequently and knowingly design policies and programs that shift the cost of rehabilitating injured workers to public programs. Many of these programs simply pay individuals to remain in a dependent, unemployed status without making any authentic attempt to provide them with the simple services and supports that would enable them to reenter employment and pursue their chosen careers.

The situation for individuals with lifelong disabilities is equally bleak. Special educators, physicians, and clinicians of all types bombard students and their families with misinformation regarding the effect of disability on their long-term employment opportunities. Over time, these myths create unwarranted low expectations that prevent children and adolescents with disabilities from viewing themselves as able workers who can dream about their future careers with excitement and hope. Special education programs and secondary schools fail to prepare

students to obtain and succeed in complex jobs in the local economy. The “system” forces students and their families to pursue SSI eligibility as the only path by which they can secure post-school access to employment and residential supports through the home and community-based waiver program, which by definition perpetuates the notion that these otherwise capable individuals are frail, dependent, and unable to maintaining even basic employment.

Even the very programs that are purported to assist individuals with disabilities who are temporarily unable to work often place these individuals in a cycle of dependence. Current benefit amounts merely allow individuals to live at a basic subsistence level, never acquiring enough resources to allow them to pursue occupational or educational goals, and even economically punishing individuals who attempt to earn or save. Tying eligibility for Medicaid or Medicare to eligibility for SSA benefits forces individuals with high-cost medical needs who could otherwise work to choose between pursuing a career and retaining the medical insurance that sustains their very lives. The ponderous complexity of post-entitlement rules and work incentives has forced Congress and SSA to create a large cadre of benefits specialists whose job is to explain to beneficiaries the otherwise incomprehensible rules and regulations that actually exist to facilitate their entry into employment while they receive benefits.

The disability determination process is upsetting, adversarial, and extremely inconsistent. Both the timeliness and the uniformity of SSA’s disability determination process leave much to be desired. Decisions often take an extremely long time to process, and individuals who appeal after initially being denied benefits often have to wait nearly another full year before a final hearing decision is reached. Furthermore, there are often significant discrepancies between the initial decisions and those made at the hearings level (GAO, 2004a).

The culture of SSA is not work-friendly. Individuals must spend months or even years convincing SSA that they are unable to work as a condition of eligibility, yet upon receipt of benefits, SSA does a complete about-face and begins to communicate to beneficiaries that work is an expectation for them. Those individuals who do choose to work are frequently penalized. Individuals who obtain employment and conscientiously report their earnings to SSA frequently continue to receive benefits because SSA simply does not devote the resources necessary to track

reported earnings and make timely modifications to beneficiary payments. The resulting overpayments create a terrible burden on individuals and frequently on their families, and lead individuals who could otherwise work to remain unemployed to avoid the economic hardship created by overpayments. Benefit overpayments typically lead both to substantial administrative and financial burdens for SSA and to frustration and possible sudden termination of benefit eligibility for beneficiaries. Although recent efforts by SSA have been undertaken to address this issue, numerous challenges remain (Livermore, 2003).

Beneficiaries who attempt to work may actually be threatening their program eligibility and health care. Individuals with very significant disabilities who may wish to make an initial work attempt believe that working even a few hours each week on a trial basis might lead to SSA initiating a CDR that could jeopardize their benefit payments before they have had a chance to establish a stable employment situation. Even transition-aged beneficiaries fear that working while in high school may jeopardize their ability to retain SSI benefits after their age 18 redetermination. Their sincere efforts to prepare for employment after exiting school may actually lead them to be denied the very services and supports that would make employment possible for them. In short, SSA policies seem to communicate to beneficiaries that if they attempt to work and are successful in this effort, somehow they should not have been eligible for benefits in the first place, thereby creating a culture of mistrust and suspicion.

Response of Congress and the Social Security Administration to the Problem

Well aware of the enormity and seeming intractability of this problem, Congress and SSA have initiated multiple efforts to promote employment and return to work among SSA beneficiaries. SSA established the Office of Employment Support Programs (OESP) in the Office of Disability to coordinate employment and return-to-work efforts. In recent years, OESP and the Office of Disability have attempted to implement a number of new initiatives to overcome known problems. They have attempted to revise the traditional SSA vocational reimbursement system, in which state vocational rehabilitation agencies (SVRAs) seemed to have been given a monopoly to provide employment services to beneficiaries by establishing the alternative provider (AP) program. The AP program attempted to increase the involvement of community provider agencies as a competitor to SVRAs in service delivery for beneficiaries. Unfortunately,

participation in the AP program was quite low and the outcomes it generated were disappointing. The program has since been subsumed within the Ticket to Work program.

State Vocational Rehabilitation Agencies

SSA has a long history of interaction with SVRAs. Since 1981, SSA has reimbursed SVRAs for services provided to SSA beneficiaries that result in specified employment outcomes. The SSA Vocational Rehabilitation (VR) reimbursement program replaced an even earlier block grant program and was designed to improve program outcomes and accountability. Under the VR reimbursement program, the State Disability Determination Service applied a set of criteria to individuals awarded SSI or DI benefits. Individuals who appeared to be possible candidates for rehabilitation were subsequently referred to the SVRA. SSA beneficiaries selected for referral to the SVRA were required to participate in the VR program or risk benefit suspension. The program also allowed beneficiaries to apply for VR services on their own.

Under the VR reimbursement program, SSA reimbursed an SVRA for the “reasonable and necessary” costs of providing rehabilitation services to an eligible beneficiary. In order for the SVRA to receive reimbursement, the services must have resulted in the individual obtaining employment and achieving earnings at or above the SGA level for nine consecutive months. When an SVRA believed a beneficiary had achieved the earnings criteria, a payment claim was submitted to SSA. States were reimbursed for the actual costs of providing direct services, and administrative and tracking costs were reimbursed based on cost formulas. State agencies were responsible for submitting evidence to SSA to document that the individual had obtained employment and had earnings exceeding SGA for nine consecutive months.

Ticket to Work and Work Incentives Improvement Act of 1999 (TWWIA) ***(P.L. 106-170)***

TWWIA was enacted in 1999 to remove barriers and disincentives to employment for persons with disabilities while increasing consumer control over the delivery of employment and rehabilitation services and supports. The ultimate objective of this legislation was to provide Americans with disabilities with more opportunities to engage in employment and achieve

increased financial well-being, while at the same time decreasing their dependence on public benefits. TWWIA was intended to (1) increase choice for Social Security beneficiaries with disabilities in selecting and obtaining employment and vocational rehabilitation services and supports; (2) remove disincentives associated with having to choose between whether to work or maintain health care coverage; (3) provide a safety net and a mechanism for expedited reinstatement of benefits; (4) implement safeguards regarding CDRs; and (5) expand work incentive supports and protection and advocacy services. TWWIA provides a number of new program opportunities and work incentives for both SSI and DI beneficiaries, including the following:

- (1) Ticket to Work and Self-Sufficiency Program
- (2) Expanded availability of health care services
- (3) Expedited reinstatement of benefits
- (4) Postponement of continuing disability reviews
- (5) Benefits Planning, Assistance, and Outreach Program

The Ticket to Work and Self-Sufficiency Program

The Ticket to Work and Self-Sufficiency Program (TTW) is a voluntary program designed to allow SSI and DI beneficiaries the opportunity to direct their own employment services and choose specific services and providers in order to initiate or return to work. It differs from SSA's traditional vocational rehabilitation reimbursement program, where referrals of beneficiaries and recipients with disabilities went to either a state vocational rehabilitation agency or alternative providers. This program is intended to give consumers control over the types of services they obtain to support them in preparing for or maintaining employment, as well as whom they choose to provide these services and supports.

To implement the TTW program, SSA awarded a Program Manager contract to MAXIMUS, Inc. to inform beneficiaries about the program, recruit Employment Networks (ENs), manage Ticket assignments, resolve disputes among ENs, and manage the payment process. MAXIMUS, Inc. has devoted extensive resources to recruiting and supporting ENs. An EN is any qualified entity

that has entered into an agreement with SSA to assume responsibility for the coordination and delivery of employment services to beneficiaries who assign their Tickets to that EN. As the TTW program was originally conceptualized, it was hoped that the TTW program would encourage the participation of employment and community organizations that have not traditionally served the SSA population.

State VR agencies must elect to become ENs if they wish to continue to receive reimbursement from SSA for services provided to beneficiaries. As an alternative to the traditional cost reimbursement payment system, VR agencies have the option of selecting an EN payment structure. ENs may choose to serve Ticket holders under an outcome payment structure in which the ENs receive payments for each month the beneficiary receives no cash benefit, for a period of up to 60 months, or under a milestone payment structure in which the EN receives periodic payments as the beneficiary achieves intermediate goals on the way to zero cash benefit.

Expanded Availability of Health Care Services

The majority of Social Security beneficiaries with significant disabilities will not enter the workforce in full-time positions with medical benefits and therefore face the loss of health care when their earnings ultimately result in the elimination of their cash benefit. Beneficiaries in the past often had to choose between working at substantial levels and keeping their health insurance coverage (Clinton, 1999). The Medicaid buy-in provision of TWWIA allows states to establish programs in which individuals with disabilities who work purchase Medicaid services, just as if they were purchasing health care benefits through an employer-sponsored program. The buy-in includes several enhancements to the current Medicaid and Medicare programs and removes some of the disincentives that existed in the past with returning to work.

The Medicaid buy-in was first established in the Balanced Budget Act of 1997 (BBA). Through BBA provisions, states could provide Medicaid coverage to working individuals with disabilities who, because of their earnings, could not qualify for Medicaid. The concept of a Medicaid buy-in is to provide a choice for SSI and DI recipients to work and continue to be eligible for long-term supports and services. In states that chose the Medicaid buy-in option, individuals in other

Medicaid eligibility categories could choose to move to this new eligibility category if they were working (Scales, Folkemer, and Jensen, 2000).

The Medicaid buy-in option authorized under the BBA was modified and expanded by TWWIA. Beginning October 2000, states could cover working individuals between the ages of 16 and 65 who, except for earnings, would be eligible to receive SSI benefits on the basis of disability. Unlike limitations under the BBA, TWWIA does not limit eligibility to people whose incomes are below 250 percent of poverty (Scales, Folkemer, and Jensen, 2000).

Enhanced Work Incentives

TWWIA also created new work incentives to promote employment opportunities for beneficiaries. Two of the most important are expedited reinstatement of benefits and postponement of Continuing Disability Reviews (CDRs). Expedited reinstatement of benefits is designed to address a major disincentive experienced by many SSI and DI beneficiaries who return to work, have their cash benefits cease, and then, because of their disability, have to stop work at a later point in time. Under the expedited reinstatement of benefits provision, if a person's Social Security benefits have ended because of earnings from work and he or she becomes unable to work due to disability, he or she may request reinstatement of benefits, including Medicare and Medicaid, if applicable, without filing a new application. In this case, beneficiaries must be unable to work because of their medical condition.

An additional disincentive for SSI and DI beneficiaries is the likelihood that work will trigger CDRs, which are conducted periodically to determine if an individual's medical condition has improved sufficiently to terminate disability benefits. Under TWWIA, SSA cannot initiate CDRs while the beneficiaries are using the Ticket. However, the cash benefits of DI beneficiaries may be subject to termination if their earnings are above SGA. As of January 1, 2002, DI beneficiaries who have been receiving benefits for at least 24 months have not been asked to go through a disability review because of the work they are doing. However, regularly scheduled medical reviews set by the Disability Determination Service could still be performed and benefits could be terminated if earnings are above SGA (SSA, 2000).

SSA's Work Incentives Support Plan

SSA has developed several programs designed to enable beneficiaries to make informed choices about work. One program, the area work incentive coordinators (AWIC), created a new position internal to the agency. The other two programs, Protection and Advocacy for Beneficiaries of Social Security (PABSS) and Benefits Planning, Assistance, and Outreach (BPAO), provide services through agencies and organizations outside the agency. The purpose of these combined programs is to provide work incentive planning and assistance to SSA beneficiaries, conduct outreach efforts to beneficiaries who may be eligible for various SSA programs, and provide advocacy services for individuals participating in SSA programs. Each of these programs is briefly described below.

Benefits Planning, Assistance, and Outreach Program. In response to the underutilization of available work incentives, TWWIIA established a community-based work incentives planning and assistance program designed to disseminate accurate information about work incentives to Social Security beneficiaries while providing them with more choices. SSA has established a program of cooperative agreements and contracts to provide benefits planning and assistance to all Social Security disability beneficiaries, including information about the availability of protection and advocacy services. BPAO increases opportunities for beneficiaries to receive the information and services they need to become employed and possibly attain self-sufficiency.

TWWIIA directed SSA to establish community-based planning, assistance, and outreach programs designed to provide accurate information and assistance on benefit programs and work incentives to SSA beneficiaries. To accomplish this goal, SSA established a program of cooperative agreements with BPAO entities across the United States. The BPAOs provide information and support in the following areas (Brooke, 2002):

- Information and referral – provide basic information in response to inquiries about all federal and state benefit programs, and/or referral to government agencies and other community resources.
- Problem solving and advocacy – solve specific federal and state benefit and work incentive issues. This may involve advocating on behalf of beneficiaries with other agencies.

- Benefits analysis and advisement – provide assessment of real or potential effects of employment or similar changes that will impact beneficiaries' overall financial well-being, and inform them of various options available and the projected outcome of each.
- Benefits support planning – provide direct assistance in the construction of a plan to promote effective monitoring and management of beneficiaries' benefit programs and work incentives.
- Benefits management – provide benefit monitoring and management assistance to recipients who are likely to experience employment, benefits, or other changes that will affect their benefit status, health care, or overall financial well-being.

Approximately half of all individuals served by BPAOs are DI beneficiaries, approximately one-third are SSI beneficiaries, and the remainder are concurrent beneficiaries. Over 85 percent of those individuals were either employed or seeking employment. Approximately 20 percent of individuals receiving services from BPAOs express an interest in assigning their Tickets to an EN (Virginia Commonwealth University, 2005).

SSA Area Work Incentive Coordinators. SSA initially created the position of employment support representative (ESR) to provide an internal source of knowledge and support for field office personnel regarding work incentives and SSA employment-related activities. After implementing a pilot ESR program, SSA concluded that a better approach to delivering this function would be through the creation of a new full-time position, the area work incentive coordinator (AWIC). A key difference between the ESR and the AWIC is that the ESRs dedicated 100 percent of their time to work incentive and employment activities. The AWIC is under the supervision of the SSA area director and may be assigned other duties in addition to work-related responsibilities. AWICs coordinate with BPAO benefits specialists, work incentives liaisons (WIL), and other personnel to provide improved services and information on SSA's employment support programs to beneficiaries who want to begin or maintain employment. The responsibilities of AWICs include coordinating local public outreach efforts on work incentives, overseeing training for personnel at local Social Security offices on SSA's employment support programs, handling sensitive or high-profile disability work-issue cases when appropriate, and monitoring local disability work-issue workloads (SSA, 2004c).

PABSS. The Protection and Advocacy for Beneficiaries of Social Security (PABSS) program is administered by SSA through direct grants to each state-designated protection and advocacy agency. These grants are made for two specific purposes: (1) to provide information and advice about obtaining VR and employment services, and (2) to provide advocacy or other services that a beneficiary needs to secure or regain gainful employment. PABSS is a relatively small program designed to complement and supplement existing protection and advocacy (P&A) programs rather than to create a large new program structure. The program provides P&A services to all eligible SSA beneficiaries and makes available dispute resolution services under TTW. Recent changes have enabled the program to represent beneficiaries in overpayment cases and other SSA administrative activities.

Development of Work Incentives

In recent years, Congress and SSA have implemented a number of work incentives for SSI and DI beneficiaries (SSA, 2000) to reduce the effect of earned income on benefits, either by allowing beneficiaries to keep more of their benefits while working or, as in the case of 1619(b), by permitting a beneficiary to retain Medicaid coverage despite earnings that preclude cash benefits. However, few beneficiaries actually return to work or even attempt to return to work once disability benefits are awarded. In an effort to encourage beneficiaries to become employed, the Federal Government and SSA have made changes in the SSI and DI programs during the past 20 years. These changes, or work incentives, are aimed at reducing the risks and costs associated with the loss of benefit support and medical services as a result of returning to work. Some SSI work incentives are the impairment-related work expenses (IRWE) exclusion; the student earned-income exclusion (SEIE); the Plan for Achieving Self-Support (PASS) program; Medicaid While Working (1619(b)); and expedited reinstatement of benefits. Some DI work incentives are the trial work period (TWP); the extended period of eligibility (EPE); and Medicare for Individuals with Disabilities Who Work. The descriptions of the work incentives described below are taken directly from SSA's "Redbook" (SSA, 2005).

Special SSI Payments for Individuals Who Work, Section 1619(a) –Section 1619(a) allows beneficiaries to receive SSI cash payments even when their earned income (gross wages and/or net earnings from self-employment) is at the substantial gainful activity level. This provision

eliminates the need for the trial work period or extended period of eligibility under SSI. To qualify, a beneficiary must have been eligible for an SSI payment for at least one month before beginning work at the SGA level, still be disabled, and meet all other eligibility rules, including the income and resources tests.

Medicaid While Working, Section 1619(b) – Under 1619(b), Medicaid coverage can continue even if earnings alone or in combination with other income become too high for an SSI cash payment. To qualify, a beneficiary must have been eligible for an SSI cash payment for at least one month, still be disabled, still meet all other eligibility rules including the resources test, need Medicaid in order to work, and have gross earned income that is insufficient to replace SSI, Medicaid, and any publicly funded attendant care. The “threshold amount” is the measure that is used to decide whether earnings are high enough to replace SSI and Medicaid benefits and is based on the amount of earnings that would cause SSI cash payments to stop in the beneficiary’s state. If gross earnings are higher than the threshold amount for a specific state, the beneficiary may still be eligible if he or she has impairment-related work expenses, blind work expenses, a Plan for Achieving Self-Support (PASS), publicly funded attendant or personal care, or medical expenses above the state per capita amount.

Impairment-Related Work Expenses – Under impairment-related work expenses, SSA deducts the cost of certain impairment-related items and services that a beneficiary needs to work from gross earnings when determining countable earnings. It does not matter if an individual uses these items and services for nonwork activities.

Trial Work Period – The TWP allows beneficiaries to test their ability to work for at least nine months. During the TWP, beneficiaries receive full DI benefits regardless of how high their earnings might be so long as the work activity has been reported and the beneficiary continues to have a disabling impairment. The TWP starts with the first month the beneficiary is eligible for DI benefits or the month in which he or she files for benefits, whichever is later. The TWP continues until the beneficiary accumulates nine months (not necessarily consecutive) in which he or she performed what is called “services” within a rolling 60-consecutive-month period. SSA

currently considers work to be services if it results in earnings of more than \$590 a month (for the year 2005) or the person works more than 80 self-employed hours in a month.

Plan for Achieving Self-Support – Individuals who receive SSI or who could qualify for SSI are eligible to have a PASS. For example, if an individual has too much income to be eligible for SSI now, using the income to pay PASS expenses may make him or her eligible for SSI. In brief, a PASS must:

- Be designed especially for the beneficiary;
- Be in writing;
- Have a specific work goal that the beneficiary is capable of performing;
- Have a specific time frame for reaching the goal;
- Show what money (other than SSI payments) and other resources will be used to reach the goal;
- Show how the money and resources will be used to reach the work goal;
- Show how the money being set aside will be kept identifiable from other funds;
- Be approved by SSA; and
- Be reviewed periodically to ensure that the plan is actually helping the person achieve progress.

Extended Period of Eligibility – If a beneficiary's disability payments are stopped because he or she worked at the SGA level, the beneficiary may be able to automatically receive benefits again. No new application or disability determination is required. (This is a different rule than the expedited reinstatement provision of TWWIA.) The **earliest** benefits can start again is the month after the end of the grace period. (The individual is paid for the first month benefits cease due to SGA and the following two months.) The **latest** benefits can start again is the 37th consecutive month after the end of the trial work period. If earnings change significantly from month to month, it is possible that benefits could be restarted during this period. Benefits can start again for any

month in the period described above in which (1) the beneficiary continues to have a disabling impairment, and (2) the beneficiary's earnings in that month fall below the SGA level.

A DI beneficiary's EPE begins the month after the trial work period ends. For 36 consecutive months, a DI beneficiary in his or her EPE may receive benefits when countable earnings are below the amount currently designated as SGA.

Despite efforts made by SSA and the Federal Government that have led to more favorable conditions for returning to work, most SSI and DI beneficiaries remain on the disability rolls. The work incentives offered by SSA remain largely underutilized; in March 2000, of the total number of eligible working beneficiaries, only 0.3 percent were using PASS, 2.8 percent were using IRWEs, 7.5 percent were receiving 1619(a) cash benefits, and 20.4 percent were receiving 1619(b) extended Medicare coverage (SSA, 2000). The major reasons cited for the extreme underutilization of these work incentives by beneficiaries were (1) few beneficiaries knew that the work incentives existed, and (2) those who were aware of the incentives thought they were complex, difficult to understand, and of limited use when entering low-paying employment (GAO, 1999).

Purpose of the Study

The purpose of this study is to conduct a comprehensive analysis that (1) examines SSA's current efforts to implement its SSI and DI disability programs; (2) documents philosophical, programmatic, and regulatory obstacles that limit the ability of SSA beneficiaries to return to work; (3) identifies evidence-based practices that promote the return to work of working-age beneficiaries of the DI and SSI programs; and (4) recommends the legislative, policy, and regulatory changes that will be necessary to ensure the successful adoption and implementation of evidence-based practices. This report is a compilation of the findings of the study, including recommendations that warrant consideration by policymakers responsible for Social Security disability programs.

The following are the four research questions the study was designed to answer:

- (1) What are the evidence-based practices that promote the return to work of working-age beneficiaries of the DI and SSI programs?
- (2) What policy changes are needed, given recent trends in program participation and employment?
- (3) Are there proven and documented practices that work best for some populations of people with disabilities and not others?
- (4) Which factors ensure that documented and evidence-based practices could be adapted/adopted by SSA and other entities that seek to ensure the employment of people with disabilities? Which factors prevent adaptation/adoption?

Research Methodology

Appendix A details the research methodology used and the four-step approach taken to implement the study. First, a comprehensive literature synthesis was completed to identify all information of relevance to the proposed study. Second, detailed structured interviews were conducted with key stakeholders, including federal SSA officials, representatives of other federal agencies, consumer and advocacy organizations, service organizations, community service providers, and business representatives. Third, a preliminary list of findings, evidence-based practices, and recommendations based on the literature review and structured interviews was used to develop seven topic papers. These papers were used to facilitate discussion and obtain reaction from participants who were invited to a consensus-building conference at the end of January 2005. Individuals with disabilities, advocacy organizations, service providers, and policymakers who attended the conference had the opportunity to further develop the proposed recommendations that appear throughout the report.

Content of the Report

After the Introduction (Chapter I), the content of the report is organized according to the major trends that emerged from the Consensus Validation Conference:

- The Mission and Purpose of the SSA Disability Benefit Programs – Chapter II
- Beneficiary Perspective and Self-Direction – Chapter III
- Income Issues and Incentives – Chapter IV
- Coordination and Collaboration Among Systems – Chapter V

These four chapters are organized using a similar format. After a brief introduction, each chapter identifies the issues and problems that study participants considered to be the greatest barriers for beneficiaries who are employed or who want to be employed. Previous attempts by Congress and SSA to address these concerns are discussed, both those that have had an impact in the past 15 years and those that have not been successful. Each of the chapters ends with proposed recommendations for consideration by policymakers for changes in the Social Security disability system and in the system of federal, state, and local programs with which SSA collaborates in serving SSI and DI beneficiaries.

Although this study makes no attempt to suggest what a new Social Security definition of disability should be, it identifies in detail the myriad problems created by the current definition used to determine eligibility for disability cash benefits and supports. In Chapter II, a brief explanation is provided of how the disability definition evolved. The policy premises underlying the current SSA disability programs are discussed in the context of recent advances in health care and rehabilitation services, changes in the national economy, and the demographics of the SSA disability population.

Chapter III focuses on the need for work to pay financially and personally for employed beneficiaries who have found that current work incentives do not go far enough to move them beyond poverty or from a near-poverty level of existence. Problems identified include beneficiaries having to define their disabilities in the most negative terms possible to be eligible for benefits, customer service at the local SSA level that needs improvement, problems resulting from overpayments made to working beneficiaries, and health care concerns. The chapter discusses the impact of the Ticket to Work and Work Incentives Improvement Act (TWWIIA), including the Ticket to Work (TTW) and BPAO programs.

Chapter IV identifies a number of disincentives to employment in the current benefit programs, especially the “cash cliff” created by the limitation placed on substantial gainful activity, and the restrictions on asset accumulation in the SSI program. Numerous recommendations are made in this chapter, including post-eligibility elimination of the concept of SGA, expansion of the BPAO program, decreasing the restrictions on assets for SSI beneficiaries, eliminating the waiting period for Medicare benefits for DI beneficiaries, and eliminating marriage penalties.

SSA interfaces with numerous service systems also concerned with the employment and support of individuals with disabilities at the federal, state, and local levels. Chapter V focuses on collaborative interactions with the health care, rehabilitation, employment and training, and education systems, as well as with the business community. In the past 15 years, SSA has been actively engaged in attempting to improve coordination and collaboration with other federal agencies. Yet there continue to be policies among the agencies that work at cross-purposes in promoting employment outcomes for individuals with disabilities. Chapter V includes recommendations for uncoupling Medicare and Medicaid coverage from SSI and DI cash benefit payments. Alternatives to the current systems of health care coverage for beneficiaries are discussed. Also recommended for consideration are changes that would make the Ticket to Work program more functional by promoting collaboration as opposed to competition between state VR agencies and ENs. Additional recommendations attempt to make current TWWIA programs and provisions more compatible with the One-Stop Career Center system of Department of Labor and more widely used by transitioning youth served by the Department of Education. The final chapter of the report, Chapter VI, is a compilation of the findings, including recommendations that warrant consideration by policymakers responsible for Social Security disability programs.

Chapter II: The Mission and Purpose of the SSA Disability Benefit Programs

Introduction

The concept of social insurance is by no means new. Modern social insurance originated in Germany in the late 1800s. These early programs were financed by compulsory contributions and covered all employees, both skilled and unskilled, young and elderly, male and female, and regardless of the state of their health. The hallmark of the early “Bismarck” model was the provision of statutorily fixed entitlements for individuals in employment. These entitlements were calculated in relation to the contributions paid. Because the contributions were mandatory, the worker who met the qualifying conditions was said to have earned the right to a benefit.

The purpose of this chapter is to provide a brief background on the Social Security disability programs and to describe the fundamental limitations of the programs that relate to eligibility and the ability of the agency to provide return-to-work services and supports to beneficiaries. Also discussed are SSA’s current efforts to promote return to work within the current definition of eligibility and policy framework, and a foundation is provided for subsequent chapters describing a comprehensive set of recommendations that will improve return-to-work services and promote employment and economic self-sufficiency among beneficiaries.

Purpose of the Disability Benefit Programs

The major U.S. disability benefit programs trace their history to the Eisenhower Administration of the 1950s. In 1956, after years of public debate, the Social Security Act was amended to add the Social Security Disability Insurance (DI) program. In essence, the DI program began as an early retirement program for older workers whose disabling conditions prevented them from working until pension age. A strict test of disability was ensured through requirements for severity of the condition and a prognosis of prolonged or terminal outcomes. The 1956 definition of disability is still in use today, in both the DI and Supplemental Security Income (SSI) programs. The strict and rigidly applied definition remains unchanged.

The term “disability” means—

(A) 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 (Social Security Act Amendments, 1956).

The very fact that, under the U.S. system, the decision about granting a disability benefit is made prior to, and without any consideration of, referral to rehabilitation reveals the underlying policy premise that severe disability equates to early and permanent retirement from the workforce. Yet, from Social Security’s beginnings, there were discussions not only of paying disability benefits but also of providing or requiring rehabilitation prior to the award of cash benefits. Berkowitz (2000) points out that some early designers of our disability programs recommended that Trust Fund money be used to provide rehabilitation services but not cash benefits to insured people who became disabled. The notion that rehabilitation should take precedence over paying benefits was echoed by Roswell Perkins, the Assistant Secretary of Health, Education, and Welfare in the Eisenhower Administration, who said, “The first line of attack on disability should be rehabilitation, in order that people be restored to useful and productive lives” (Berkowitz, 2000, p. 3).

In contrast to the underlying policy premise of the DI program — income replacement insurance for workers who retire early due to injury or illness — the SSI program is based on a welfare model. The SSI program was created in 1972 as means-tested cash assistance programs for elderly individuals and people with disabilities who have not worked or who are not expected to work. As such, it was intended to serve as a safety net for individuals who had not acquired the work history necessary to receive assistance under the DI program (Daly and Burkhauser, 2003). While the eligibility criteria have changed somewhat throughout the 30 years of the program, the goals of the program have remained the same.

A Rigorous Test of Eligibility for SSA Disability Benefits

The eligibility criteria for both the DI and SSI programs have always been very rigid. Applicants for both DI and SSI must demonstrate the presence of a severe cognitive or physical impairment. In addition to the presence of a significant impairment, applicants must show that they are not able to perform substantial gainful activity (SGA), currently set at \$830 per month, which

equates to annualized earnings of \$9,960. Thus, only individuals with the most severe disabilities, who are in serious economic need, are able to receive benefits through the program.

Because SSI is a means-tested program, applicants face additional criteria related to current countable assets, which cannot exceed \$2,000 for single, nonblind beneficiaries. While SGA has been indexed to the national wage since 2001, the asset limit for these SSI beneficiaries has remained unchanged since 1989 (Kijakazi, 2000). An SSI beneficiary's eligibility or benefit amount can also be affected by any other unearned income received, including other federal and state benefits programs, as well as the income of an individual's spouse or other family members. As a result, the SSI beneficiary population is substantially more economically destitute than it was at the program's inception during the Nixon Administration.

Not only do DI and SSI beneficiaries have to demonstrate acute economic hardship at the point of application, the benefits themselves are very low. For DI beneficiaries, benefit amounts in no way fully replace an individual's lost wages. For "high-earnings" beneficiaries, the wage replacement rate may be approximately 25 percent of prior earnings, compared with 56 percent for "low-earnings" beneficiaries (SSA Office of the Actuary, 2004). For SSI beneficiaries, the current maximum federal payment for an individual before state supplements is \$579 per month, or about 73 percent of the federal poverty level for an individual. Given the level of current SSI benefits, a total reliance on these benefits for income support will not enable most individuals to be economically self-sufficient.

The Changing Societal View of Work Disability

When Social Security Disability Insurance was conceived in the 1950s, it was designed to serve individuals age 50 and over who had no expectation of returning to work. The original definition envisions a program structure that divides those who have work potential, and are therefore ineligible, and those who have no work potential and are eligible. A list of very specific medical conditions was established; if the claimant fit into one of these and was not working, disability was determined. If the claimant did not fit into one of these categories, a more individualized assessment was conducted to determine whether the condition prevented the individual from

performing the kinds of work that might be available, given the claimant's age, education, training, and experience.

Over the next half-century, changes in the economy, medicine, and rehabilitative technology have complicated the issue of work incapacity, making it difficult to draw a line between those who can and cannot work. In addition, there have been changes to the legal definition of disability itself to include those under age 50 and replace "long-continued and indefinite duration" with a 12-month minimum. Although the core definition remains unchanged, the context in which it is applied operates very differently.

SSA's current disability programs remain grounded in the "medical model" of disability, in which disability is viewed as biological condition resulting from a cognitive or physical impairment that leaves an individual unable to work. This model does not reflect the new disability paradigm that recognizes the role that the social and physical environments play in the life experiences of people with disabilities (Silverstein, 2000). In a recent study, the GAO summarized its research on the federal disability programs over the past several years and reached the following conclusion:

GAO's work on federal disability programs, including DI, has found that these programs are neither well aligned with 21st Century realities nor are they positioned to provide meaningful and timely support for Americans with disabilities. Our work suggests that these programs remain grounded in outmoded concepts of disability, and are not updated to reflect scientific, medical, technological, and labor market improvements (GAO, 2005, p. 14).

Rehabilitation and return to work are not recognized objectives of the Social Security disability programs (Social Security Advisory Board, 2003). SSA's return-to-work efforts have had limited results to date, in large part because they have been implemented in a policy and regulatory environment that is over a half-century old.

The Problem

Policy Premises Underlying the Definition of Disability

Our nation's current disability benefit programs are based on a policy principle that assumes that the presence of a significant disability and lack of substantial earnings equates to an inability to work. Applicants are required to demonstrate a permanent incapacity to work in order to obtain SSI or DI cash benefits. The all-or-nothing nature of the disability programs creates enormous challenges for SSA as it attempts to design and deliver return-to-work services and promote employment among beneficiaries. SSA and its collaborating agencies are attempting to provide rehabilitation and return-to work services and supports to beneficiaries who have already been determined to be permanently unable to work (in the case of DI) or who are not expected to obtain employment in the foreseeable future (in the case of SSI).

Policymakers, researchers, and advocates have consistently identified numerous problems with the current definition of disability used in the SSI and DI programs (Barnhart, 2003; Wittenburg and Loprest, 2004; Wunderlich, Rice, and Amado, 2002). Four key problems associated with the current definition of disability are identified below:

- (1) The current definition of disability hampers SSA's return-to-work efforts because applicants are required to demonstrate a complete, permanent inability to work in order to qualify for benefits.
- (2) The current definition fails to recognize the concept of partial disability.
- (3) The current definition does not take into account that, for many consumers, disability is often a dynamic condition.
- (4) The length of the application process in current Social Security disability programs and the waiting periods in the DI program actually contribute to the ineffectiveness of return-to-work efforts and the inability to intervene early in the disability process.

In the remainder of this section, each of these problems is described in detail. Where appropriate, the experiences of other countries and other U.S. disability management programs are discussed

to highlight the impact of the current definition of disability on the efforts of individuals with disabilities to obtain employment or return to work.

Delinking the Concept of Disability from Work Incapacity

In order to be eligible for SSA cash benefits, an individual must prove that, as a result of a disability, he or she is permanently incapable of performing any job in the nation's economy deemed appropriate for the applicant's age, education, and work experience. Yet it is abundantly clear that millions of individuals with disabilities, many of whom would otherwise meet the SSA definition of disability, are working in full- and part-time employment situations and pursuing rewarding careers.

The current eligibility criteria ignore the incredible advances in medicine and technology that enable many individuals with severe disabilities to lead independent and economically self-sufficient lives. The criteria do not acknowledge the progress made through improved educational services and the development of evidence-based employment strategies such as supported employment. Perhaps more important, the definition has little relevance within our current public policy framework for individuals with disabilities (Silverstein, 2004), which is based on a presumption that individuals with disabilities are able to work and have a right to the accommodations and supports that will enable them to lead independent lives.

The current definition also falls short by failing to acknowledge that individuals with disabilities who attempt to enter and maintain employment may frequently encounter extra costs that would generally not be faced by other workers. For example, the costs associated with acquiring and maintaining adaptive equipment, assistive technology, specialized software, vehicle modifications, and other accommodations may prohibit the individual from obtaining the supports necessary to enter employment. Other individuals may incur ongoing costs such as personal assistance services, specialized transportation fees, or necessary medications. A disability benefit policy that is based on a concept of total incapacity to work denies too many individuals the services and supports they need to escape the disability rolls and become self-sufficient.

Finally, the current programs too frequently set eligibility for disability benefits as a precondition for other federal and state programs that can provide the housing, transportation, child care, or personal assistance services and supports necessary to maintain employment and economic independence. Many people with severe disabilities who might otherwise qualify for SSI or DI can and do work full time and do not receive any disability benefits. However, as a consequence of working, these individuals may be unable to access any additional help or support to offset the costs of their disability.

A number of other countries have developed policies and programs that acknowledge that having a disability often leads to additional long-term costs on the part of the individual and his or her family. In contrast to programs designed to replace lost wages (like the DI program), these programs attempt to compensate the individual for the additional costs associated with disability. For example, the United Kingdom's (UK's) disabled person's tax credit (DPTC) is designed to neutralize the costs of having a disability by decoupling the need for help with additional costs from being in actual receipt of disability benefits. To qualify, individuals must have less than £16,000 in savings (about \$32,000), so the credit is not geared toward only low-income workers, as is the U.S. earned income tax credit (EITC). The amount of the DPTC depends on the number of hours worked and the severity of the disability, so it applies to individuals working either full or part time. Under the program, individuals with disabilities who work do not have to wait until the end of the tax year to file for retroactive payment or to have it taken off their taxable income, as in the case of the U.S. system. Instead, employers in the UK pay these funds as a supplement to wages right in the workers' paychecks, so that they augment their earnings as they are working.

Policymakers and advocates agree that the all-or-nothing policy premise in the Social Security disability program eligibility requirements creates significant challenges for SSA's return-to-work efforts. Congress and SSA have been unable to overcome the contradictions inherent in designing and providing return-to-work services to beneficiaries who have already been determined to be permanently unable to work within the existing policy framework. For DI beneficiaries, the lack of a gradual reduction in benefits as a beneficiary's earnings increase makes employment a highly risky choice for many individuals. For SSI beneficiaries, the inability to accumulate assets over time makes movement toward economic self-sufficiency

extremely difficult. As a result, SSA has continuously struggled with the dichotomy of spending scarce resources to provide return-to-work services within a policy framework established to provide supports to individuals who are permanently removed from the workforce or unlikely to obtain employment in the future.

Recognizing the Concept of Partial Disability

The current definition of disability fails to recognize the concept of partial disability or temporary disability. For example, many people with severe disabilities may not be able to work full time but are willing and able to work part time if that were an option under which they could maintain entitlement to some benefits. The highly inflexible system harms individuals with disabilities in two ways.

First, some individuals who may be capable of working 20 hours per week, but whose condition prevents them from sustaining full-time employment, may find that they are ineligible for SSA benefits. These individuals may be denied benefits based on the fact that they earn wages above the SGA threshold (yet do not earn enough to be economically self-sufficient), or their prior work activity makes it more difficult for them to prove their permanent inability to perform any job in the economy. These individuals may face the choice of continuing to work at low levels but remaining ineligible for benefits, or stopping work altogether to gain access to needed benefits.

Second, individuals with disabilities with no prior work history, but who may be able to work part time with appropriate supports, are denied these supports because they are not eligible for SSA benefits. For example, for some individuals with disabilities, eligibility for SSI benefits will lead to eligibility for Medicaid, which will enable them to access personal assistance services and other employment supports. These individuals may feel that they have no choice but to apply for disability benefits since, in the absence of those benefits, they are unable to maintain employment. However, once determined eligible for benefits, these individuals may be afraid to attempt to work, since an unsuccessful work attempt may threaten the cash benefits they already receive.

Other federal benefit programs recognize the concept of partial disability, but the design of these programs tends to funnel out individuals who might benefit from partial disability payments in

the all-or-nothing Social Security program. For example, in the current system, workers' compensation, private insurance companies, and the Veterans Administration (VA) provide some type of partial benefit program to individuals that meet a definition of permanent disability. However, in the workers' compensation and private insurance systems, applicants who qualify are required to apply for the SSA program, thereby funneling individuals from systems that provide partial benefits out to the larger DI program, where partial benefits are unavailable.

Recognizing the Dynamic Nature of Disability

The current definition of disability does not take into account that for many consumers, disability is a dynamic condition. For example, many individuals on the DI rolls who experience psychiatric disabilities, multiple sclerosis, rheumatoid arthritis, lupus, and many other conditions describe their disabilities as episodic in nature. At certain times, they are fully able to obtain and maintain employment. However, at other times their conditions require them to disengage from the workforce. The eligibility criteria used by the Social Security disability programs do not allow for easy transitions on and off benefits and thus create incentives for these individuals to remain permanently unemployed once they have become reliant on the programs.

Available data indicate that there is significant variation in the work activity of existing DI and SSI beneficiaries. In an analysis of SSA data, the Government Accountability Office (GAO) found that nearly half of all DI beneficiaries earning from 75 percent to 100 percent of SGA in 1985 experienced significant reductions in earnings in subsequent years (GAO, 2002c). Similarly, recent data indicate that only half of all SSI beneficiaries who report earnings in a given year report earnings in each of the subsequent three years (Balkus and Wilschke, 2003/2004).

Other countries have developed disability benefit programs that are based on a more dynamic concept of disability. Wittenburg and Loprest (2004) studied disability benefit programs in four European countries and found that eligibility and reassessment processes in these countries tend to more closely resemble a continuum, with the individual moving through a series of stages, in contrast to the all-or-nothing eligibility criteria of the Social Security programs. In the European countries examined, eligibility rules change continuously as the individual moves from a temporary sickness or temporary disability program to a permanent disability program.

Additionally, individuals may move from one type of program to another based on their vocational needs. Individuals who benefit from rehabilitation may move into a less permanent status, or individuals who are not benefiting from rehabilitation services may move seamlessly into a more permanent disability status.

Providing Early Intervention Services

The length of the application process in the SSI and DI programs can contribute to the ineffectiveness of return-to-work efforts. In both programs, applicants must spend months or even years documenting their inability to work, which makes it unlikely that they will seek to obtain employment immediately after being determined eligible. For DI beneficiaries, the problem is compounded by the fact that there are lengthy waiting periods for both cash benefits and Medicare benefits. Thus, DI beneficiaries are denied the services and supports necessary to promote return to work at the very time they would likely benefit most from those services.

Social Security may be viewed as the nation's largest insurance carrier. Like all well-administered indemnity programs, SSA needs to maintain an active oversight of who gets on the rolls and how long they stay there. It is a basic rule of the insurance industry that successful companies must "manage cases against the risk," meaning that they provide services that will reduce exposure to claims and unnecessary costs. As a government-administered indemnity program, it is no longer enough for SSA to simply pay the medical bills and distribute benefit checks. To reduce future costs, SSA must devise ways to identify potential disability applicants and apply early intervention strategies that return people to work before they apply or divert them back to employment immediately after they make application.

Large and small companies in the United States understand the importance of providing services and supports to individuals with disabilities immediately after the onset of disability. The process of effectively dealing with employees who become disabled is referred to as "disability management." Disability management means using services, people, and materials to (1) minimize the impact and cost of disability to the employer and the employee, and (2) encourage return to work of an employee with disabilities in a cost-effective manner. There is growing evidence that the earlier the employer intervenes through disability management services, the

faster the ill or injured worker will return to work. In fact, there is some evidence suggesting that the longer ill or injured employees stay out on disability leave, the less likely they are to ever return to work (Habeck and Hunt, 1999; Williams and Westmoreland, 2002).

Reducing the DI rolls by implementing a coordinated array of prevention, early intervention, and diversion strategies will require SSA to make a major paradigm shift and totally redefine both its mission and how it conducts its work on a day-to-day basis. In order to be successful in these endeavors, SSA must work in an aggressive and proactive manner to indemnify against future risk, as opposed to simply passively processing applications submitted by former workers with severe disabilities and then managing their ongoing payments. The possibilities presented by prevention, early intervention, and diversion techniques are encouraging. However, the ultimate success of these efforts may be limited by the problems discussed above related to the programs' eligibility criteria.

Attempts by SSA to Impact Its Definition of Disability Through Modified Program Rules

The SSA concept of disability was developed a half-century ago and has not changed in spite of the enormous changes in the national economy and in societal views of individuals with disabilities. SSA has long recognized the contradictions and outdated policy premises that form the basis of the current programs and has taken measures to promote employment among beneficiaries. The efforts, however, have focused on those who are already on the programs and thus have met the initial strict eligibility criteria. Over the past two decades, the agency has slowly modified program rules to encourage work attempts and operated a program in collaboration with the Rehabilitation Services Administration (RSA) to offer rehabilitation services to individuals after they have been determined eligible for SSI or DI. With the passage of the Ticket to Work and Work Incentive Improvement Act (TWWIIA) in 1999, SSA expanded its return-to-work efforts to include the creation of the Ticket to Work and Self-Sufficiency Program, as well as several other new programs designed to expand access to public health insurance and employment supports. In the words of Social Security Deputy Commissioner Martin Gerry, "We are trying to change the idea that there is something inconsistent between

benefits and work” (Gerry, 2005). The new reform paradigm within SSA is reflected in a series of innovative demonstration efforts that SSA is operating or planning to initiate to test the effectiveness of delivering services and supports earlier in the process and eliminating additional disincentives in current programs. These demonstrations include the following:

SSDI Benefit Offset Demonstration Project – TWWIA requires SSA to conduct an evaluation that tests the effect of allowing DI beneficiaries to work without the fear of losing all benefits by reducing monthly benefits by \$1 for every \$2 of earnings above an established threshold. In September 2004, SSA awarded a contract to Abt Associates to design a national demonstration. SSA is also in the process of developing individual state demonstrations in four states (Connecticut, Utah, Vermont, and Wisconsin).

Mental Health Treatment Study – The Mental Health Treatment Study demonstration will test the extent to which eliminating programmatic work disincentives, establishing an accurate diagnosis, and delivering appropriate mental health and employment supports will lead to better employment outcomes and other benefits. This demonstration is targeted to Title II beneficiaries with a primary impairment of schizophrenia or affective disorder.

Temporary Allowance Demonstration Program – The Temporary Allowance Demonstration Program is designed to provide temporary cash and medical benefits to individuals who are likely to benefit from aggressive and immediate medical care. The program will target applicants who are likely to meet the Social Security definition of disability and are likely to experience medical improvement in the near future. This demonstration is in the early planning stages.

Youth Transition Demonstration – The Youth Transition Demonstration projects are designed to test the impact of a comprehensive package of services and SSI waivers on the postsecondary educational and employment outcomes of SSI beneficiaries between the ages of 14 and 25. The demonstration projects are designing and implementing interventions that include services and supports such as benefits advisement, cash and counseling approaches, service coordination, disability program navigators, enhanced individual development accounts (IDAs), and job placement and training services.

The demonstration initiatives described above illustrate SSA's attempts to improve its return-to-work efforts by redefining the policy premises underlying the program. SSA is slowly coming to view the design and delivery of return-to-work services as a major part of its mission. Efforts to test a gradual reduction in DI benefits to offset earnings increases reflect a recognition of the dynamic nature of disability; that is, that a beneficiary's ability to sustain employment above SGA will vary considerably over time and will be affected by medical, social, and economic factors. The Temporary Allowance and Mental Health Treatment Study demonstrations recognize the importance of providing rehabilitation and medical services and supports to beneficiaries before the individual becomes permanently detached from the workforce. Finally, the Youth Transition demonstration acknowledges that many adolescents and young adults with severe disabilities who previously have been viewed as incapable of employment can pursue self-chosen careers and become economically self-sufficient when provided with the proper services and supports.

The Urgent Need for Policy and Program Changes

Although SSA has taken steps to improve its return-to-work services, a more comprehensive change in the agency's process and underlying philosophy is necessary in order to make SSA disability programs more work-oriented. SSA needs to integrate return-to-work strategies into all relevant phases of its disability determination process and benefits systems to enable workers with disabilities who can return to work to do so. To accomplish this task, the agency must address the contradictions inherent in the current definition of disability, the existing eligibility process, and many current program regulations.

The disincentives to employment that face SSA beneficiaries take many forms: fear of a loss of benefits due to an unsuccessful work attempt; low expectations resulting from the current disability determination process requiring a beneficiary to prove an inability to work; lack of access to health insurance; the coupling of benefit payments and health insurance eligibility; inability to access necessary rehabilitation services and supports; and the sheer complexity of SSA rules and regulations themselves. Beneficiaries often face seemingly insurmountable challenges as they attempt to obtain and sustain employment. In the next three chapters, a comprehensive review of SSA's return-to-work efforts is presented in three areas — beneficiary

perspectives and self-direction, income issues and incentives, and coordination and collaboration with multiple federal and state systems.

In the area of beneficiary perspectives and self-direction, many of the problems reported by beneficiaries in their daily interactions with SSA are described. These problems include the lack of responsive customer service, inability to obtain accurate and complete information on the effects of employment on benefit level and health care coverage, the devastating effects of overpayments that often occur when a beneficiary attempts to go to work, and the disincentives to marriage in the current program regulations.

The income issues and incentives chapter presents a detailed description of the disincentives caused by SSA's efforts to promote employment opportunities within a system designed for individuals who are permanently retired from the workforce or individuals who are viewed as unable or unlikely to work in the future. Emphasis is placed on the need to eliminate the existing "cash cliff" in the DI program by creating a gradual reduction in benefits as earnings increase, as well as continued attachment to the DI and Medicare programs for DI beneficiaries who maintain employment for extended periods. The chapter also focuses on disincentives in the SSI program that prevent beneficiaries from building the assets necessary for long-term economic self-sufficiency, as well as the complexity of the DI and SSI program rules that make self-directed financial planning extremely difficult for many, if not most, beneficiaries.

In the chapter addressing coordination and collaboration with multiple federal and state systems, we address SSA's current efforts to work collaboratively with public and private health care providers, the federal-state rehabilitation system, the federal employment and training system, the educational system, employers, the business community, and the private insurance industry. The resulting recommendations are based on the premise that the scope and complexity of reforms required to significantly increase employment opportunities for SSA beneficiaries will require concerted efforts by partner agencies providing the rehabilitation, educational, and health care supports required for long-term employment success.

Chapter III: Beneficiary Perspective and Self-Direction

Elizabeth and Salvador were married in February of 2005. Prior to the marriage, Elizabeth received SSI benefits of \$579, and Salvador received both a Social Security check of \$500 and an SSI benefit of \$99. Before the wedding, the combined income they had to live on was \$1,178 per month. After the marriage, there was an immediate impact on the SSI payments. Instead of two SSI beneficiaries, they became an eligible couple. Their combined income dropped to \$889 per month, a loss of \$289 per month from their budget.

Elizabeth and Salvador's change in marital status had an immediate impact on SSI payments, resource limits, and excluded income. It also created disincentives to work. As individuals, Elizabeth and Salvador could earn more and retain entitlement to SSI cash benefits. Since she had no other income, Elizabeth could earn up to \$1,243 before losing SSI cash benefits. Salvador, because he had other income, could have earned \$263. Combined, as single individuals they could earn up to \$1,506 before losing SSI payments. But as an eligible couple, Salvador and Elizabeth would lose all SSI cash payments if they earned \$843.

In April, Elizabeth was offered a job making \$12.50 per hour for 20 hours a week, or \$250 a week (which is a little over \$1,000/month). Because Salvador already had \$500 of unearned income, Elizabeth could earn only \$843 in a month before Salvador lost Medicaid coverage under the 1619(b) provision of the Social Security Act. Salvador has very high medical needs, and losing Medicaid would be devastating. Elizabeth was, therefore, unable to take the job.

Salvador and Elizabeth are not alone. Many SSI-eligible couple beneficiaries who could start or increase work would risk their spouse's Medicaid coverage by doing so. If these individuals were not married, or if married SSI beneficiaries were treated the same as unmarried SSI beneficiaries, there would be no loss of health care benefits.

Introduction

A great amount of time and resources have been spent on the policy debate concerning various ways to reduce the amount of tax dollars currently dedicated to the payment of medical and financial supports for individuals with severe disabilities. Unfortunately, the voice of beneficiaries, the most essential members of the movement toward systemic improvements, is frequently lost in the whirlwind of political arguments for legislative and regulatory change.

Without a strong emphasis on how policy choices affect individual beneficiaries, the hope for effective change is slim.

Individuals with disabilities apply to SSA or other benefit providers because they are in dire need of financial support or other essential benefits, such as health insurance. Often, the refusal or removal of these benefits leads to instant and severe hardship. The web of benefits necessary for full support, such as housing, Medicaid, SSI, Social Security Disability Insurance (DI), Food Stamps, Energy Assistance, and other local supports is often so complex that it is nearly impossible for any one person to understand it all. The current network of benefits compounds rather than alleviates feelings of powerlessness. If beneficiaries are to attempt to obtain employment or return to work, they must feel secure that their efforts will be rewarded, financially and personally. Without an increase in security or confidence in their overall financial status, the barriers that exist among SSA and SSI beneficiaries and work may seem insurmountable.

This chapter describes some of SSA's current attempts to improve customer service and public information about work incentives from the perspective of beneficiaries. First, a number of obstacles to return to work and weaknesses in the current program are identified. Second, recent efforts by SSA to address these weaknesses are analyzed. Also discussed are some health care options available to beneficiaries in the current economy. Finally, the chapter makes recommendations for change that will encourage beneficiaries to reduce their dependence on federal benefits and increase their economic self-sufficiency.

The Problem

There is still a need to go through the window of swearing to the government that your disability prevents you from working in order to get the supports you need in order to then go out and find a job. I just think that is a fundamental flaw that the Ticket to Work legislation was a small effort at addressing, but I still think we have big problems in that we make a person take an oath in order to get supports. It's particularly problematic for young people. The notion that an 18-year-old would retire at age 18 and would have to swear to the government that they can't work in order to get health care and supports to me is bad policy (Andy Imparato, President, American Association of People with Disabilities, December 2004).

When the DI program was created in 1956, it was designed as a financial support for people over 50 years of age who were forced to permanently leave the workforce prior to retirement age because of a disability (Social Security Advisory Board, 2003). Subsequent programs entitled adults disabled in childhood to receive benefits, and SSI allowed children under age 18 to receive a benefit because of a disabling condition if the family had low income and resources. As the programs expanded, they failed to reflect the huge changes in medical treatment and societal perception of impairment and employment opportunities that have occurred since program inception (GAO, 2004a).

In order to receive benefits, an applicant must define his or her situation in the most negative terms possible — an inability to work, both now and in the future. The applicant must document to the government that he or she is unable to work at any significant level. This process helps to internalize the message that the individual is incapable of working. Once the individual has applied for benefits, disability determination staff affirm that he or she has severe work incapacity, reinforcing socially prevalent negative messages about disability and work. If the individual is not approved for benefits at the initial application level, the person must then proceed through a series of appeal steps in order to obtain essential supports. This process can take years and a significant amount of effort and stress (GAO, 2004a). Once awarded, this hard-fought prize is even more highly valued, and the individual is initially unlikely to jeopardize eligibility by attempting to obtain employment or return to work.

Once determined eligible for disability benefits, beneficiaries face a host of complex program rules and policies related to continuing eligibility for cash benefits and access to health care. Many beneficiaries, confused or uninformed about the impact of employment on their life situations, have shied away from opportunities to become self-sufficient through work. Past efforts of Congress and SSA to encourage beneficiaries to work have included the addition and expansion of work incentive provisions, as well as changes to certain program rules recognized as limiting or negatively impacting beneficiaries. In spite of these efforts, many significant barriers remain.

Beneficiaries considering the possibility of returning to work must weigh the benefits of employment against potential costs. These costs include a reduction in overall monthly income due to earnings limitations, limits to the availability of health care and other necessary employment supports, penalties associated with the development of assets, the probability of significant overpayments of benefits, and difficulties associated with understanding and managing benefit and employment impacts over time. Major improvements to the current Social Security disability programs, such as those recommended below, are needed immediately if there is to be an increase in the number of beneficiaries leaving the rolls as a result of work. Without such improvements, it is unlikely that significant numbers of beneficiaries will assume the risks and losses inherent in an effort to return to work.

Customer Service

For a number of years, SSA has been reducing staffing levels in its local offices (Consortium of Citizens with Disabilities, 2000). At the same time, the number of individuals applying for and receiving benefits has steadily increased. The result is an overworked SSA workforce that must deal with an overwhelming and growing workload. Insufficient staffing has often led to long lines and poor service. The processing of appeals and back-to-work issues is not performed in a timely manner. Misinformation is frequent, and mistrust is common.

Beneficiaries often report that SSA needs to improve customer service. Frequently reported problems include offices and meeting spaces that are too noisy for individuals with hearing loss, lack of information in accessible formats for individuals with vision loss, and misunderstandings about how work incentives might relate to specific impairments. Long waits for service in field offices are common, as is the frequent loss of essential paperwork sent to SSA. In some field offices, it is not uncommon for the main telephone numbers to be busy for extremely long periods of time. Trying to access specific staff members is often quite difficult, and it is frequently reported that staff do not return messages left by beneficiaries or their advocates in a timely manner.

Health Care Concerns

Medicaid and Medicare health insurance coverage is often essential to beneficiaries. A significant percentage of beneficiaries live near or below the poverty level (SSA, 2004e). All have disabling conditions, many of which require expensive treatments for an extended period of time. Without access to necessary health care, both morbidity and mortality will increase. In fact, in a recent study, beneficiaries listed loss of health insurance as the largest barrier to return to work (MacDonald-Wilson, Rogers, Ellison, and Lyass, 2003).

Even though individuals generally receive health insurance after becoming entitled to cash benefits under Social Security disability or SSI, the coverage may not completely meet the beneficiary's needs. This is especially true of Medicare, which has not provided full comprehensive coverage since its inception in 1965. Part A (Hospital Insurance) and Part B (Supplemental Medical Insurance) require deductibles, co-payments, monthly premiums, and, for many, some other form of supplemental health coverage. Medicare managed care plans through health maintenance organizations, called Medicare Advantage Plans, are available to offer somewhat more comprehensive coverage, but they have widely differing access rules and availability at state and county levels.

As described in Chapter I, many states have opted to offer Medicaid buy-in programs that provide Medicaid coverage to working individuals with disabilities. Eligibility tests for these programs vary widely from state to state. While the Medicaid buy-in provides a new opportunity for beneficiaries to engage in work activity, eligible individuals sometimes encounter problems with the program, such as the unavailability of providers accepting Medicaid. Also, not all buy-in programs provide the same pharmaceutical benefits. For example, some limit the number of prescriptions an eligible beneficiary can receive (Goodman and Livermore, 2004).

Relying on only one source of health coverage has proved to be inadequate for many beneficiaries. Both Medicare and Medicaid have restrictions and eligibility requirements that may create challenges for beneficiaries. Medicaid recipients may not receive some optional benefits, may face restrictive income and asset requirements (Sheldon, n.d.a), or may encounter limited physician choice. Beneficiaries must complete a 24-month qualifying period to receive

Medicare. Also, until the Medicare Modernization Act Medicare (MMA) Part D becomes effective in January 2006, Medicare beneficiaries must pay for prescription medications entirely out-of-pocket. Once MMA prescription coverage has begun, beneficiaries will still have a significant out-of-pocket share for prescriptions.

Deficiencies in the Wage Reporting System Resulting in Overpayments

The reduction and/or loss of SSI and DI benefits as a result of work and earnings can serve as a disincentive to employment for beneficiaries. The inherent work disincentive in the benefit programs is further exacerbated by the likelihood of substantial benefit overpayments that occur as an unintended consequence of work. SSA relies heavily on beneficiaries to report work activity and other changes in circumstances that impact benefit eligibility and payment amount. If work activity is not reported in a timely manner by beneficiaries, overpayment of benefits is generally a result. However, as many beneficiaries and advocates have discovered, in spite of appropriate wage reporting by individuals, the failure of SSA to act on reported earnings information in a timely manner and adjust benefits accordingly likewise results in substantial overpayments for many beneficiaries.

According to SSA, earned income is the most common reason for overpayments in the SSI and DI programs (SSA, 2002). Based on data from an SSA study, the GAO recently reported that overpayments attributable to work and earnings averaged about 31 percent of all DI overpayments annually between 1999 and 2002. Overall, total DI overpayment detections increased from about \$772 million in FY 1999 to about \$990 million in FY 2003 (GAO, 2004b). Newly detected SSI overpayments were nearly \$2 billion, or 6 percent of total outlays in 2001 (SSA, 2003). The extent of overpayments in the disability programs not only compromises the integrity of the programs but also serves to undermine the resolve of beneficiaries to increase their work efforts and reduce reliance on benefit supports. Beneficiaries considering work must weigh the potential of having to repay a large benefit overpayment as an additional cost of employment.

Numerous factors have been identified as impeding the ability of SSA to make accurate benefit payments, resulting in overpayments to beneficiaries. These factors include the complexity of the disability program rules, insufficient access to timely and current earnings data, as well as

complexities and inefficiencies in the current DI work activity CDR process (GAO, 2002a, b; GAO, 2004b; Livermore, 2003).

Complexity of Program Rules

Determining accurate monthly payment amounts in the SSI program involves matching an individual's need with his or her financial situation for a given month. As changes are experienced in earnings level, adjustments must be made to ensure accurate benefit payments. Projected monthly earnings amounts provided by SSI beneficiaries are used by SSA to determine monthly benefit amounts for the following 12-month period. Overpayments result when projections of earnings are incorrect or changes in earnings are not reported or acted upon. Additionally, the rules governing how earnings and other income are counted and how exclusions are applied are complex and create confusion among beneficiaries regarding reporting requirements. For example, a working SSI recipient may have his or her benefits recalculated, resulting in eligibility for DI benefits. This results in separate letters to the beneficiary: one letter states that the SSI recipient has been overpaid (paid too much SSI) during certain months that he or she was entitled to DI; a separate letter from DI states that he or she had been underpaid DI during the months he or she was owed DI. This is called the "windfall offset" provision, because the overpayment for SSI is taken out of the person's first DI checks.

Discrepancies in the treatment of income between the SSI and DI programs likewise contribute to confusion and difficulties in the reporting of income and subsequent benefit adjustments. For SSI purposes, benefit eligibility in a given month is based on earnings received in that month, and usually the amount of benefit is based on earnings or other income received two months before the payment month. For the DI programs, benefits are based on wages earned in a month. While SSI cash benefits are adjusted when beneficiaries reach \$65 in monthly gross earnings, a DI cash benefit is not impacted until the beneficiary engages in SGA-level work following completion of the trial work period. In addition, the array of work incentives available in each program and their impact on countable income determinations vary significantly. Disparities in program rules are particularly problematic for concurrent beneficiaries who must understand and negotiate both programs as well as the interface between the two programs to avoid substantial overpayments.

Insufficient Access to Timely and Accurate Earnings Data

Access to timely and accurate earnings information is essential if overpayment of benefits is to be avoided. This is particularly true for the SSI program, which pays monthly benefits based on the actual amount of income received by a beneficiary. Individual circumstances and earnings may change often, requiring SSA to continuously reassess and adjust payment amounts. Reliance on beneficiary reports of income is problematic given the complexity of income definitions and rules and the challenges it poses for beneficiaries who are attempting to understand the impact of even minor changes in their earnings on their eligibility and benefit amount.

Complex and Time-Consuming Nature of DI Work Activity CDR Processing – Work activity continuing disability reviews (CDRs) are performed in the DI program to determine if a beneficiary is engaging in substantial work following the trial work period. The work activity CDR process is complex and time-consuming, involving the development of information related to a beneficiary's work effort, verification of earnings level achieved and monthly wages earned, and the assessment of work effort against the SGA guideline, including the development and application of any subsidies and work incentives relative to the SGA determination.

The inability of SSA to effectively manage the work activity CDR caseload and make SGA determinations and benefit adjustments in a timely manner has resulted in overpayment of benefits for many DI beneficiaries. Factors identified as contributing to this problem are well documented and include insufficient management information to support internal caseload monitoring; the lack of screening mechanisms to identify DI beneficiaries at risk of large overpayments; inadequate automation of the complex process; and staffing constraints related to expertise, competing caseloads, and duplication of effort between field offices and program service centers (GAO, 2004b; Livermore, 2003).

Marriage Penalty

There are several provisions in the Social Security Act that terminate or reduce benefits because a beneficiary marries. This section will be restricted, however, to discussing the combined disincentives to marry and work created by the eligible couple provisions of the SSI program.

SSI beneficiaries often live significantly below the poverty level and may slide further into poverty by marriage. Spousal income is deemed to be available to the SSI beneficiary, often causing loss of essential income and health care supports upon marriage to an individual who does not receive SSI. If an SSI-entitled individual marries someone else who is eligible for SSI, there is a status change that lowers the potential SSI benefit to both individuals, increases the reduction in available income caused by work, and significantly increases the risk to health care created by working.

Eligible couple status is assigned to SSI beneficiaries who live together and are married or “holding out” to the community as if they are married. The SSI program treats an eligible couple as one SSI unit. The highest possible federal benefit payment for the eligible couple unit is reduced by one-third from the total combined benefit for two unmarried individuals.

When two SSI recipients become an eligible couple, not only is their maximum combined SSI benefit reduced, but the impact of other income against the potential SSI payment is increased. Each single SSI individual beneficiary receives an exclusion of \$20 for all types of income and an additional exclusion of \$65 of earned income when SSA determines benefit payments. A couple, however, receives only one \$20 and one \$65 exclusion. The result is that work has a greater negative impact on SSI benefits received by eligible couples. This creates a disincentive to marry for SSI beneficiaries, a disincentive that is exacerbated by work activity because of potential loss of health care.

Most states offer Medicaid entitlement automatically to SSI beneficiaries. Extended Medicaid for people who work, authorized under Section 1619(b) of the Social Security Act, allows SSI beneficiaries to retain Medicaid entitlement even though they have too much income to receive an SSI cash payment. For Section 1619(b) to apply, the person must meet all other eligibility criteria, such as disability status and resources under the allowable limit. The person may retain Medicaid only if it is the individual’s own earned income that causes the loss of entitlement to cash payments. Because SSI is the payer of last resort for basic needs, any income, including the earnings of a spouse, impacts receipt of SSI. If two SSI beneficiaries are married, the income of either member of the couple is counted against the possible benefit of both. What is earned

income to the working member of the couple is treated as unearned income to the spouse. Since the 1619(b) provisions require that the SSI beneficiary meet all SSI eligibility criteria except income attributable to earnings, only the working spouse retains Medicaid.

Fortunately, if both husband and wife work, they may both retain Medicaid under Section 1619(b). It often happens, however, that one member of a couple is ready or willing to try work, but the other member of the couple is medically unstable, unable to find work, or otherwise not working. The result is that the member of the couple who could work might be unable to work to his or her full potential without risking essential medical services for the spouse. How much the working member of the couple could earn would depend on other income. If there were no other income, for example, the working member of the couple could earn slightly less than \$1,823 per month in 2005 before the nonworking spouse would lose Medicaid. If the couple had high unearned income, the amount the working member of the couple could earn would be very low.

Previous Attempts by Congress and SSA to Improve Customer Service and Beneficiary Control

Congress and SSA have implemented many legislative changes, program modifications, training initiatives and automation efforts in the past 15 years. Many of these have resulted in improved customer service but have not had a direct impact on beneficiary sense of control to date. Some examples of these modifications include testing of quarterly online wage verification in SSA's Chicago Region; implementation of the Office of Hearings and Appeals' (OHA) Case Processing and Management System (CPMS) to facilitate tracking of appeal files; streamlining disability claims processing (GAO, 2004a; GAO, 2004c); and the Social Security Protection Act, which clarified income and asset definitions to streamline the adjudication of SSI applications (SSA, 2004d). Although any effort to streamline processing and improve customer service should be lauded, the volume and level of detail necessary to discuss all the hundreds of programmatic changes at length would be overwhelming. In order to limit the list to a manageable volume, the following discussion outlines the initiatives that are clearly directed toward the improvement of beneficiary understanding and choice.

The Ticket to Work and Work Incentives Improvement Act

As described in Chapter I, many components of the Ticket to Work and Work Incentive Improvement Act (TWWIIA) were designed to improve work incentives for individuals with disabilities. Expedited reinstatement of benefits, for example, made it easier for individuals who lost entitlement to SSI or Social Security benefits due to work activity to return to benefit status if work was stopped due to the same or a related disability. The increase in the extended period of Medicare coverage permitted individuals who lost entitlement to Social Security disability benefits due to work to retain Medicare for at least an additional 54 months beyond the period specified in earlier legislation. The rules for Medicaid buy-in programs were liberalized to allow individuals with higher income to be eligible, should states choose to adopt the higher limits. The two changes in the Act that are most relevant to beneficiary control, however, were the Ticket to Work (TTW) itself and the provisions requiring SSA to improve the information available to beneficiaries on the effect of employment on their continuing eligibility for financial and health care benefits.

The Ticket – The purpose of the TTW program is to provide eligible beneficiaries with greater choice and control of the employment support services they need to assist them in obtaining employment or returning to work. While the program remains in its infancy, results to date have fallen short of expectations. SSA has contracted with Mathematica Policy Research (MPR) to conduct a comprehensive evaluation of the TTW program. MPR released its initial evaluation report in February 2004 (Thornton et al., 2004), with subsequent reports to be released annually through 2007. The initial MPR report documented a number of key findings.

- **Beneficiary participation is low.** As of August 2003, less than 1 percent of Ticket holders had assigned their Ticket to an Employment Network (EN). (While the participation rate has risen slightly since 2003, overall participation remains extremely low.)
- **Most Ticket assignments have been to state vocational rehabilitation agencies (SVRAs).** Since the launch of the TTW program in February 2002, the overwhelming majority (over 85 percent) of Ticket assignments have been made to SVRAs.
- **EN recruitment and retention is difficult.** Recruiting and retaining ENs has been a significant challenge for the TTW program.

- **EN Ticket assignments are concentrated among a few providers.** Over half of all ENs have not accepted any Tickets, although they have not disenrolled from the program. Over 80 percent of all ENs have accepted five or fewer Tickets.
- **EN financial viability is still uncertain.** Results of MPR interviews with ENs indicate that virtually all ENs report that they are losing money on their TTW operations. This finding is corroborated through EN testimony to the Work Incentive Advisory Panel (WIAP) and the U.S. Congress (Webb, 2004).
- **Providers complain about TTW marketing.** Many ENs feel that SSA has done an insufficient job in terms of marketing the program to beneficiaries.

TWWIA identified four target groups that were anticipated to have a difficult time receiving services under the TTW program: those who (1) need ongoing support and services, (2) need high-cost accommodations, (3) earn a subminimum wage, or (4) work and receive partial cash benefits. While evidence in this area is quite limited, it appears that individuals in these groups have, to some extent, been able to assign their Tickets to state VR agencies, but are often viewed as too costly or risky to be served by ENs that continue to struggle to maintain financial viability.

SSA has required that state VR agencies serving current Ticket holders automatically assign the Ticket to the state VR agencies in most circumstances. In order to receive services from a state VR agency, consumers must sign a form that outlines steps necessary to achieving their vocational goals. Once signed by the beneficiary, this plan, called an individualized plan for employment (IPE), will be sent to the program manager with a blank assignment form as a Ticket assignment, even if the individual consumer involved has not been informed and has not offered consent. This policy appears to clearly violate the principles of consumer direction and choice that were the foundation on which the Ticket legislation was built.

SSA's Work Incentives Support Plan

SSA has developed several programs designed to enable beneficiaries to make informed choices about work. Two programs—area work incentive coordinators (AWICs) and work incentive liaisons—are internal to the agency. The other two programs—Protection and Advocacy for

Beneficiaries of Social Security (PABSS) and Benefits Planning, Assistance, and Outreach (BPAO)—provide services through agencies and organizations outside the agency. The purpose of these combined programs is to provide work incentive planning and assistance to SSA beneficiaries, conduct outreach efforts to beneficiaries who may be eligible for various SSA programs, and provide advocacy services for individuals participating in SSA programs. Each of these program components was described in Chapter 1. Two of the programs, WILs and BPAOs, are discussed in further detail below.

Work Incentive Liaisons – An additional group of internal work incentive specialists has been put into place in each SSA field office. These specialists, called WILs, serve as a primary contact for beneficiaries, rehabilitation professionals, and agencies that work with people with disabilities. WILs have been a valuable source of information regarding the work incentives. A significant drawback to this effort, however, has been the limited amount of time and resources that the WILs have been able to devote to their additional work incentive job assignments, given their other job duties. Beneficiaries often report that WILs frequently change, making it difficult to establish a working relationship with WILs who serve their specific geographic area. Problems reported less frequently are that many WILs do not understand the work incentives and that some are not even aware that they are considered WILs.

Benefits Planning, Assistance, and Outreach – TWWIIA authorizes SSA to operate a national network of BPAO programs that are intended to provide beneficiaries with accurate and complete information on the effects of employment or increased earnings on the status of their cash benefits and health care coverage. Nationally, 114 BPAO organizations had provided services to nearly 168,000 beneficiaries as of March 31, 2005 (VCU-BARC, 2005). Many types of organizations are providing BPAO services. Centers for Independent Living (CILs) are providing services in 52 communities, accounting for nearly half of all BPAO organizations. Nonprofit community organizations, ranging from Goodwill Industries to mental health centers, provide services in 21 locations. State vocational rehabilitation agencies operate BPAO programs in 18 states. Other BPAO organizations include advocacy organizations (e.g., United Cerebral Palsy), universities, and legal aid agencies (including protection and advocacy organizations).

Of the 167,950 beneficiaries served by the BPAO programs to date, 49.2 percent are DI beneficiaries, 28.4 percent are SSI beneficiaries, and 15.4 percent are concurrent beneficiaries. Individuals with psychiatric disabilities (33.6 percent), system diseases (15.2 percent), cognitive disabilities (8.9 percent), and non-spinal-cord orthopedic disabilities (8.9 percent) account for two-thirds of all individuals served. More than 90 percent of the individuals who receive intensive benefit support through the BPAO program are either employed or in the process of seeking employment. Most are currently not working but have a desire to change their employment status. Slightly more than half indicate that they are not employed but are actively seeking employment, and nearly 30 percent fewer are currently employed part time, working less than 30 hours a week. Less than 6 percent of intensive benefit support beneficiaries were employed full time, working 30 or more hours a week (Virginia Commonwealth University, 2005).

The impact of the BPAO programs on beneficiaries' subsequent employment experiences cannot be determined through currently available data. In 2003, the SSA Office of Quality Assurance conducted a consumer satisfaction survey of beneficiaries served through BPAO programs. However, the methodology employed in conducting the survey does not allow the results to be used to examine program effectiveness. At the present time, SSA is considering various approaches that can be used to conduct a rigorous evaluation of the program.

Use of Technology for Outreach and Adjudication – SSA has made significant improvements in the use of technology for outreach and adjudication. The SSA Web site is rich with valuable information and is fully accessible and well constructed. Though a strong indicator of SSA's commitment to embrace technology, the effectiveness of this medium is limited because only a small percentage of individuals with disabilities have readily available Internet access (National Organization on Disability, 2000). Also, even though they are presented well, the SSA programs themselves are still complex and confusing.

There have been other internal attempts to improve accuracy and accountability for the adjudication of work issues. The Modernized Return to Work system and the Disability Claims Folder were two such initiatives. Both offered better control of disability work reports. Personal Computer Continuing Disability Review (PCCDR) was another initiative developed to assist

Social Security claims representatives in adjudicating work issues in a timely and accurate way. Recently, these three initiatives were rolled into EWORK, the software that Social Security field office staff are required to use when adjudicating work issues. Although consumers themselves do not access the software, the structure of the software creates a significant improvement in accountability for work-issue processing. Instead of a paper trail, SSA now takes work reports electronically. EWORK immediately sends a note to the field office with adjudicative responsibility that the beneficiary has reported work. An electronic file accessible from all agency locations is created, and reminders are sent to field office staff that the issue is pending. In addition to the improvement in accountability, the EWORK system should improve consistency in the adjudication of work reports because EWORK screens force claims representatives to consider work incentives that may apply.

The EWORK system was rolled out over the last few months of 2004. With time, it should improve information exchange among offices and should improve adjudication of Title II work issues. Unfortunately, the system is completely separate from the SSI system; therefore, it is still possible that a beneficiary who receives both Social Security and SSI disability benefits will need to report work separately to Social Security and SSI claims representatives. SSA is in the process of developing software to add to EWORK that will supplement the report of work, routing it to individuals responsible for both SSI and Social Security disability adjudication at the same time.

Recommendations for SSA Policy Change: Beneficiary Perspective and Self-Direction

I think a system based on work incentives won't work; instead, there has to be a system where people feel protected until they are truly comfortable with their ability to sustain themselves through work. The system has to acknowledge the cyclical nature of many disabilities and the difficulty most beneficiaries have regaining any employment if they have previously lost employment.... The reason for work incentives seems to be the draconian results that occur without them. Create a system less interested in terminating benefits ... and work incentives become much less necessary. Work incentives are the result of the piecemeal approach that has been such a damaging part of these programs from the beginning (James McCarthy, Director of Governmental Affairs, National Federation of the Blind, November 2005).

The lack of a comprehensive, beneficiary-directed system of supports creates enormous risks in the lives of already vulnerable individuals. When an unsuccessful work attempt can have a significant negative impact on an individual's financial and health status, it is unrealistic to expect large numbers of beneficiaries to attempt to leave the benefit rolls. Congressional and regulatory policymakers must design alternatives that are better at recognizing the financial risks faced by beneficiaries. To address these concerns, Congress and SSA must address these concerns through improvements in the delivery of customer service, modifications to the TTW program, expansion of SSA's efforts to promote consumer choice, eradication of overpayments, and the elimination of marriage penalties.

Recommendations Specific to Customer Service

Efforts to improve SSA's customer service will require a combination of improved architectural and programmatic accessibility, changes to staffing patterns and work assignments, enhancements to the role of work incentive liaison, continued improvements to SSA's automated processing efforts, and increased outreach to SSA beneficiaries. Specific recommendations are provided below.

SSA should develop and implement a plan to improve the architectural and programmatic accessibility of SSA field offices. SSA offices need to be more sensitive to universal access issues. SSA staff members need to be better informed, more available, and more sensitive to the concerns and limitations experienced by beneficiaries who come to Social Security field offices. An ongoing program on disability awareness should be provided to all frontline staff. Field office interviewing space should be designed to provide better access for individuals with hearing impairments and all disabilities. Using better sound barriers, for example, would facilitate hearing and improve privacy.

SSA field office personnel functions, staffing patterns, and work assignments should be redesigned to prioritize activities that assist beneficiaries attempting to work. The existing system of "work credits" for field office employees should be modified so that employees receive credit for the complex work involved in processing work reports and other post-entitlement issues. SSA should make the WIL a full-time position in most large field offices,

instead of merely an additional job duty for a staff member with many other responsibilities. Liaisons should receive intense, ongoing training to ensure that they provide accurate and complete information to beneficiaries attempting to use various work incentives to increase their employment opportunities. In addition, SSA should significantly increase the number of AWICs in the field. There are currently 58 AWIC positions, with one housed in each area office. AWICs conduct public outreach on work incentives; provide, coordinate, and oversee training on SSA's employment support programs for all local SSA personnel; handle some highly sensitive disability work-issue cases; and monitor the disability work-issue workloads in their assigned areas. Feedback from beneficiaries consistently indicates that SSA field office staff struggle with correctly implementing the complex work support rules for beneficiaries with disabilities. If SSA expanded the number of AWICs, it is reasonable to expect that more training and oversight could be provided to improve this situation.

The effort to automate processing of work reports not only needs to continue but needs to expand to coordinate work reports in the SSI and Social Security benefit programs.

Information transfer processes should be improved so that an individual who has reported a change to one employee of SSA can be assured that the information reaches and remains available to all necessary offices and staff members. EWORK, SSA's newest work-issue adjudication software, should improve information processing, but greater efforts should be made to improve communication and local office accountability for work-issue processing.

SSA should significantly improve outreach efforts to beneficiaries to inform them of the existence, advantages, and reporting requirements of various work incentives. SSA should work with beneficiaries and advocacy groups to be more creative in choosing outreach mechanisms by providing materials in accessible formats and by sending direct mail contacts to individuals reminding them of work incentives and the need to report changes and work activity. Efforts should be specifically targeted to better reach individuals who do not have Internet access.

Recommendations Specific to the Ticket to Work Program

In order for beneficiaries to successfully leave the benefit rolls, they must be able to gain access to the services and supports necessary to enable them to obtain and maintain satisfying

employment. The TWWIA legislation is an effort to provide increased access to employment services and beneficiary control of their own careers. To fulfill this purpose, the TTW program needs considerable modification. Specific recommendations to improve the TTW program are provided below.

Congress and SSA should expand Ticket eligibility to include beneficiaries whose conditions are expected to improve and who have not had at least one “continuing disability review”; childhood SSI beneficiaries who have attained age 18 but who have not had a redetermination under the adult disability standard; and beneficiaries who have not attained age 18. The low participation rates during the initial implementation of the TTW program make it essential that SSA continue to identify those individuals on the disability rolls who are most likely to obtain and maintain employment for extended periods of time. It is important to note that if Congress were to adopt this recommendation, there would be additional costs associated with its implementation and, therefore, by Office of Management and Budget rules there would be a requirement to provide an offset to pay for the change.

SSA should review and modify the TTW regulations to ensure that Ticket assignment practices do not violate the voluntary nature of the program and beneficiary rights to grant informed consent. One of the major goals of the TTW program is to offer options for rehabilitation outside the traditional VR system. However, SSA regulations allow the state VR agency to automatically assign a beneficiary’s Ticket if the person is eligible for a Ticket at the point that the beneficiary signs his or her individualized plan for employment (IPE). It is essential that changes be undertaken in order for the program to succeed in its intended purpose.

SSA should design and implement a strong national marketing program that will expand and intensify its efforts to inform beneficiaries about the TTW and other SSA programs. The marketing program should allow SSA to inform beneficiaries about the TTW program at least once each year. The program should also provide information to beneficiaries on the other support services available to them in their local communities that can assist them in the pursuit of their career goals.

Recommendations Specific to Facilitating Beneficiary Choice

The SSA-funded network of BPAO programs has been highly successful in providing basic information on SSA program provisions, work incentives, and employment services and supports available to beneficiaries attempting to obtain employment. At the same time, the BPAO program is limited in terms of the types of individuals that can be served and the types of information that can be provided. The BPAO program currently lacks the capacity to adequately supply information to all beneficiaries who need these services. The following recommendations address these concerns.

The BPAO grant program should be elevated to an integrated federal grant-making responsibility, combining resources and oversight from the Centers for Medicare and Medicaid Services (CMS), Office of Special Education and Rehabilitation Services (OSERS), Housing and Urban Development (HUD), and the Employment and Training Administration (ETA). SSA must continue to engage RSA and its other federal partners in dialogue to encourage them to jointly fund benefits counseling. Since these agencies all benefit when individuals have access to accurate and complete information regarding the effect of employment on benefits and health care, it makes sense that they participate in the purchase of this service.

SSA should consider changes to the existing BPAO program to improve the accuracy and quality of services provided to individual beneficiaries. SSA should immediately complete a comprehensive evaluation of the BPAO program and implement program modifications based on the evaluation results. The evaluation should focus specifically on efforts to promote quality assurance and avoid conflicts of interest with BPAO provider agencies.

Recommendations Specific to Reducing SSA Overpayments to Beneficiaries

The problem of SSA overpayments to beneficiaries is very complex. To address this problem, SSA should focus efforts on enhancing automated approaches to post-entitlement earnings processing, centralizing the processing of post-entitlement earnings reporting, and informing beneficiaries of their work-reporting responsibilities. Several recommendations are provided below.

SSA should expand its efforts to increase the use of electronic quarterly earnings data and automated improvements to expedite the processing of work activity and earnings that affect eligibility and benefits. In doing so, SSA should adopt a uniform definition of wages for both programs that bases the definition on when wages are paid as opposed to when they were earned. In addition, SSA should simplify the process of estimating and verifying wages, particularly for the SSI program, in order to reduce the effort expended by beneficiaries and SSA in wage-accounting activities.

SSA should pilot the creation of centralized work Continuing Disability Review (CDR) processing in cadres similar to PASS and special disability workload cadres. These units might be staffed with CRs who have undergone training similar to the training provided to AWICs. This approach would establish a specific unit as the single repository for earnings information that could be held accountable for following up and processing the information requested and received.

Congress should direct SSA to enhance its efforts to educate beneficiaries on reporting requirements, the impact of wages on benefits, and available work incentives. Additional options for reporting income by beneficiaries to SSA should be tested. Agency resources should be directed toward monitoring the extent to which SSA district offices are providing receipts to beneficiaries for reported income. Finally, program rules governing overpayments should be changed to substantially limit liability for repayment of benefits in situations where beneficiaries have reported earned income consistently to SSA as required by law.

Recommendations for Eliminating the Marriage Penalty

SSI beneficiaries should be allowed to make choices regarding their marital status without regard to the effect of their actions on their benefits and health care. The following recommendations address this concern.

Congress and SSA should undertake a complete review of the SSI program and make program modifications that eliminate the financial disincentive to marriage inherent in the present program. The drop in available SSI income places eligible couples even further below

the poverty line than they are as unmarried individuals. The risk of terminating a spouse's Medicaid creates a huge disincentive for members of an eligible couple to work. In addition, continued Medicaid protection should be extended to both members of an eligible couple when the earnings of either member causes the loss of SSI.

Congress should amend the current Title XVI disability legislation to modify the manner in which 1619(b) eligibility is applied to eligible couples. Given the intent of the 1619 provision to provide a safety net to beneficiaries in ensuring continued access to health care, a member of an SSI eligible couple who is not working should not be penalized with the loss of Medicaid as a result of his or her spouse's work activity. Access to continued Medicaid for the nonworking member of the eligible couple could be provided through 1619(b), based on amended eligibility criteria, or through the establishment of a separate protected status group.

Summary

The SSA disability system was originally developed for individuals who left the workforce with the expectation that they would never return. However, the rapid pace of medical advances, improved societal attitudes, and an increased focus on rehabilitation now allow many beneficiaries who previously would have been permanently excluded from the workforce to engage in full- or part-time employment. Congress and SSA must understand that beneficiaries who attempt to obtain and maintain employment face many challenges and often view the decision to work as endangering their ability to pay for their basic needs and maintain access to health care. To assist these individuals, Congress and SSA must ensure that beneficiaries receive high-quality customer service and have access to accurate and complete information that will enable them to make informed career choices. They must be able to access appropriate and effective employment services and supports. They must be assured that their attempts to obtain employment will not lead to large overpayments that may further jeopardize their economic self-sufficiency or jeopardize their ability to access health care services. Finally, SSA's disability program regulations should never create situations in which beneficiaries are penalized because of their desire to be married.

Chapter IV: Income Issues and Incentives

Gary is 32 years old and has been receiving SSI and DI benefits since he was 26, when he applied for and was granted disability status by SSA. Gary's DI benefits are relatively low because he had a limited work history before he was granted disability benefits, so he also qualifies for SSI benefits. Gary has worked several times since becoming disabled, and he says, "The last time I went to work I held my job for nearly eight months. After I stopped working, I got a letter from SSA telling me I had been overpaid about \$700 and underpaid about \$250. It was the most bizarre thing I had ever seen. Some of my friends tell me I can earn as much as I want for a year without my benefits being cut, and another friend says I can only earn about \$800 a month. This whole thing makes my head want to explode!"

Gary understands that he has two different benefits and that the rules differ for each one, but he does not want to owe the government any money. He decided to turn down a small inheritance from his aunt because it would have made him ineligible for Medicaid. Instead, he asked his mother to keep the money and pay for a college course for him. "I want to be rid of Social Security benefits, but I can't make up what I get in cash and medical benefits until I get more training. Since I got that notice about how I owed the government money, I'm afraid to do anything!"

Introduction

Social Security Administration disability benefits programs (Disability Insurance and Supplemental Security Income) are characterized by a plethora of complex rules governing how various forms of income and assets are treated in terms of benefit eligibility and payment amount. Both disability programs make a significant distinction between income that is earned (i.e., received in exchange for work effort or as remuneration for work performed) and unearned (i.e., all other income that does not meet the definition of earned income or wages). In addition, the SSI program imposes resource limits and includes a wide range of regulations that define which resources count and under what circumstance they count, as well as numerous citations detailing a host of specific income exclusions. The manner in which SSA treats these various forms of income and resources has a significant effect on the behavior of beneficiaries. The rules may serve to either encourage or reinforce behavior or to punish or decrease behavior. The manner in which these rules influence efforts by beneficiaries to attempt employment is the particular focus of this chapter.

The myriad problems related to the DI and SSI income and resource rules and their impact on beneficiaries' decisions about work have been acknowledged repeatedly by beneficiaries, scholars, advocates, and disability policy specialists for many years. The following sections will examine several of the most persistent problems in both the DI and SSI programs in terms of how income and resources are counted, describe the efforts SSA has made to date to resolve the problems, and offer specific recommendations for the future.

The Problem

Employment Disincentives in the Disability Benefit Programs

The single most significant disincentive to employment in SSA disability programs is the sudden loss of cash benefits as a result of earnings above the substantial gainful activity (SGA) level for Title II disability beneficiaries. While disincentives remain in the SSI program, the way earned income is treated by this program is, for the most part, quite positive. SSI earned income rules encourage work by providing increased financial well-being through employment and continuing Medicaid coverage under the 1619(b) provisions. It is only in rare circumstances that an SSI recipient does not come out ahead by working. This is definitely *not* the case in the DI program. The primary eligibility criterion for DI benefits focuses on the verification of a medical condition that will result in death or has lasted or can be expected to last for at least 12 months, and which results in an "inability to work at a substantial level." In effect, if the applicant is able to work at a substantial level (as defined by SSA), the person is not eligible for benefits, regardless of the person's medical condition. SSA's definition of "work" in this context is SGA, which is defined as the value of a person's work expressed as a monthly dollar figure. For FY 2005, the SGA guideline is set at countable gross earnings of \$830 per month.

Unlike the work incentives offered to SSI recipients, which allow for a gradual reduction in cash benefits as the recipient's earnings increase, the DI program operates in an all-or-nothing fashion. The effect of earned income on DI benefits consists of a complex set of work incentive "phases," with the end result being loss of cash payments if and when countable gross earnings consistently exceed the SGA guideline. During the first work incentive phase, known as the trial work period (TWP), beneficiaries are permitted to retain benefits regardless of how much is

earned. TWP months occur whenever gross earnings exceed the current TWP guideline, which is \$590 for FY 2005. The TWP ends when nine months of TWP-level employment are accumulated within a rolling 60-month period. When the TWP ends, beneficiaries move into the second phase of work incentives, known as the extended period of eligibility (EPE). During this 36-consecutive-month period, beneficiaries retain full benefits until SSA determines that the person is demonstrating SGA-level work. If this level is determined while the beneficiary is in the EPE, benefit payments are due for any month that earnings fall below the SGA guideline.

When a pattern of SGA-level work is demonstrated, beneficiaries are permitted a third work incentive phase, known as the grace period. This allows the beneficiary to retain full benefits for the first month SGA-level work occurred and two following months for a total of three consecutive months. After the EPE ends, the beneficiary may be terminated from the DI program if earnings continue to remain above the SGA guideline. If the grace period is used up during the EPE and the beneficiary subsequently ceases employment or earns less than SGA, benefit checks may resume. However, if the grace period is used up, after the EPE is over, a single month of SGA-level work may cause termination of benefits. The manner in which DI benefits cease entirely when earnings reach the SGA level is often referred to as the “cash cliff.”

Studies show that far less than 1 percent of DI beneficiaries return to work and earn at substantial wages (Gerry, 2005). Many benefits experts, as well as the U.S. Government Accountability Office (GAO), have suggested that this cash cliff that creates a clear disincentive to work for most DI beneficiaries (GAO, 1996a; Sheldon and Trach, 1998; National Council on Disability, 1997a; O’Day, 1999). SSA has made an effort to lessen the negative impact of the cash cliff effect by indexing the SGA level annually (starting in 2001); allowing exclusions from countable gross earned income, such as impairment-related work expenses (IRWEs) and subsidies; and averaging earnings over a period of months and allowing short-term unsuccessful work attempts (UWAs). However, many beneficiaries continue to choose not to work for fear of benefit loss, or intentionally suppress their earnings under the SGA amount in order to retain their full DI cash benefit and program eligibility (LaPlante, Kennedy, Kaye, and Wenger, 1996).

It is not at all surprising to discover that beneficiaries are suppressing earnings in order to retain benefits. The SSA definition of “substantial work” and the SGA earnings guidelines are generally too low in relation to benefit payments, creating a major disincentive to working above the SGA level. Although many DI applicants and beneficiaries might be able to maintain employment at or marginally above the SGA level, this level of income is often NOT sufficient to replace the full DI payment. The average monthly DI payment in 2004 was \$895 (SSA, 2004a), while the SGA guideline was \$810. The combination of average cash payments plus earnings means that a beneficiary would have to earn, on average, \$1,720 per month to replace the income received by working at just below the SGA level. If the DI beneficiary receives additional cash benefits for dependent family members (what SSA terms “auxiliary benefits”), the point at which a beneficiary breaks even when he or she earns more than SGA is even greater than \$1,720 per month. It is very difficult for individuals to earn enough to replace the amount of their lost DI cash benefit, even though the SGA amount increases every year. In addition, the SGA guideline is measured by gross earnings, not net wages received after taxes, and does not account for the additional expense and effort incurred by working. Unless a beneficiary can get a job that pays more than the DI benefits paid to the family after all deductions and expenses are accounted for, there is little or no financial incentive to work above SGA.

This effect is even more pronounced for people with the highest benefit payments and those with the least ability to earn wages comparable to the DI payment. For a significant number of DI beneficiaries, a greater financial outcome would be achieved by working part time below the SGA level while still retaining full DI benefits and Medicare. Return-to-work strategies attempted by SSA will only be effective if and when the applicant is convinced that working will be of greater financial benefit than not working. Individuals stop participating in the labor force when they decide that the benefits of working or seeking work no longer outweigh the costs of doing so. Benefits include wages and health insurance as well as nonfinancial benefits such as personal satisfaction and socialization. The costs of working include the effort involved to perform the job, commuting time, cost of clothes and other work expenses, and intangible factors such as frustration or conflict with co-workers and supervisors. A major cost is the value of the activity forgone while working; that is, whatever benefits the person would have derived from whatever activity they could have done instead of working.

In summary, until the DI rules are changed to make work truly pay, many beneficiaries will continue not to work or will choose to work part time and earn less than the SGA level.

Complex Rules Govern the Effect of Income on Disability Benefits

The complexity of the SSA rules creates significant disincentives to employment for both DI and SSI beneficiaries. First, the series of work incentive phases inherent in the DI program—including TWP, EPE, cessation month/grace period, and SGA determinations, in combination with the methods for reducing countable income through IWREs and subsidies—is simply too much to expect a beneficiary to understand or negotiate. The sheer complexity of the work rules causes beneficiaries to be leery of paid employment. When beneficiaries cannot readily comprehend nor predict exactly what will happen when work is attempted, the result is that work is forgone entirely or, at best, minimized. The perceived risk is simply too great. While the advent of BPAO services authorized by TWWIIA is a positive step forward, the fact remains that the DI program is just too complicated.

Second, while the work rules for the SSI program are relatively simple compared with those for the DI program, the rules governing unearned income and resources are also incomprehensible for many beneficiaries, their families, and advocates. When one examines the rules for concepts such as deeming, in-kind support and maintenance, countable resources, and the many resource exclusions, it is clear that the average untrained layperson has little or no chance of understanding or applying these rules without expert assistance. Beneficiaries often feel overwhelmed by the application of SSA regulations that they view as arbitrary and irrational. The more insecure beneficiaries feel about how their behavior will affect benefit payment amounts or eligibility, the less likely they are to risk anything that may cause problems.

It is unfortunate that attempts by SSA to address the employment disincentives in the DI and SSI programs often add to the complexity of program rules. Rather than stripping the programs back to the original core premises and starting over with a simplified framework, SSA makes incremental changes by adding more exclusions, incentives, deductions, credits, and waivers. The rules become more and more intricate and the behaviors we intend to reward occur less and less often as people become unable to deal with the ever-increasing complexity and confusion.

It is important to note that one of the primary reasons for the complexity in current SSA regulations is the regulatory environment in which SSA currently operates. Major changes to the existing system proposed by SSA as a way to provide greater incentives to employment and promote economic self-sufficiency usually incur costs that must be paid for by offsets. It is important to note that any change proposed by SSA, such as the elimination of the 24-month Medicare waiting period, is strictly bound by Office of Management and Budget (OMB) rules that require identified offsets in other program areas.

Harsh Income and Resource Limits Create Barriers to Employment

Social Security DI benefits are a form of insurance funded from the Social Security Trust Fund that beneficiaries (or their parents) have contributed to through FICA deductions. For this reason, entitlement for DI benefits is based on becoming an “insured worker” rather than on a financial means test, other than countable earnings under the current SGA guideline. DI beneficiaries may accumulate unlimited assets or resources, and may supplement their SSA benefit with most forms of unearned income without suffering any adverse impact on DI eligibility. (There are some exceptions when the unearned income is a form of public disability benefit.) For most DI beneficiaries, the ability to save money and accumulate assets is unimpeded by SSA rules.

In stark contrast, SSI is a federal “welfare” program financed through general income tax funds. SSI is a means-tested program with limits on both income and resources. SSI recipients risk loss of both cash benefits and Medicaid if countable unearned income exceeds the current federal benefit rate (\$579 in FY 2005) and/or countable resources exceed \$2,000. (\$3,000 is permitted for an SSI eligible couple in which two SSI recipients are married to one another.) Earned income is treated more favorably due to the 1619(a) rules that permit earnings to exceed the SGA limit and the 1619(b) extended Medicaid provisions that permit eligible recipients to earn up to their state threshold amount (and, under certain circumstances, up to an individualized threshold amount) before SSI eligibility and Medicaid are lost. Furthermore, if the income and resource limits are exceeded for more than 12 consecutive months, the individual is fully terminated from the SSI program and must complete the initial application process again in order to reestablish entitlement.

While the resource limits of \$2,000 for an eligible individual and \$3,000 for an SSI eligible couple have not increased since 1989, the SSI program does offer various exclusions to the income and resource rules that allow for some limited asset accumulation. For example, SSI excludes one home of any value as long as the SSI recipient resides in it. In addition, SSI recipients are permitted to own unlimited property essential for self-support (PESS). This includes equipment, real property, or cash accounts that are part of a business for someone who is self-employed. SSI also permits recipients to own one vehicle, which may be of any value if it is needed to get to and from medical appointments or a job, or is modified to accommodate the recipient's disability. It is interesting to note that SSA only allows one house and one vehicle for an eligible couple, which SSA defines as two SSI recipients married to each other. This is one of several marriage penalties built into the income and resource rules for the SSI program and described in detail in Chapter II.

In addition, SSI recipients may use a work incentive known as a Plan for Achieving Self-Support (PASS) to save money or set aside income in order to pay for things needed to attain an occupational goal. Funds set aside under an approved PASS do not count when SSI eligibility determinations are made or when SSA is determining the SSI benefit amount. Unfortunately, few SSI recipients are aware of even the most basic income and resource exclusions described above. Work incentives such as PASS and PESS are long-standing provisions in Social Security policy, but they remain relatively unknown and underutilized.

States have the option to supplement cash benefits to SSI beneficiaries. The option is designed to alleviate poverty and is frequently applied to accommodate the higher cost of living particular to a state or locale. When implementing the state supplement option, states have the right to set their own limits on resources and are not bound to the SSI limit. For example, although federal SSI policy allows \$2,000 in countable resources, recipients could be held to a lower resource limit of \$1,500 in order to receive the state SSI supplement.

There are additional income and resource tests that individuals must meet to maintain eligibility for optional Medicaid waiver programs, as well as the special extended Medicaid coverage provided to certain former SSI recipients, and the Medicare savings programs in which Medicaid

pays for Medicare premiums, co-payments, and deductibles. All of these programs have their own unique rules governing income and resource limits for eligibility. Furthermore, some states levy a “share-of-cost” or “patient liability” for Medicaid recipients in optional categories of coverage whose countable income is over specified limits. This means that a portion of the individual’s income has to be paid back to the state Medicaid agency to offset the cost of care provided. Needless to say, understanding these diverse sets of rules is impossible for most individuals with disabilities, their families, or agency personnel. In some cases, individuals simply choose not to rock the boat by working in order to avoid any chance that essential Medicaid eligibility could be lost, or patient liability could be charged. This is particularly frustrating for DI beneficiaries, who are *not* limited in asset accumulation by SSA but are penalized by the state Medicaid agency due to participation in the home and community-based services (HCBS) waiver program or inclusion in institutional waiver programs for persons with mental retardation/developmental disabilities. In order to retain the Medicaid-funded services that may make community participation possible, the individual must choose to forgo most forms of asset accumulation.

Individual development accounts (IDAs) have been a recent response to the inadequacy of income support and means-tested benefit programs to help the poor. IDAs are time-limited matched savings accounts for eligible low-income workers for the purposes of saving for a first home, college, or for starting or growing a business. These programs are currently authorized under the Welfare Reform Act of 1996 and the Assets for Independence Act (AFIA). While employment is certainly a critical pathway to self-sufficiency, Sherraden (1995) argues that people move out of poverty by saving and investing, not by income generation alone. However, evidence suggests that people with disabilities are underrepresented in the population currently aided by IDAs. In addition, the earned income tax credit frequently complements IDA programs, but these are also assumed to be relatively underutilized by persons with disabilities. At the present time, no data systems are available that track variables such as disability in the use of incentives such as IDAs or the EITC. SSA has recognized the importance of asset accumulation through IDAs and currently allows IDAs funded under the Welfare Reform Act and AFIA to be excluded as countable resources in the SSI program. In

addition, the Youth Transition Demonstration Initiative funded by SSA includes additional SSI waivers for other IDA programs.

Many New Beneficiaries Who Could Work Delay Employment Out of Fear of Benefit Loss

As discussed in Chapter III, the definition of disability contained in the Social Security Act is inextricably linked to the inability to perform work at the Substantial Gainful Activity level SGA level. SSA further defines disability in terms of meeting a “duration requirement.” This means that the inability to engage in SGA-level work has to have already lasted for at least one year or is expected to last for a continuous period of at least one year or is expected to result in death (20 CFR 404.1503). Because of this duration requirement, individuals who return to work at the SGA level within 12 months of when their disability began may risk losing entitlement, since they would fail to meet SSA’s definition of disability. As the regulations presently stand, individuals with disabilities who attempt to work soon after disability onset incur the greatest risk of being found ineligible for Social Security disability benefits. This is an unfortunate situation, since individuals who are recently disabled have the strongest attachment to the workforce and thus are most likely to be successful in returning to work. Research in the field of disability management (DM) suggests that the longer ill or injured employees stay out on disability leave, the less likely they are to ever return to work (Sun Life Financial, 2001).

There are regulations under both the DI and SSI programs to protect the benefit eligibility of some individuals who return to work soon after disability onset. In the DI program, individuals who have completed the initial five-month waiting period required before benefit payments may begin and who have received notification of benefit award are afforded the protection of the trial work period (TWP). The rules related to meeting the disability duration requirement and governing the circumstances under which working at SGA soon after disability onset cause ineligibility are very complex. Because of this complexity and perceived risk, beneficiaries are fearful of attempting to work while in application status or for several years after benefits are awarded. In some cases, this fear persists indefinitely, since beneficiaries become convinced that any work effort will be interpreted as improvement in medical condition that may cause termination. In earlier times, this was actually a legitimate concern, since evidence of work

activity at any level was viewed by SSA as a potential indication of medical recovery and was used as a rationale for initiating a full medical review. While TWWIIA changed the rules so that work activity alone could not be used as a basis for initiating a medical review, this provision only applies to DI beneficiaries who have been entitled for at least two years. Once again, these rules discourage beneficiaries from trying to reenter the workforce soon after becoming disabled or immediately after becoming entitled to benefits. Policies of this type, which serve to delay work attempts, are counterproductive, since extended absence from the workforce creates a separation from the habit of work, entrenches a “disability mindset,” and allows preexisting work skills to deteriorate or become obsolete.

Delays in Accessing Health Insurance and Risk of Losing Health Insurance Once Obtained

DI beneficiaries who are newly eligible for benefits are not entitled to Medicare until they have completed a 24-month qualifying period. If those individuals receive DI or disabled widow(er)s benefits, they must serve an additional five-month waiting period before the qualifying period begins. This means that a total of 29 months must pass from the initial eligibility for DI benefits until Medicare coverage may begin. In contrast, individuals who are determined eligible for SSI must be eligible for benefits for only one month in order to qualify for Medicaid in most states. In the 11 states that adopted slightly more stringent rules for Medicaid than the SSI income and asset rules (known as 209(b) states), most SSI beneficiaries need only apply to county Medicaid agencies to receive health coverage as soon as SSI entitlement is established. States that exercise the 209(b) option are Connecticut, Hawaii, Illinois, Indiana, Minnesota, Missouri, New Hampshire, North Dakota, Ohio, Oklahoma, and Virginia. Having necessary medical supports in place permits beneficiaries to manage their disabilities more effectively, making it easier to contemplate a return to work. Having to wait for those supports, as under the DI program, further separates beneficiaries from the workforce.

Previous Attempts by Congress and SSA to Impact Income Issues and Incentives

SSA is aware that its own internal rules and regulations governing the treatment of income and resources act as a barrier to employment for DI/SSI beneficiaries. Over the past decade, several attempts have been made to change the rules to encourage paid employment. These efforts are delineated below.

Efforts to Lessen the Impact of the SGA “Cash Cliff”

During the past 15 years, SSA has taken several steps to diminish the disincentives surrounding SGA determinations. In 1990, SSA implemented a change in program rules that increased the level of gross earnings that constitute SGA from \$300 to \$500 a month. This change resulted in limited improvement in the system, given that the \$200 increase accounted solely for growth in wages since 1980, when the SGA level had last been adjusted. A second proposed rule change in 1990, which was not implemented, was a plan to index the SGA level to average wage growth in future years. The failure to implement such an index was particularly damaging in view of the subsequent increase in the federal minimum wage level. Subsequent program rule changes resulted in a further increase of the SGA guideline to \$700 in July 1999; finally, in January 2001, a major regulatory change provided for an annual adjustment of the SGA guideline to reflect wage growth. While the increases in the SGA guideline are positive, they have not corrected the fundamental problem. As discussed at length previously, it is still of greater financial benefit for many DI beneficiaries to retain full DI payments and hold earnings under the SGA guideline. Until SSA is able to correct this defect in the system, relatively few beneficiaries will choose to work at a level that would cause termination. As long as beneficiaries who perform SGA and lose cash benefits are worse off financially than those who do not work or those who earn less than SGA, little progress will be made.

Another reason beneficiaries choose not to engage in employment above the SGA level is a prevailing belief that DI benefits will not be available again if they are needed at a later date. TWWIIA created a new work incentive called expedited reinstatement (EXR) of benefits to make it easier for former beneficiaries who were terminated from the DI/SSI program due to

excess earned income to come back into the disability program without having to fully reapply. This provision was enacted in 2001 and was designed to alleviate the fear of sudden and permanent detachment from the DI program. It is clear, however, that beneficiaries continue to worry about losing their connection to the program, and this fear continues to have an effect on work activity.

TWWIIA also requires the Commissioner of SSA to implement research demonstrations using various models for sliding scale benefit offsets designed to ameliorate the disincentives posed by the DI cash cliff. While the regulations governing the \$1 for \$2 offset demonstration have been published, the cash benefit offset pilots have not begun as of this report (Federal Register, April 14, 2005). The Ticket to Work and Work Incentives Advisory Panel (2002) has supported and recommended the implementation of \$1 for \$2 benefit offset pilot projects and has provided extensive recommendations for the conduct of such demonstrations.

Efforts to Allow Increased Asset Development

PASS and PESS are important, long-established work incentives that allow SSI beneficiaries to accumulate income and/or resources without risking loss of benefits while working toward a future occupational goal or maintaining self-employment and small business ownership. However, PASS and PESS are relatively unfamiliar to SSA personnel and service provider agency staff, as well as beneficiaries. In order for these programs to have any widespread or lasting impact, SSA needs to embark on a major public awareness, outreach, education, and technical assistance campaign. In addition, these programs preclude savings for non-employment-related purposes and are perceived as being complex and bureaucratic in nature.

SSA has also been increasingly interested in the use of individual development accounts (IDAs) as a method for helping beneficiaries accumulate assets while retaining eligibility for SSI and Medicaid. IDAs are temporary matched savings accounts designed to assist low-income workers in buying a first home, starting or growing a business, or attending postsecondary education (Sherraden, 1995). To qualify for the program, individuals must meet one or more of the following eligibility definitions:

- Eligible for Temporary Assistance for Needy Families (TANF);
- Eligibility for earned income tax credit (EITC); or
- Earnings at or below 200 percent of poverty.

IDA program features include regular minimum deposits from earnings in IDA savings accounts later matched with IDA match funds for a temporary period of time. For example, for every dollar of earned income saved, a participant may receive the equivalent of \$2 in matching IDA funds at the time of an asset purchase (e.g., tuition payment, down payment on a home, inventory for a business). AFIA and local programs set minimum deposit standards and maximum match thresholds (e.g., \$25 per month and matching contributions not to exceed \$2,000 per person). Other program features include regular financial education, asset-based training, and other components that are unique to local programs. In March 2003, SSA incorporated several changes to the treatment of assets in SSI: (1) disregarding retroactive payments of DI and SSI benefits; (2) earned income tax credits; and (3) child tax credits for a period of nine months following the month the payment was received (SSA POMS SSI 00830.670). Furthermore, personal savings from income that are deposited in AFIA-funded IDA accounts are excluded from SSI resource tests and are excluded from countable income in SSI definitions, which may mean (a) the maintenance of SSI benefits, (b) qualification for cash benefits among former 1619 eligibles, or (c) increasing cash payments while building temporary savings for later reduced dependency on SSI. In 2001, SSA incorporated the provision of IDAs consistent with the AFIA in the Balanced Budget Act and Workforce Investment Act. This provision excludes savings and matching funds in AFIA-eligible accounts from resource tests in SSI, TANF, Food Stamps, and Medicaid (Sweeney, 2004; Corporation for Enterprise Development, 2004).

Despite these changes, the number of people with disabilities who are accessing the programs is unknown. While it is suspected that people with disabilities are accessing IDA programs, EITCs, and child tax credits, few hard statistics are available. Demonstration projects sponsored by SSA and the National Institute on Disability Rehabilitation and Research (NIDRR) are in the formative stages of advancing the application of IDAs among youth and adults with disabilities, including the incorporation of benefits planning and work-incentives counseling. Anecdotal evidence suggests that the current infrastructure is inadequate to meet the needs of persons with

disabilities and community-based programs. For example, nonprofit community development corporations are largely unfamiliar with accommodation needs, universal design concepts, and the availability of resources within the community-based service systems and VR. Furthermore, IDA matching funds, as well as operating resources, are inadequate and are only in the exploratory, conceptual stages for the integration of skill sets and resource leveraging necessary to augment services.

Recommendations for SSA Policy Changes: Income Issues and Incentives

The following sections highlight recommendations for change that, if implemented, would remove barriers to employment currently caused by the treatment of income and resources in the DI and SSI programs.

Recommendations for Easing the SGA Cash Cliff for DI Beneficiaries

Congress should modify the current Title II disability legislation to eliminate SGA as a post-entitlement consideration for continued eligibility for Title II disability benefits. Under the current DI rules, substantial gainful activity continues to be a primary factor not only in establishing initial eligibility but also in maintaining eligibility after benefits are awarded. The policy premise that SGA defines “inability to work” has a detrimental impact on a beneficiary’s motivation to go to work and conveys a mixed message about employment and continuing entitlement to SSA benefits. In a system in which disability takes on a meaning other than inability to work, SGA should be abandoned as a primary standard for continued benefit eligibility once initial eligibility for the DI program has been established. It is recommended that the current system be changed to allow DI beneficiaries who work to retain their beneficiary status and access to benefits in spite of earnings over the current SGA guideline.

Congress should modify the current Title II disability legislation to provide for a gradual reduction in DI cash benefits based on increases in earned income. Unlike SSI, under current program rules there is no provision for a gradual reduction in the DI cash benefit as earnings increase. Instead, a Title II beneficiary will either receive the full cash benefit in a given month or no income support at all. DI program rules should be amended to provide for a gradual

reduction in cash benefits once earnings exceed an established earned income disregard level. To minimize complexity and confusion for beneficiaries, it is recommended that the earned income disregards and exclusions be comparable to those currently in place in the SSI program.

Additionally, any gradual reduction in the beneficiary's DI benefit should also be applied to dependent beneficiaries (dependent children and spouses) or the disincentives will remain for beneficiaries with dependent family members. Elimination of the SGA cash cliff coupled with a gradual reduction in cash benefits as earnings increase will provide an incentive for employment by ensuring an overall positive financial outcome for DI beneficiaries. These program changes would have the added benefit of eliminating the need for labor-intensive tracking of trial work periods, extended periods of eligibility, SGA determinations, and assessments of special conditions, such as job coaches.

Congress should modify the current Title II disability legislation to establish a system of continuation of program eligibility for DI beneficiaries through the creation of a “beneficiary nonpayment status.” The current DI benefit system consists of a complex set of work incentive phases with the end result being loss of cash payments if and when countable gross earnings consistently exceed the SGA guideline. In addition, once the EPE ends, beneficiaries lose their connection to the program if earnings continue to remain above the SGA guideline. In addition to the elimination of the post-eligibility SGA criteria and implementation of a gradual benefit reduction, program rules should be amended to provide for a continuation of beneficiary status when cash benefits are ultimately lost due to earnings. Similar to SSI beneficiaries in 1619(b), DI beneficiaries with earnings in excess of allowable limits should retain beneficiary nonpayment status, providing for immediate reinstatement of benefits should earnings be lost or reduced at a later time.

Recommendations for Reducing Restrictions on Assets for SSI Beneficiaries

Congress should direct SSA to develop and test program additions and regulatory modifications that will enable SSI beneficiaries to accumulate assets beyond existing limits through protected accounts and other savings programs. While PASS and PESS work incentives allow for accumulation of assets related to self-employment or achieving a future occupational goal, they are too limited and do not allow beneficiaries to save for other non-

employment-related goals. IDAs, EITCs, and other alternative savings programs allowed under many state Medicaid buy-in programs must be explored. Policies should be crosscutting in nature, leveraging and augmenting resources, services, and outcomes for employment and health-care-related programs.

SSA should change current program rules and work with other federal agencies to modify and expand the value of IDA programs for SSA beneficiaries. To expand options and availability for beneficiaries, current SSI program rules should be amended to extend the exclusions that currently apply to TANF and AFIA IDAs to other state and local IDA programs. In addition, while homeownership and educational goals are important, using savings for things such as assistive technology, automobiles, home repair, transportation, and other purposes should be explored. Home repair is particularly noteworthy given the decline in affordable housing stock. IDAs for home repair may enable home accessibility options otherwise unaffordable to a beneficiary. Finally, shorter, more immediate savings outcomes are frequently effective for reinforcing positive money management practices and personal responsibility.

SSA should work collaboratively with other federal agencies to expand benefits counseling services to include the full range of financial education and advisement services.

Beneficiaries must have the information, incentive, and resources necessary to make informed decisions about their financial goals and planning. In so doing, it is important that train-the-trainer models be sponsored so that the infrastructure is established to increase capacity to provide financial advisement services over time.

Recommendations for Improving Access to Health Care for DI Beneficiaries

Congress should modify the current Title II disability legislation to eliminate the Medicare 24-month qualifying period for DI beneficiaries. Providing critical health insurance as quickly as possible after disability onset may act to stem the progression of disability over time and encourage beneficiaries to better manage their illnesses or disabilities. With the addition of the prescription drug coverage available as of January 2006 through the Medicare Modernization Act, this recommendation becomes even more important.

Recommendations for Decreasing the Complexity of the DI/SSI Program Rules Governing Income and Resources

Congress should direct SSA to simplify regulatory earnings definitions and wage verification processes so that they are consistent across the SSI and DI programs. SSA should pursue consistent and simplified rules for defining earnings and treatment of earned income across the SSI and DI programs. Such a change will not only reduce confusion among beneficiaries but also will also reduce the current administrative burden on SSA in the verification and benefit adjustment process.

Congress should direct SSA to modify regulations related to the treatment of earnings in the DI program by applying the same rules currently applied in the SSI program. Specifically, based on a gradual reduction in DI cash benefits, current SSI rules governing the treatment of earnings used to pay for work-related expenses under impairment-related work expenses (IRWE) and blind work expenses (BWE) should be applied in the same manner to the DI program. This will allow beneficiaries to recover some, or, in the case of BWE, all of the cost of work-related expenses in an equitable manner regardless of the type of disability benefit received. Applying these work incentives in the same manner will also minimize confusion for beneficiaries.

Summary

In an effort to encourage employment for beneficiaries, Congress and SSA have made legislative and regulatory changes in the DI and SSI programs over the past 30 years. The work incentives that have resulted from these changes are aimed at reducing the risks and costs associated with loss of benefit support and health insurance when a beneficiary is employed. Despite these efforts, significant disincentives to employment in the Social Security disability benefit programs persist. For example, while the Section 1619(a) and (b) provisions encourage work by providing increased financial well-being and continued access to Medicaid, SSI beneficiaries continue to face a system of complex rules regarding the treatment of income and resources and their effect on continued benefit eligibility and payment amount. The disincentives to employment for DI beneficiaries are even more pronounced, given the risk of benefit loss and reduction in overall net income as a result of work at the SGA level.

Beneficiaries must carefully consider the risk factors involved when weighing the uncertainties of success in employment against the relative security of benefit support. To be effective in encouraging employment, the SSI and DI programs must be amended to provide incentives and supports to beneficiaries on a number of levels. Congress and the Social Security Administration must take necessary action to remove the financial disincentives, particularly in the DI program, to ensure that work pays. Changes to current program rules must likewise be pursued to enable beneficiaries to maintain a connection to the benefit programs over time. Finally, the complexity of the program rules governing income and resources must be simplified and the availability of benefits counseling services expanded through collaborative efforts across federal agencies.

Chapter V: Coordination and Collaboration Among Systems

Jane is 54 years old and has multiple sclerosis (MS). She worked all of her adult life in secretarial or administrative support positions, but finally had to stop work due to her disability at the age of 52. She went on her employer's long-term disability benefits, but both her doctor and the insurance case worker encouraged her to apply for Social Security Disability Insurance (DI). Jane's employer did not discuss any return-to-work options with her or offer her the option of working a lighter schedule or moving to part-time employment.

Jane's DI benefits began 10 months after she applied. At the time, she had private health insurance through her husband, but she was divorced shortly after getting on DI benefits. Jane could not afford the COBRA coverage available through her ex-husband or from her previous employer and had not yet served her 24-month Medicare qualifying period. Medications to treat her MS cost in excess of \$1,000 per month, so she applied for Medicaid under the medically needy or spend-down program; however, she was found ineligible due to excess resources. Jane spent all her savings and financial resources on health care expenses until she reached the point that she was eligible for the medically needy program. She became eligible for Medicaid and eventually qualified for Medicare as well.

Several years later, Jane's medical condition had improved somewhat and she wanted to find a way to return to work on a part-time basis. Since she did not feel that her physical health was good enough to allow her to immediately start working full time, she had difficulty finding an Employment Network to accept her Ticket. She did receive services from the state VR agency and was sent to a benefits specialist. Once Jane learned what impact earned income would have on her Medicaid eligibility, she decided that working part time was not worth the possible loss of Medicaid prescription drug coverage.

Introduction

Expansion of the disability programs and the poor employment rates of adults with disabilities have become major concerns for SSA and disability policymakers across the country (GAO, 1994; GAO, 1996b; GAO, 1998b; Social Security Bulletin, Spring 1996; Congressional Budget Office Report, 2004). Too often, this alarming growth of the Social Security disability rolls has been represented and perceived as SSA's problem to solve in isolation, when in fact it is a larger societal problem. Receipt of Social Security disability benefits is merely the last stop on a long journey that many people with disabilities make from the point of disability onset to the moment at which disability is so severe that work is not possible (Burkhauser, 2002; McMahon,

Danczyk-Hawley, Reid, Habeck, Kregel, and Owens, 2002). All along this journey, individuals encounter the policies and practices of the other systems involved in disability and employment issues. When these systems fail to stem the progression of disability or work at cross-purposes with one another to prevent successful employment retention or return to work, it is the Social Security disability system that bears the eventual brunt of this failure. Ultimately, however, the costs associated with having so many Americans exiting the nation's workforce to lead lives of dependency on federal disability benefits are borne by all U.S. citizens.

Any meaningful effort to slow down or reverse this relentless advance toward federal disability benefits will require significant and sustained collaboration and coordination between the Social Security Administration and the other federal agencies with a stake in developing disability and employment policy. A significant opportunity to establish such systems collaboration was created on February 1, 2001, when President George W. Bush announced the New Freedom Initiative as part of a nationwide effort to remove barriers to community living for people with disabilities. The New Freedom Initiative is a comprehensive federal plan that represents an important step in ensuring that all Americans have the opportunity to learn and develop skills, engage in productive work, make choices about their daily lives, and participate fully in their community. The initiative's goals are as follows:

- Increase access to assistive and universally designed technologies;
- Expand educational opportunities;
- Promote home ownership;
- Integrate Americans with disabilities into the workforce;
- Expand transportation options; and
- Promote full access to community life.

This initiative is particularly important because it involves so many departments of the Federal Government and has the force of the White House solidly behind it. Through Executive Order 13217, President Bush directed six federal agencies—including the Departments of Justice (DOJ), Education (ED), Labor (DOL), Health and Human Services (DHHS), and Housing and

Urban Development (HUD), as well as SSA—to “evaluate the policies, programs, statutes, and regulations of their respective agencies to determine whether any should be revised or modified to improve the availability of community-based services for qualified individuals with disabilities” and to report back to the President with their findings. The Departments of Transportation (DOT) and Veterans Affairs (VA), the Small Business Administration (SBA), and the Office of Personnel Management (OPM), though not specifically named in the executive order, also joined in the implementation effort. While it is still too early to assess the full impact of the New Freedom Initiative, the platform it provides for systems coordination, collaboration, and integration is very promising.

This chapter examines five major systems with which SSA must coordinate its efforts in order to create positive change in the employment of persons with disabilities:

- Health care system – including Medicaid, Medicare, and private health insurance.
- Rehabilitation system – including the state vocational rehabilitation (VR) systems, private rehabilitation systems involved with short-term and long-term disability insurance, workers’ compensation programs, and community rehabilitation programs.
- Employment and training system – including DOL programs such as One-Stop Career Centers, state employment agencies, and unemployment insurance (UI) programs.
- Education system – including transition services for students with disabilities in public schools, vocational/technical education, and postsecondary educational entities such as community colleges and universities.
- Business community – including private employers, small businesses, and large corporations.

For each system, the current status of coordination and collaboration will be examined and the attempts Congress and SSA have made in the past 15 years to improve systems collaboration and coordination will be reviewed. After the discussion of the various systems, recommendations are provided for policy changes Congress and SSA could make that would improve coordination and collaboration in each area.

Health Care System

Working with the major federal health care systems is nothing new for SSA, since it works closely with the Centers for Medicare and Medicaid Services (CMS) in the implementation of both the Medicare and Medicaid programs. Federal law guarantees that SSI recipients are eligible to receive Medicaid coverage and, in many states, SSA is charged with making Medicaid eligibility determinations. Both Medicare and Medicaid are inextricably linked to the disability benefits provided by SSA, and policy shifts made by CMS in either of these programs are felt keenly by DI/SSI beneficiaries.

The Problem

The solution lies in taking a long-range view and attacking the problem at its source: our dysfunctional health care system, which is grossly inefficient, and often does harm when it is supposed to be doing good. It doesn't make sense to fine-tune individual programs when the whole system is broken (William Novelli, CEO of AARP, February 2005).

One of the most commonly cited reasons Disability Insurance (DI) and Supplemental Security Income (SSI) beneficiaries offer for not engaging in work activity is the perceived and real risk of losing health care benefits (Hanson et al., 2003). Catherine Kelly Baird, of the California Governor's Committee on the Employment of People with Disabilities, describes this concern among beneficiaries: "The big scare is always jumping out of a safety net because of the very profound fear that once you lose your benefits, you will never be able to get them again" (Catherine Baird, key stakeholder interview, November 2004). For individuals with disabilities who may have significant health care needs or high costs, the thought of losing health care coverage can be particularly frightening.

Health insurance considerations are also of paramount importance when beneficiaries make decisions about continuing to work versus making application for disability benefits. Honeycutt (2003) found that over two-thirds (70 percent) of recipients were covered by some form of health insurance in the year before their application, but less than half (46 percent) of all applicants continued to be covered at the time of their DI application. Of those with coverage at the time of

application, 20 percent had Medicaid or “medical assistance.” The desperate search for affordable health insurance fuels the increased SSI/DI application rates as it simultaneously diminishes the rates of termination due to employment. Health care concerns may represent the single most salient factor contributing to increasing rates of dependency on federal disability benefits and depressed rates of competitive employment for individuals with disabilities (NCD, 1997b).

Previous Attempts by Congress and SSA to Impact the Health Care System

This section will examine the two federal health care systems (Medicaid and Medicare) separately, as these programs function so differently. The final section will examine SSA’s efforts to impact the private health care system — primarily employer-sponsored health care plans.

Medicaid Issues. In the past 15 years, SSA has made a significant effort to reduce the employment disincentives related to loss of Medicaid coverage. In 1987, SSA collaborated with the Health Care Financing Administration (HCFA, now CMS) to permanently implement the 1619(b) extended Medicaid coverage for SSI recipients who work. This provision provides continued Medicaid coverage for individuals whose incomes are too high to qualify for an SSI cash payment but are not high enough to offset the loss of Medicaid and/or publicly funded attendant care. It allows SSA to disregard earned income when determining Medicaid eligibility up to the state’s designated threshold amount (SSA POMS SI 01715.015 – Special Groups of Former SSI Recipients). This one provision is arguably the most powerful work incentive in the SSI program (Sheldon, n.d.b; Virginia Commonwealth University, 2002).

SSA has also worked in close partnership with CMS to expand Medicaid buy-in programs for individuals with disabilities who work. As described in Chapter I, the Ticket to Work and Work Incentives Improvement Act of 1999 (TWWIIA) includes two key provisions designed to expand authority originally granted to states under the 1997 Balanced Budget Act (BBA) to provide Medicaid coverage to working people with disabilities. The Medicaid buy-in program is targeted at individuals who otherwise would not qualify for Medicaid coverage because their earnings or personal assets exceed established thresholds. Under TWWIIA, states have considerable flexibility in terms of establishing asset, resource, and income limits for working individuals with disabilities between the ages of 16 and 64. In addition to the Medicaid buy-in program,

Section 203 of the Act created a grant program through the Department of Health and Human Services (HHS) that would encourage and support states in developing a buy-in program. These grants, termed Medicaid Infrastructure Grants (MIGs), permitted states considerable freedom to address a variety of work-incentive issues in their state systems. Eligibility for MIG grants was based to a large extent on the state's willingness to provide personal assistance services to employed individuals with disabilities.

Currently 32 states have implemented buy-in programs and, while Medicaid buy-in programs have been operational for several years now, enrollments in many states remain relatively low (Goodman and Livermore, 2004). In some cases, this may be due to poor public awareness efforts. Other factors affecting enrollment may include the procedures used by states to verify disability and work activity, and whether or not the enrollment process is automated. The effectiveness of buy-in programs is also contingent on the ability of people with disabilities to make informed choices. The buy-in has added another dimension of complexity to the already complex employment decisions of people with disabilities. Unless the employment support system for people with disabilities is markedly simplified in the future, the need for benefit specialists will continue to increase, limiting the effectiveness of federal and state initiatives attempting to promote the employment of people with disabilities.

Unfortunately, SSA and CMS have not worked collaboratively to identify and eliminate work disincentives inherent in the various Medicaid waiver programs. The effect of earned income is still a major problem for individuals enrolled in the medically needy or spend-down program, Home and Community Based Services (HCBS) waivers, extended Medicaid coverage for former SSI recipients who become entitled to Title II childhood disability benefits, and other special state-specific waivers. Income and resource rules governing both eligibility and patient liability or share of cost for these waiver programs often penalize paid employment. While 1619(b) provisions may protect basic Medicaid eligibility for SSI recipients who work, there are no such provisions to protect the special services and supports Medicaid pays for through the waiver programs.

A promising new collaborative effort between SSA and CMS are the work incentives for participants in the Florida Freedom Initiative (FFI). The FFI is a demonstration currently being

conducted by CMS through the Florida Agency for Persons with Disabilities. The demonstration is based on a cash and counseling model in which participants receive a monthly cash allowance instead of traditional services provided by the agency. Participants use the allowance to purchase necessary services from the provider of their choice. SSA is collaborating with CMS by modifying a number of SSI program rules to test whether a combination of CMS and SSA waivers will improve the employment outcomes of participants. This project is far too new to generate definitive results, but it is an example of SSA and CMS working together to enhance consumer choice, control, and empowerment.

Medicare Issues. In addition to FFI, SSA has actively engaged CMS in developing solutions to the problem of beneficiaries fearing the loss of Medicare coverage due to paid employment. With the passage of the Ticket legislation in 1999, the extended period of Medicare coverage (EPMC) was created. This extended premium-free Medicare coverage for beneficiaries who lose cash benefits due to work for a minimum of 93 months after the end of the trial work period. In many instances, Medicare coverage may extend well beyond 93 months. In addition, SSA and CMS worked to create a Medicare buy-in option for qualified disabled and working individuals (QDWI). This provision allows eligible individuals to purchase Medicare Part A if Medicare benefits were lost due to return to work at a substantial level. To be eligible for QDWI, an individual must have countable income of more than 120 percent but less than 135 percent of the federal poverty level, countable resources not exceeding twice the SSI limit, and not otherwise be eligible for Medicaid. Eligibility for Medicaid benefits under the QDWI program is limited to payment of Medicare Part A premiums. Finally, the new Medicare Modernization Act (MMA) will add a prescription drug benefit, a provision that has significant consequences for SSA beneficiaries with serious health conditions requiring medications.

Unfortunately, there are still Medicare issues that create barriers to the return-to-work efforts of SSA beneficiaries. The 24-month Medicare qualifying period (MQP) that DI beneficiaries must serve before Medicare coverage begins often denies individuals access to health care supports at the point at which they are most urgently needed. By the time beneficiaries start receiving DI payments, most have lost employer-sponsored health coverage and have been unable to afford to pay the COBRA premiums. By not providing even the minimum levels of health insurance

provided by Medicare for two full years, the medical condition of some beneficiaries may deteriorate to the point that employment is impossible.

Medicare costs are taking up an increasing portion of the overall federal budget, and the program could become part of the growing problem of funding the U.S. health care system, U.S. Comptroller General David Walker warned at an event in May 2005. Walker said, “If there’s one thing that can bankrupt the country, it’s health care. It’s out of control.” According to Reuters/Yahoo! News, the Bush Administration recently estimated that the total cost of the new Medicare prescription drug benefit alone will be \$724 billion over the next 10 years (American Health Line, May 2005).

Private Health Insurance Issues. Private health coverage remains elusive for people with disabilities for numerous reasons. First, most U.S. health care coverage is provided through employer-sponsored plans accessed affordably while the person (or a legal partner) is employed (Glied and Borzi, 2004). Data shows steadily decreasing enrollment rates across all categories, but the most significant reductions occur in low-income categories (Davis, 2002) where other data locates many workers with disabilities (Hanson, Neuman, Dutwin, and Kasper, 2003).

Illness or injury resulting in disability can be a cause of unemployment, leading to loss of health insurance at inopportune times for a return to work or sustained health care (Bagenstos, 2004). While it is theoretically possible to purchase health care coverage on the open market between jobs, through COBRA protections or state high-risk insurance pools, the out-of-pocket cost at these times is prohibitive for individuals who are unemployed with no regular source of income. Medicaid coverage, outside of recent and still little-used Medicaid buy-ins, may not be even considered by large numbers of those eligible as a means of accessing uninterrupted health coverage after or in between employment situations.

Attaining coverage when severe preexisting conditions (i.e., the disability) are in evidence presents another challenge (Miller and Luft, 1997). In order to access the public health insurance system such as Medicaid, individuals with disabilities must have little income and few assets. It is common for people to bankrupt themselves trying to pay for the medical services they need. There is recent data that links high medical bills as the top reason for filing bankruptcy (Himmelstein, Warren, Thorne, and Woolhandler, n.d.).

Both SSA and CMS are aware of the problems beneficiaries with disabilities face in accessing employer-sponsored health insurance due to the cost of premiums, co-payments, and deductibles. In an effort to improve this situation, the Omnibus Budget Reconciliation Act of 1990 (OBRA '90) required all states to enact a program to identify cases in which enrollment of a Medicaid recipient in a group health plan is cost-effective. An individual's enrollment in a group health plan is considered cost-effective if the expenditures in Medicaid payments are likely to be greater than the cost of paying the premiums and cost-sharing obligations under an employer group health plan for those services. The state-run Health Insurance Premium Payment (HIPP) programs can provide beneficiaries with access to private, employer-sponsored health coverage through premium payments. The beneficiary can use employer-sponsored coverage and access Medicaid for any services not covered under the employer's plan. The problem is that to use HIPP coverage, the person must have access to an employer-sponsored plan. This becomes a bit of a vicious cycle, since so many people with disabilities are currently unemployed or employed in part-time jobs that do not offer health insurance.

A 1997 study conducted by the Government Accountability Office (GAO, 1997) showed that HIPP enrollment has been low across states primarily because of difficulty in identifying potential enrollees. Many state Medicaid eligibility workers have limited knowledge about HIPP, and those who are aware of the program find it difficult to determine which beneficiaries have access to employer-sponsored health coverage. Many Medicaid recipients do not disclose their access to employer-sponsored health coverage because they fear they will lose Medicaid eligibility. Complex private health coverage rules for enrollment add to the confusion and ambivalence in participating in the program. Employers also play a role in the low enrollment rate in HIPP programs. To pay premiums, Medicaid requires information about the employers' health plans. Many employers fail to respond to requests for health insurance information for Medicaid recipients, and without the employers' support, Medicaid recipients cannot access this coverage.

From the employer's or insurer's perspective, transitioning workers with disabilities off private insurance and onto the public benefit rolls makes sense. This is a perfect example of how private insurance companies and/or self-insured employers manage risk by limiting their short-term exposure. In the current system, there is every incentive for insurance companies to identify

those individuals with the most severe conditions and move them as quickly as possible onto the Social Security rolls. In fact, this practice is so common that an entire industry has emerged to expedite movement of beneficiaries through the various short-term and long-term disability programs and ultimately onto the public disability system (McMahon et al., 2002). While the lack of private health insurance continues to be a major contributing factor in the growth of the SSI/DI rolls, SSA has not attempted to engage the business community or the insurance industry in a collaborative problem-solving process. This represents a major missed opportunity.

Vocational Rehabilitation System

The Problem

The passage of TWWIA was a demonstration of SSA's recognition that the primary reason so many beneficiaries with disabilities remain unemployed is their inability to access the services and supports needed to make work a reality. This section describes past and current attempts by SSA to improve employment outcomes by offering incentives to state VR agencies and, recently, to community rehabilitation programs or other service providers.

Previous Attempts by Congress and SSA to Impact the Rehabilitation System

Social Security's past efforts to work collaboratively with the rehabilitation system have focused overwhelmingly on the SVRAs. It has only been since the passage of the Ticket to Work and Work Incentives Improvement Act in 1999 that SSA began a serious attempt to reach out to the world of private nonprofit and for-profit rehabilitation agencies. These efforts began with the establishment of the SSA VR reimbursement program in 1983. As described in Chapter I, the SSA VR reimbursement program was a massive effort that increased in size and cost every year from 1983 to 2002 (Kregel and Revell, 2003). In FY 2002, the program served more than 10,000 individuals at a cost to SSA of over \$130 million, although reimbursements have declined in recent years (Rowlette, 2004). Many states viewed the SSA VR reimbursement program as a major source of revenue and relied on these funds to operate their programs. SSA cost reimbursement accounts for approximately 5 percent of all case service monies available to the state VR agencies and represented a crucial source of revenue during a period of extreme budget pressures in many states.

The problem with the VR reimbursement program from SSA's perspective was that the employment outcomes continued to be disappointing and SSA was continuously under pressure from consumer groups to expand the choice of service providers. In 1994, SSA expanded the reimbursement program to include "alternative providers." This allowed other public or private rehabilitation agencies to apply for provider status in order to receive SSA cost reimbursement in the same way the SVRAs did. The alternative provider program, as it came to be called, was never very successful, because most private rehabilitation agencies did not have sufficient resources or cash flow to be able to delay reimbursement for such a long time.

The TWWIA legislation made state VR agencies critical to the overall implementation of TTW. They are currently the only entity that can provide services to SSA beneficiaries under the traditional SSA VR cost reimbursement payment mechanism, a program that has been in place for more than 20 years and has grown significantly in the recent past. SVRAs are also unique in that they have a legislative responsibility to provide services to all eligible beneficiaries under their current authorizing legislation, Title I of the Rehabilitation Act. Finally, SVRAs are able to use existing Title I monies, coupled with funds from other sources, to serve beneficiaries while simultaneously receiving funds from SSA to reimburse the SVRA for the same services it is obligated to provide under Title I.

The dominance of the VR agencies in Ticket assignments is ironic, since the TTW program appears to have been created in large part to establish an alternative to the SVRAs for SSA beneficiaries seeking employment supports as they attempt to return to work. The legislation attempts to enhance consumer choice and independence by allowing beneficiaries to choose from an array of available providers that compete freely for the opportunity to receive the individual's Ticket and provide employment services. In implementing the TTW program, SSA has devoted significant resources to attempting to entice nontraditional employment service providers to participate in the program and provide previously unavailable services to beneficiaries. As of October 11, 2004, SSA had mailed Tickets to 10,050,310 beneficiaries, and 67,383 Tickets had been assigned to Employment Networks (ENs) and state VR agencies. Of the 67,383 assignments, 61,347 or 91 percent have been assigned to state VR agencies.

Based on initial evaluation results, the TTW program has failed to live up to the high expectations for it (Thornton et al., 2004). Beneficiary participation in the Ticket program is very low, with only 1 percent of Ticket holders having assigned their Ticket to an EN. When assignments do occur, they are overwhelmingly to SVRAs, which indicates that consumer choice has not been significantly improved. Recruitment and retention of ENs has been very challenging and EN Ticket assignments are concentrated among a few providers, with over 80 percent of all ENs having accepted five or fewer Tickets. Finally, virtually all ENs other than the state VR agencies report that they are losing money on their TTW operations. Obviously, the payment mechanisms are not working as they were intended and are not acting as incentives for new providers to offer employment services or supports to SSA beneficiaries. Currently, the TTW regulations are under review by SSA and are expected to be significantly revised (Gerry, 2005).

Collaboration with the Rehabilitation Service Administration – The State Partnership Systems Change Initiative. Under a March 1998 Executive Order, the President created the National Task Force on Employment of Adults with Disabilities. The first initiative under this executive order was the establishment of the State Partnership Systems Change Initiative (SPI). The purpose of SPI was to support selected project states in the development of innovative service delivery systems that would increase employment of individuals with disabilities, such as employer partnerships, customer-driven services, waivers and buy-in, state policy change initiatives, benefits assistance, and employment supports and programs.

SSA and RSA funded a combined total of 18 demonstration projects. SSA awarded grants to 12 states to develop innovative projects to assist adults with disabilities in their efforts to reenter the workforce. RSA funded systems change projects in six states. These awards helped states develop statewide programs of services and support for their residents with disabilities that attempted to increase job opportunities and decrease their dependence on benefits. Other federal agencies, such as DOL and HHS, joined SSA in support of these projects. The SPI projects were completed only recently and evaluation of project results is currently under way.

Collaboration with Private Rehabilitation Agencies and Community Rehabilitation Programs (CRPs). As previously described, SSA began to interact with private rehabilitation

agencies as early as 1994 with the initiation of the alternative provider initiative and has increased interaction with these entities through the TTW program. Thus far, the relationship between SSA and the private rehabilitation community has been difficult, primarily due to the payment mechanisms inherent in the TTW program and what CRPs often view as preferential treatment provided to the SVRAs. Many of the recommendations that have been made by the SSA Ticket Advisory Panel address these concerns.

Employment and Training System

The Problem

SSA has made a monumental effort in the past five years to increase coordination and collaboration with DOL's Employment and Training Administration (DOLETA). The passage of the Workforce Investment Act (WIA) of 1998 initiated a major reorganization of the nation's employment programs that was intended to consolidate preparation and employment services into a unified system of support. Key to this reorganization was the creation of a national network of One-Stop Career Centers throughout the United States and its territories, to provide a single place where job seekers and potential job seekers can receive the services that they need to become employed or reemployed (Morris and Farah, 2002). Although previous DOL employment programs, such as the Job Training Partnership Act, had been largely ineffective in serving individuals with significant disabilities, WIA presented a new opportunity for beneficiaries to successfully access and benefit from the same employment services as those available to the general public (Bader, 2003). Prior to the passage of WIA, formal interaction between SSA and DOL had rarely occurred.

Previous Attempts by Congress and SSA to Impact the Federal Employment and Training System

The following section describes prior and current collaborative efforts on the part of DOL and SSA. As previously noted, collaboration between these two federal agencies began primarily with the passage of the WIA 1998 when DOL moved toward full implementation of the One-Stop Career Center system.

Work Incentive Grants – One of the first areas in which SSA worked collaboratively with DOLETA was on the Work Incentive Grant (WIG) initiative that began in 2001. This initiative provided competitive grants designed to enhance the employability, employment, and career advancement of people with disabilities through enhanced service delivery in the new One-Stop system established under WIA. The WIG program provides grant funds to consortia and/or partnerships of public and private nonprofit entities working in coordination with the One-Stop system to augment the existing programs and services and ensure programmatic access and streamlined, seamless service delivery for people with disabilities. Although SSA did not provide funding for WIG projects, it did envision the inclusion of benefits planning and counseling as a service available in One-Stop Career Centers. WIG project personnel were permitted to attend the required Benefits Planning, Assistance, and Outreach (BPAO) training and also were invited to training events funded through the SSA/RSA collaborative State Partnership Initiative. Although only a few of the WIGs became BPAO providers, it is clear that SSA was working to facilitate the coordination of their own employment demonstration projects with WIGs interested in collaboration.

Disability Program Navigator – In 2002, recognizing that specialized supports would be necessary to make certain that SSA beneficiaries would have the opportunity to fully participate in WIA programs, SSA and DOL collaboratively developed, funded, and piloted a new position — disability program navigator — to assist individuals with disabilities to access and benefit from One-Stop Career Centers. The disability program navigator position is designed to assist individuals with disabilities work their way through the complex eligibility criteria and program rules in the various disability systems that often discourage people with disabilities from working. Disability navigators assist people with disabilities access the wide variety of programs available to support their successful entry or reentry into the workforce, connecting such individuals to programs and the benefits, services, and/or supports they provide, and following up to ensure that each individual is receiving the level of benefits, services, and/or supports needed. In addition, navigators serve as a One-Stop Career Center resource on Social Security work incentives and other employment support programs, including the Ticket to Work program and the provision of services through BPAO organizations, the protection and advocacy systems (P&As), SSA's employment-related demonstration projects, and state vocational rehabilitation

agencies. As of June 2004, DOLETA had established disability program navigators in 17 states. An outcome evaluation of the program is in its initial stages.

Developing Work Records and Earnings Histories – In another example of collaboration with DOL, SSA area offices have begun establishing agreements with state unemployment insurance (UI) agencies to use the quarterly wage data they collect to assist with developing work records and earnings histories. This is an excellent strategy, since UI data offers more complete data than the IRS files and provides this data quarterly instead of annually. Since overpayments due to unreported work activities create significant problems in the DI system, this development is extremely positive. In a similar collaborative effort, SSA has established the ability to periodically match all SSI beneficiaries against wage and new-hire data in the Office of Child Support Enforcement's National Directory of New Hires, thus enabling the agency to more expeditiously identify individuals with earned income.

Office of Disability Employment Policy – SSA has also been involved in a minor way with the activities of DOL's Office of Disability Employment Policy (ODEP). ODEP currently has a number of demonstration initiatives under way, including its recent series of Customized Employment Grants. The purpose of the Customized Employment Grant Initiative, begun by ODEP in FY 2001 and continued in FY 2002, is to provide funds to selected Local Workforce Investment Boards to build the capacity in local One-Stop Career Centers to provide customized employment services to persons with disabilities who may not now be regularly targeted for services by the One-Stop Career Center system.

In response to the employment goals in the President's New Freedom Initiative, ODEP also has recently developed the Small Business and Self Employment Service (SBSES). This new program provides information, counseling, and referrals about self-employment and small business ownership opportunities for people with disabilities. The SBSES is housed in and operated by the Job Accommodation Network. The main objective of the SBSES is to support people with disabilities in their efforts to start and successfully manage profitable small businesses. Although the program briefly references the Social Security benefits and work incentives such as PASS in its informational materials, there is no linkage to the SSA Web site or

any other site containing specific information on the effect of self-employment on disability benefits. (For more information, go to www.dol.gov/odep/programs/promotin.htm.) Similarly, SSA fails to reference any assistance that people with disabilities can receive in developing small businesses or microenterprises on its Web pages or in its printed informational materials.

Another area of the DOL system that SSA also needs to work more closely with is state unemployment insurance programs. One of the current problems with the UI system is that applicants have to be “able to work” and actively seeking work to get UI benefits. These benefits are generally not payable to unemployed individuals who are sick or unable to work for any reason (DOLETA, 2005). It is not uncommon for UI benefits to be denied to individuals who indicate that they are disabled, even though disability and employment are not necessarily mutually exclusive. In some cases, BPAO providers have reported that state UI workers have denied benefits to people who indicate that they receive any form of SSA disability benefit. Apparently, the rationale here is that people who get SSA disability benefits are by definition too disabled to work at a substantial level — truly a catch-22 situation. Since UI benefits are not payable to people who are disabled (i.e., unable to work), many applicants are afraid to mention that they have impairments or are on disability benefits. A more functional strategy would be for SSA and the state VR agencies to work with the state UI agencies to develop ways to probe for indicators of disability during the initial interview or application for unemployment benefits (Golden, O’Mara, Ferrell, and Sheldon, 2005).

Educational System

The successful transition of students with disabilities from school to work or postsecondary training and education is a major policy initiative for several federal agencies, including the U.S. Department of Education (ED), DOL, and SSA. Many of the students who are the target of these initiatives are receiving Social Security disability benefits such as SSI or Title II Childhood Disability Benefits (Miller and O’Mara, 2003). In a recent NCD report discussing financial aid barriers faced by youth with disabilities, Moore states, “It is in the best interest of this country that the next generation of young people with disabilities is competent and adequately prepared to enter the workforce rather than depending on Social Security and welfare benefits” (Moore, 2003). Unfortunately, misinformation and fear of losing cash benefits and/or medical benefits

have prompted transition-aged beneficiaries and their families to limit their employment and educational options, even though they have a strong desire to enter the labor force (Brooke, 2003). As discussed below, there is a clear need for all systems involved with transition-aged youth to coordinate their efforts to provide accurate and complete information to beneficiaries and their families as they attempt to exit secondary education and transition into the community.

The Problem

The problem on the educational systems front is really twofold. First, many SSI recipients first apply for benefits as children while enrolled in public schools. These individuals often remain on the rolls well into adulthood, with very few transitioning from high school into substantial employment after graduation (GAO, 1996b; GAO, 1998b). Failure of the public school system to implement successful transition services or programs creates an ongoing dependency on public benefits. The impact of Social Security benefits on transition-aged youth is seldom considered during the formal transition planning process conducted by school personnel. This failure to focus on Social Security and other public benefits during transition is not only a missed opportunity, but harm may be caused when students and family members are not educated about or prepared for the effect of earnings on cash benefits and medical insurance (Miller and O'Mara, 2003).

Differences in public policies and programs may account not only for the growth of younger entrants on the SSI and DI rolls but also the confusion about eligibility and program purposes. In the NCD report *Transition and Post-School Outcomes for Youth with Disabilities: Closing the Gaps to Postsecondary Education and Employment* (NCD, 2000), the conflict between IDEA and SSA rules is illustrated.

For example, technical assistance provided by the U.S. Department of Education's Office of Special Education Programs (OSEP) through the National Transition Alliance (Halloran and Austin, 1998, p. 3; NTN, 1998) staunchly promotes application to the SSI program by youth in special education. This raises concerns about schools encouraging "students with certain disabilities" to apply for SSI. This strategy could be viewed as inconsistent with the IDEA requirement for services based on each child's individual need, rather than on a category or type of disability. OSEP is required by IDEA to implement "transition" policies and programs that are designed to promote successful

transition of youth from secondary school to the world of work and adult life. At the same time, SSA is required by the Social Security Act to implement policies and programs that provide cash benefit to children and youth whose disability prevents their employment. The eligibility requirements are different for children and adults. To become enrolled (that is, to be determined eligible by SSA), youth over 18 years of age must present themselves as being unable to be employed. At the very minimum, these public policies and their interpretation appear to be in direct conflict.

Second, there is the problem of poor educational attainment of DI beneficiaries who enter the disability system later in life. A 2004 study conducted by the Congressional Budget Office found that a significant number of baby boomers aged 51 through 61 years are leaving the labor force due to disability, primarily musculoskeletal or cardiopulmonary conditions. Unfortunately, this group is characterized by low educational attainment, with over 25 percent not having completed high school and only 5 percent having an undergraduate college degree. These beneficiaries also tend to have histories of low-skilled, fairly low-wage employment, such as factory or service work (Congressional Budget Office, 2004). Efforts to help this population return to work will be stymied by their lack of education and marketable job skills — particularly in today's highly competitive information economy. It is now more important than ever that people of all ages have access to higher education and the financial means to pay for training and education (Moore, 2003).

Although SSA recognizes the connection between postsecondary education and/or training and the ability to achieve competitive employment, no efforts have been made to date to engage higher education in any federal interagency collaborative efforts. The Social Security disability programs do offer work incentives that encourage postsecondary education, such as the student earned income exclusion (SEIE) and the Plan for Achieving Self-Support (PASS), but the impact of these incentives has been limited.

Previous Attempts by Congress and SSA to Impact the Educational System and Youth

The following section describes specific projects that SSA has implemented to try to enhance successful transition of beneficiaries from secondary school to employment and adult life in the

community. For the most part, these projects have been operated either directly by SSA or as grants from SSA to community-based organizations.

Graduating to Independence – SSA has become increasingly aware of the importance of working with educational systems, particularly public high schools, in its efforts to promote employment of younger beneficiaries. In the late 1990s, SSA created an education kit called “Graduating to Independence” (GTI) aimed specifically at youth in transition from education to employment and their families. The kit is designed for use by educators and professional organizations to instruct young beneficiaries and their families about SSA’s work incentives. The multimedia kit contains a videotape and several computer disks in addition to written materials that combine facts with motivational examples. SSA has been fairly aggressive in distributing the GTI kits, sending them to school districts across the country and handing them out at national conferences. The impact of this public information effort has not been evaluated to date.

SSA’s “I Can Work” Project – Beginning in 2000, SSA initiated a special school-to-work transition pilot project through a contract with MAXIMUS, Inc. in the states of Maryland and Florida. This program targeted youth age 15 to 16 years old who were SSI recipients and enrolled in the public education system (Smith, 2002). The interventions included vocational assessment and employment-focused transition planning combined with a case management approach in which referrals to community resources were coordinated. Actual employment services and supports were delivered by community agencies such as the state VR agency and other community rehabilitation programs. Efforts were also made to provide information about the effect of paid employment on Social Security benefits and the use of applicable work incentives. Based on the written report submitted to SSA by MAXIMUS, Inc. summarizing the results after three years of implementation, the pilot program was successful in increasing participation in transition planning, increasing family participation in the Individualized Education Planning (IEP) process, and increasing the employment of participants during school and after graduation (Smith, 2002). No external independent evaluation has been conducted on this program to date, so objective assessment of project results is not available.

Cooperative Agreement with D.C. Children’s National Medical Center – An innovative program was undertaken by Children’s National Medical Center and the school system in Washington, D.C., in the late 1990s to provide transition planning for SSI youth 11–21 years of age. Participants received vocational counseling with their parents, attended transition workshops, and were given opportunities for leadership development and college preparation (McGill, 2002). SSA’s four-year cooperative agreement with Children’s Medical Center has ended, but the Adolescent Employment Readiness Center continues to exist.

Youth Transition Process Demonstration – In 2003, SSA initiated Youth Transition Demonstration (YTD) projects designed to test the impact of a comprehensive package of services and SSI waivers on the postsecondary educational and employment outcomes of SSI beneficiaries between the ages of 14 and 25 years. SSA has awarded seven cooperative agreements in six states: California, Colorado, Iowa, Maryland, Mississippi, and New York. The demonstration projects are designing and implementing interventions that include services and supports such as benefits advisement, service coordination, disability program navigators, enhanced individual development accounts, and job placement and training services. In addition, SSA is testing the effect of waiving five SSI program rules for participants:

- Participants determined by their age 18 reviews to no longer be eligible for SSI benefits may retain those benefits as long as they participate in the project.
- Participants may receive the student earned income exclusion (SEIE) through the age of 25.
- Participants will benefit from a \$1 for every \$4 benefit offset for earnings above the general earned income exclusion.
- Participants will be allowed greater flexibility in the establishment and implementation of IDAs.
- Participants will be allowed to establish goals for PASS accounts that target either postsecondary education or employment outcomes.

The Youth Transition Demonstration projects are too new for any results to be evident, but the effort is commendable. SSA is well aware of the importance of early intervention with the

younger beneficiaries in any efforts to enhance employment outcomes for adults with disabilities. The earlier students are exposed to employment and the more the expectation of work is reinforced and supported during school, the greater the likelihood that they will be gainfully employed upon graduation (Miller and O'Mara, 2003).

Employers, Business Community, and Private Insurance Industry

The Problem

SSA has had very limited involvement with employers or the business community around the issues of return to work, early intervention, or preventing individuals from joining the disability rolls. So far, SSA has focused its attempts to engage employers primarily on programs that encourage businesses to hire beneficiaries.

Previous Attempts by Congress and SSA to Impact the Employer, Business, and Private Insurance Systems

The following section describes the efforts SSA has made to engage the business community in efforts to reduce the disability rolls or at least stem the recent growth. For the most part, SSA has focused on finding ways to encourage businesses to hire persons with disabilities, as evidenced by the Ticket to Hire program detailed below. This section also examines some of the state-of-the-art approaches businesses are using to decrease the incidence of disability at the workplace as well as return ill or injured workers to employment more quickly. There are some interesting lessons on prevention and early intervention coming out of the private insurance systems using innovative disability management techniques, which may be applicable to the Social Security disability system.

Ticket to Hire – Currently, SSA operates the Ticket to Hire program in conjunction with the Ticket to Work initiative. This program is a national referral service for employers interested in hiring individuals who experience disability. The Ticket to Hire program links employers to the approved Employment Networks in their area that have qualified candidates with disabilities who have assigned their Ticket. The Ticket to Hire program is a free, Web-based service that employers can access through the SSA Web site.

Disability Management Programs – While the past 15 years have witnessed tremendous growth in the public disability rolls, private businesses have been learning how to manage the costs associated with disability. Since the late 1980s, there has been a growing awareness in the business and private insurance communities that focusing on cutting short-term costs of medical coverage and wage replacement programs for employees who are ill, injured, or disabled actually increases total expenditures over the long term (Habeck and Hunt, 1999; Integrated Benefits Institute, 2004). The lost productivity costs of employee absences due to illness, injury, or disability may be up to seven times higher than the cost of wage replacement payments such as short-term disability (STD) or long-term disability (LTD) alone. Combined wage replacement payments and lost productivity costs outweigh medical payments for workers' compensation and group health by more than four to one (IBI, 2004). Companies are beginning to realize that the costs of disability are measured not just by insurance premiums but also by lost workplace efficiency, disrupted customer relationships, expenses related to hiring and training new workers, and added administrative costs (Watson Wyatt and Washington Business Group on Health, 1999). The new thinking is that the optimal outcome of any disability claim is the employee's return to a healthy and productive life — not ongoing dependence on a progression of wage replacement payments.

To reduce the full and true cost of disability, businesses increasingly have been implementing disability management (DM) programs. This term refers to a proactive, employer-based approach to (a) prevent and limit disability; (b) provide early intervention for health and disability risk factors; and (c) foster coordinated disability administrative and rehabilitation strategies to promote cost-effective restoration and return-to-work strategies (Williams and Westmoreland, 2002). DM is characterized by a prevention and remediation approach that seeks to prevent disability from occurring, or to intervene very quickly after the onset of illness, injury, or disability with the goal of returning individuals to productive employment (Habeck and Hunt, 1999). Research has shown that the following are the most effective components of DM programs:

- Common case management techniques characterized by ongoing open communication among ill or injured employees, supervisors, physicians, and designated case managers to resolve issues preventing a speedy return to work.

- Aggressive return-to-work policies and strategies, including modified job duties, transitional job duties, job site accommodations, and vocational counseling.
- Active coordinated management of work and non-work-related disability issues.
- Identifiable, simple, and coordinated points for intake and claims reporting for all disability issues (Calkins, Lui, and Wood, 2000; Williams and Westmoreland, 2002).

The growing success of DM approaches has some profound implications for stemming the growth of the Social Security disability rolls. Perhaps if more companies consistently utilized this approach, fewer ill or injured workers would experience a progression of disability benefits (PODB) that ultimately ends up in an application for Social Security disability benefits. Even if DM techniques served to merely delay or slow down the PODB phenomenon, it would result in substantial savings for the DI Trust Fund. SSA would be well served to initiate collaborative efforts with private insurers and the business community that would result in slowing the progression of injured workers onto the DI roles.

Recommendations for SSA Policy Changes

The following sections delineate recommendations for ways SSA could improve collaboration with each of the five major systems discussed above: the health care system; VR system; federal employment and training system; educational systems; and employer, business, and private insurance systems. Recommendations are specifically targeted at steps Congress and SSA could take to enhance collaboration among the various systems to improve the employment outcomes of DI and SSI beneficiaries and reduce dependency on public benefits

Collaborating with the Health Care Systems

While SSA and the Centers for Medicare and Medicaid Services (CMS) have made significant strides in coordinating their respective systems in the past 15 years in order to promote employment outcomes for people with disabilities, a substantial amount of work remains. The following are examples of policies that continue to work at cross-purposes.

CMS and SSA should work together closely to modify existing program regulations in order to uncouple Medicare and Medicaid coverage from DI/SSI cash payments, similar to the way in which Medicare coverage is currently provided to persons with end-stage renal disease or the Medicaid buy-in program. Anecdotal reports indicate that many individuals would forgo cash payments entirely if they could access affordable health care.

SSA, CMS, and state Medicaid agencies need to work together to identify and eliminate the many employment disincentives currently built into the Medicaid waiver, Medicaid buy-in, and Health Insurance Premium Payment (HIPP) programs. Income and resource rules governing both eligibility and patient liability or share of cost often penalize paid employment for individuals receiving services through Medicaid waiver programs. In addition, there remain many aspects in state Medicaid buy-in programs that are problematic, such as low resource or asset limits, deeming of spousal income, and limited pharmacy coverage. Finally, implementation of the HIPP program needs serious attention. There are numerous places in this program where the systems fail to interface correctly. SSA needs to become a more active partner in helping state Medicaid agencies train workers, inform beneficiaries, and educate employers about this special assistance with health care costs. It does not make fiscal sense to have beneficiaries choosing to stay on expensive public health care benefits when employer-sponsored plans are available.

SSA and CMS should work collaboratively to examine the Medicare programs for policies that do not promote paid employment or that encourage earlier application for DI benefits. As recommended elsewhere, eliminating the 24-month Medicare qualifying period would enable some beneficiaries to access needed health care at a crucial period in their return-to-work efforts. Another alternative would be to expand the Medicare buy-in option. Currently, this option is offered only to individuals who were awarded DI benefits but subsequently became ineligible due to engaging in SGA. Another policy change that would encourage employment would be to allow beneficiaries to deduct the cost of health care premiums from earnings for the purposes of SGA determinations. This might encourage beneficiaries to work more and participate in employer-sponsored health care plans that may require premiums, co-payments, and deductibles otherwise viewed as unaffordable.

Congress should direct SSA and CMS to conduct a complete review of the current Medicaid and Medicare programs to identify and correct inconsistencies between the two programs that result in disincentives to employment for beneficiaries. There are currently numerous system interface problems between the Medicaid and Medicare programs that CMS needs to address with input from SSA in order to promote employment of beneficiaries. These two programs work in complete isolation from one another, and the resulting silos cause problems in many areas. One of the areas that needs work is the Medicare Savings Program, in which Medicaid pays all or part of the Medicare premiums and also covers the co-payments and deductibles for beneficiaries who meet specified income and resource limits. The effect of earned income on eligibility for these programs is not conducive to work. In addition, the interaction of Medicaid buy-in programs and the Medicare Modernization Act on prescription drug coverage poses problems. These are not issues that CMS should address without significant involvement with SSA, since they affect return-to-work efforts of beneficiaries. Finally, Medicare expenditures are not included when calculating individual threshold amounts for 1619(b) extended Medicaid coverage. This practice penalizes SSI recipients with dual eligibility in both Medicare and Medicaid programs who are earning more than the standard state threshold amount but who have unusually high medical expenses.

SSA should convene a task force composed of representatives of private insurance providers, large employers, and small business to design, implement, and evaluate a series of demonstration activities that will assess the effectiveness of public-private insurance partnerships in expanding access to health care for individuals with disabilities. SSA has never attempted to engage the business community or the insurance industry in collaborative efforts on the issue of health care coverage. This represents a significant missed opportunity that must be addressed. The public and private health care systems are currently working at cross-purposes. A blending or braiding of public and private funds may well be more cost-effective and could possibly lead to a more seamless and integrated health care coverage system for people with disabilities. This task will undoubtedly be difficult, but the consequences of having the public and private health care systems continue to work in isolation from each other are significant.

Vocational Rehabilitation System

SSA's efforts to work collaboratively with the vocational rehabilitation system to improve the rates of Substantial Gain Activity (SGA)-level work for its beneficiaries have not been particularly successful to date. The main problem seems to be the way SSA pays for these outcomes. However, the general concept of having SSA provide financial incentives for employment outcomes is a sound one, and alternative payment mechanisms should be investigated and piloted to test their effectiveness. Specific recommendations include the following:

SSA should modify Ticket to Work (TTW) program regulations to allow the SSA's Vocational Rehabilitation (VR) traditional VR cost reimbursement program to carry on as a parallel program to the Employment Network (EN) outcome or outcome-milestone payment mechanisms. The cost reimbursement and EN payment systems should operate as parallel programs in which both the VR agency and the EN would receive payments for serving the same beneficiary. This approach would facilitate VR-EN partnership in which the SVRA could get reimbursed for its costs and then hand off the case to an EN for follow-up, and the EN would receive the outcome payments through the Ticket. The funding security this approach would foster for the ENs would position them better financially to accept Tickets from individuals who do not use VR services.

SSA should modify the TTW regulations to ensure that an EN is able to accept Ticket assignment from a beneficiary, refer that individual to a VR agency for needed services, and not be required to reimburse the VR agency for those services. TWWIA did not specify a rigid set of requirements with regard to the nature of agreements between ENs and VR agencies, only that they are required. The current TTW regulations do not specify the terms of the agreements and do not require ENs to automatically reimburse VR agencies for services provided to beneficiaries by the EN. However, in practice, virtually all current VR-EN agreements require that when an EN refers a beneficiary to a VR agency for services, it must reimburse the VR agency for the cost of services (Kregel & Revell, 2003). This creates a tremendous disincentive for ENs, which are struggling to find economically viable business models under which to operate the TTW program. The fact that, under the terms of nearly all current agreements, the monies that must be repaid to SVRAs may constitute 25 percent to 50

percent of the total Ticket reimbursement to the EN makes a huge difference in an EN's ability to successfully participate in the Ticket program.

Federal Employment and Training System

With the advent of the One-Stop Career Center approach to delivering employment and training services nationally, SSA recognized a unique opportunity to gain assistance for its beneficiaries and has actively pursued collaborative projects with DOLETA.

SSA should undertake an analysis of the impact of allowing DOL One-Stop Career Centers to receive cost reimbursement payments for successfully serving beneficiaries under the TTW program. Beneficiaries might have access to more choice of providers if SSA granted the same reimbursement mechanism to One-Stop agencies that it currently reserves for the state VR agencies. While this would be a controversial move, it might encourage One-Stop Career Centers to take a more active role in providing employment services and supports to individuals with disabilities.

Congress should direct SSA and DOLETA to evaluate the impact of the Workforce Investment Act (WIA) performance standards on beneficiary participation in WIA programs and design and test a set of waivers that will assist beneficiaries to access and benefit from WIA core and intensive services, as well as individual training accounts. While SSA has been involved with special DOL projects targeting consumers with disabilities, such as the Disability Navigator Initiative and the Work Incentive Grants, there has been little involvement in the regular WIA-funded core services (including outreach, job search and placement assistance, and labor market information) or intensive services (including comprehensive vocational skill and/or interest assessments, development of individual employment plans, and career counseling and career planning provided through the One-Stop Centers). Of particular interest are the WIA-funded training services in which participants may receive short-term occupational skills training and/or training in basic skills. Participants use individual training accounts to select an appropriate training program from a qualified training provider. The problem with the WIA standard adult services is that eligibility is very narrowly defined and determined. Only individuals who meet the criteria for groups such as dislocated workers or recipients of public assistance such as Temporary

Assistance for Needy Families (TANF) generally qualify. In addition, agencies that provide the WIA-funded adult services are held to rigorous DOL performance standards relating to number of placements, length of employment retention, number of hours worked, and wages earned. These performance standards inadvertently create a disincentive to enroll people with disabilities, since they are perceived to be less successful (or more difficult to support) in competitive employment. SSA beneficiaries would have access to another valuable source of employment preparation, training, and job placement services if DOL offered WIA providers additional performance credit for serving persons with disabilities. The WIA-funded youth services could also become a useful source of transition and early intervention services if the same performance credit were extended for serving youth with disabilities as a priority population.

Congress should direct SSA and DOL to evaluate the effect of changing unemployment insurance policies to all the payment of benefits when combined with vocational rehabilitation or other employment support services, instead of denying UI benefits to individuals who are sick or injured. The UI system could be an essential partner in the early identification of and intervention with potential SSI/DI beneficiaries. It does not make good fiscal sense to deny someone UI benefits if it simply hastens application for Social Security disability benefits. Since some state UI and VR agencies are co-located in One-Stop Career Centers created by WIA, there should be existing mechanisms for collaboration and coordination of this type.

Educational System

The educational system should be a critical partner with Social Security in efforts to promote employment and economic self-sufficiency for SSA beneficiaries. These systems have access to current and future disability beneficiaries at a very early age and have the resources of individualized education and transition planning at their disposal. Unfortunately, these systems have not been engaged by SSA on any large scale in order to advance the successful transition from school to paid employment. The following recommendations offer several steps that SSA should pursue.

Congress should direct SSA to expand the current student earned income exclusion (SEIE) and the Plan for Achieving Self-Support (PASS) to encourage involvement of SSA beneficiaries in postsecondary education and training. The maximum age for the SEIE should be raised to 25 from its current level of 22. This would create an incentive for beneficiaries to participate in postsecondary education and training programs. In addition, the PASS program should be revised to allow beneficiaries to set a goal of career exploration or postsecondary education as an allowable goal under the program.

SSA should work with the Department of Education to ensure that benefits planning and financial management services are available to the transition-aged population. Early intervention in the area of benefits counseling would result in getting valuable information about the effect of earned income on benefits and the many work incentives available for use in meeting career goals out to students with disabilities and their families. While the BPAO initiative has been successful to date, there remains a problem with delivering benefits counseling to the school-age beneficiary population. The BPAO program only can serve students beginning with the age of 14, and benefits specialists are not trained to meet the unique counseling needs of young students and their families. SSA should work with ED to ensure the inclusion of benefits counseling and financial planning as part of the IEP process and transition planning.

Congress should consider a policy change that would disregard all earned income and asset accumulation limits of beneficiaries who are transitioning from secondary education to postsecondary education or employment for at least one year after education or training is completed. This will allow youth to accumulate funds through scholarships, grants, and employment that will help them acquire the education and training needed for competitive employment without fear of losing financial and health care supports. A one-year period after completion of education will allow these young adults to establish themselves in their career path and move toward economic self-sufficiency. SSA is testing higher earned income and asset limits in its Youth Transition Demonstration (YTD).

Employers, Business Community, and Private Insurance Industry

SSA needs to engage the business community in its quest to increase employment outcomes for people with disabilities on two fronts. First, the business community is the primary source of employment for SSA beneficiaries. SSA has a compelling interest in encouraging businesses to hire people with disabilities. Second, the business community is the source of many disability applicants who acquire disability later in life. Practices of the business community and the insurance industry that fail to return workers with disabilities to gainful employment contribute to the progression of disability benefits phenomenon that ultimately ends at Social Security's doorstep.

Congress should direct SSA and the IRS to evaluate the possible effects of a disabled worker tax credit as a means of increasing the use of DM programs in business to prevent progression of injured and disabled workers onto the public disability rolls. The concept of a disabled worker tax credit, similar to the work opportunity tax credit created in the context of welfare reform, should be evaluated as a potential strategy for controlling the inflation of the DI rolls. This credit could be offered to businesses on a per worker basis whenever an ill or injured worker is returned to employment instead of moved onto the public benefits rolls. Another possibility is to offer companies broader tax incentives for implementing a federally approved or certified program of disability management. While tax incentives are certainly attractive to the business community, they often are perceived by businesses as being bureaucratic and involving unnecessary red tape or paperwork. Any initiative would need to be sensitive to these concerns and would best be designed with significant input from the business and insurance communities.

Congress should direct SSA to collaborate with the Small Business Administration (SBA) and the Rehabilitation Services Administration (RSA) to develop and implement an employer outreach program targeted toward small and mid-size businesses. While encouraging the expansion of DM programs is a useful strategy, these programs tend to be offered primarily by large corporations, while most Americans are employed by small to mid-sized businesses (Drury, 1991). In 1994, the SBA published statistics showing that firms with 100 or fewer employees employed 35 percent of all U.S. workers. Companies with fewer than 500 workers employed more than half of all Americans and accounted for 99 percent of all business

establishments. Interestingly enough, small firms (those with fewer than 100 employees) are a major employer of worker's compensation rehabilitants who cannot return to their former jobs, as well as placements from state VR agencies and private VR programs (Drury, 1991) These statistics suggest that there might be some innovative ways to engage small business that SSA could test through partnerships with other federal and state agencies. In particular, collaborative approaches between the SBA and the RSA could make small businesses a priority for outreach efforts conducted by the state vocational rehabilitation agencies. The focus of these outreach efforts would be to educate small business owners on disability issues and strategies for retaining workers by using return-to-work approaches such as job accommodation, job modification, vocational counseling, and case management. The state VR agencies would be uniquely qualified to provide these services at the workplace but would need to develop a much closer connection to local small business communities in order for this approach to work (Drury, 1991).

SSA should examine ways to encourage beneficiaries to establish small businesses or microenterprises as an alternative to traditional wage employment. Not only is self-employment identified as a priority in the President's New Freedom Initiative but research indicates that self-employment offers more flexibility and accommodation for an individual with a severe disability or medical condition than working for an existing employer (Griffin and Hammis, 2003). The PASS work incentive offers an excellent way to set aside income and resources to capitalize a business, but, as previously noted, this work incentive remains underutilized. The problem could potentially be resolved by making a concerted effort to inform not only VR agencies but also business entities such as local Small Business Development Centers (SBDCs) and SBA officials about the potential a PASS offers to entrepreneurs who experience disability. Another possible approach would be to examine why PASS plans containing a self-employment goal fail to be approved by SSA PASS specialists. Perhaps some common areas of weakness could be identified and steps taken to correct the problem. SSA is testing various types of small business and microenterprise approaches as a key part of its Work Incentives for Participants in the Florida Freedom Initiative demonstration.

Summary

Despite concerted efforts by Congress and federal agencies, the chronic unemployment of SSA beneficiaries remains a vexing problem. Beneficiaries are frequently unable to access the employment services and other supports they need to obtain employment, despite the fact that many beneficiaries feel they are capable of and motivated to work. As a result, many individuals feel trapped on the disability rolls, unable to pursue economic self-sufficiency without jeopardizing the health care and support they need. This situation continues to strain our nation's fiscal resources.

The complex obstacles to employment faced by SSA beneficiaries require a comprehensive set of solutions. New approaches must be identified that emphasize beneficiary control of career planning and the ability to access self-selected services and supports. Public and private health care providers must develop new collaborations and new approaches to combining coverage from multiple sources to improve program efficiencies. SSA must continue to work with RSA and DOL to improve implementation of the TTW program and identify new approaches that will overcome the traditional inability of SSA beneficiaries to benefit from services provided by the nation's employment and training programs. Secondary and postsecondary educational institutions must emphasize benefits counseling and financial management training as the foundation for beneficiary self-direction and economic self-sufficiency. Federal agencies and the business community must realize that collaborative approaches to incorporating beneficiaries into the workforce are needed as a way to reduce dependence on federal benefits while simultaneously enhancing the productivity and competitiveness of large and small businesses.

Chapter VI: Summary of Findings and Recommendations

The purpose of this study was to conduct a comprehensive analysis that (1) examines SSA's current efforts to implement its SSI and DI disability programs; (2) documents philosophical, programmatic, and regulatory obstacles that limit the ability of SSA beneficiaries to return to work; (3) identifies evidence-based practices that promote the return to work of working-age beneficiaries of the DI and SSI programs; and (4) recommends the legislative, policy, and regulatory changes that will be necessary to ensure the successful adoption and implementation of evidence-based practices. This chapter summarizes the findings from the entire study in relation to the four specific research questions that guided the overall research effort and outlines a comprehensive set of recommendations that will serve as a basis for future program reform.

Research Question 1

What are the evidence-based practices that promote the return to work of working-age beneficiaries of the DI and SSI programs?

Since 1980, Congress has granted the Social Security Administration (SSA) the authority to conduct demonstration projects that investigate the efficacy of possible policy or programmatic changes that may improve the ability of beneficiaries to obtain and maintain employment. The demonstration authority provides the agency considerable flexibility in designing and implementing research activities, even allowing SSA to waive certain DI and Medicare program rules to test potential changes that may enhance program administration or lead to Trust Fund savings.

In exchange for this demonstration authority, Congress placed several requirements on SSA's design and implementation of demonstration programs. First, SSA demonstrations must be of adequate scope and must be designed with sufficient methodological rigor that the results will generalize to the entire DI population or a specific subgroup within the entire population. Second, SSA must inform Congress when it initiates a demonstration and must provide regular reports throughout implementation. Third, SSA must communicate findings and make

recommendations to Congress that will translate the results of the demonstrations into significant policy changes.

To date, SSA's demonstration authority has not resulted in the validation of evidence-based practices that promote employment and return to work for beneficiaries. In November 2004, the Government Accountability Office (GAO) released a report that was critical of the manner in which SSA had used its demonstration authority (GAO, 2004a). GAO concluded that the current demonstration authority provides a valuable opportunity for SSA. The agency is allowed to waive program rules in demonstrations and has the unique advantage of being able to fund these activities through Trust Fund monies, not just through congressional appropriations. Even with these advantages, GAO concluded that SSA "has yet to use it to propose or assess major policy options that could result in saving[s] to the Trust Fund" (GAO, 2004a, p. 24).

GAO identified four specific shortcomings in SSA's prior demonstration efforts:

- (1) SSA lacks a formal process for developing a long-range demonstration agenda that will establish clear priorities for future research. Current demonstration planning occurs with insufficient input from internal and external stakeholders.
- (2) SSA has not used its demonstration authority to test potential program modifications prior to launching new program initiatives. For example, if SSA had tested various components of the Ticket to Work (TTW) program before launching the program nationwide, it may have been able to identify problems and develop solutions prior to implementation.
- (3) SSA's design of demonstration programs has frequently lacked sufficient methodological rigor. Prior demonstration projects have not been of sufficient scope or conducted on a wide enough scale to result in the validation of evidence-based practices that could potentially form the basis of policy reform.
- (4) SSA lacks a process to ensure that it carefully considers the policy ramifications of demonstration project results. In addition, the agency has done a poor job of communicating results of its demonstrations to Congress.

A number of factors account for this lack of evidence-based practices related to employment and return-to-work services for SSA beneficiaries. Political pressures sometimes lead policymakers and program administrators to rush promising but unproven practices into the field in an attempt to address the critical needs of beneficiaries. Changing congressional priorities have sometimes made it difficult for SSA to conduct the methodical, long-term investigation of employment practices necessary to determine whether a promising pilot program will develop into an evidence-based service alternative.

In an era of increasingly tight fiscal resources, Congress and SSA cannot afford to devote scarce funds to unproven national programs that ultimately do not live up to initial expectations. Access to comprehensive, scientifically valid research information prior to committing large-scale resources to new efforts is essential to achieving long-term program reform. Congress and SSA should resist the temptation to rely on short-term solutions to long-standing problems and accept the need to conduct methodologically rigorous evaluations of clinical interventions and devote the time and resources necessary to develop and validate additional evidence-based employment practices that will guide policy development and service delivery in the future.

Research Question 2

What policy changes are needed, given recent trends in program participation and employment?

Although SSA has taken steps to improve its return-to-work services, a more fundamental change in the agency's process and underlying philosophy is necessary in order to make the SSA disability program more work-oriented. SSA needs to integrate return-to-work strategies into all relevant phases of its disability determination process and benefits systems to enable workers with disabilities who can return to work to do so, and reassess the root causes of its problems. To accomplish this task, the agency must address the contradictions inherent in the current mission and purpose of its disability programs.

Promoting employment and return to work among SSA beneficiaries will require SSA to make a major paradigm shift and totally redefine both its mission and how it conducts its work on a day-

to-day basis. In order to be successful in these endeavors, SSA will have to work in an aggressive and proactive manner to indemnify against future risk, as opposed to simply passively processing applications submitted by former workers with severe disabilities and then managing their ongoing payments. Furthermore, a comprehensive return-to-work program cannot be implemented by SSA alone. Successful efforts at program reform will require significant collaboration and coordination among SSA; other federal agencies, such as the Department of Labor (DOL), Rehabilitation Services Administration (RSA), Centers for Medicare and Medicaid Services (CMS), Housing and Urban Development (HUD); the Small Business Association (SBA); employers; the disability services community; and the private insurance industry. The alarming expansion of the Social Security disability rolls cannot be viewed as SSA's problem to solve — it is a societal problem. It is in the best interests of American society to slow down this relentless progression from initial illness or injury to complete and total disability. No one wins when millions of Americans are removed from the productive labor force to live a life of dependency on federal benefits.

Research Question 3

Are there proven and documented practices that work best for some populations of people with disabilities and not others?

The overall lack of evidence-based practices in employment and return-to-work services also applies to strategies used to meet the employment needs of specific groups of individuals with disabilities. Among the many vocational approaches identified in the literature for specific groups of individuals with disabilities, few have been adequately described and, with one exception, none have a systematic body of rigorous research documenting improved program outcomes. The sole example of an employment approach that has been empirically validated with a specific population of individuals with disabilities is the work that has been done to validate the effectiveness of supported employment as a strategy to help mental health consumers (i.e., individuals with psychiatric disabilities) achieve competitive employment (Bond, 1992; Bond, Drake, Becker, and Mueser, 1999; Heyman, Turton, and Schneider, 2002; Honey, 2000; Lehman, 1995).

A crucial influence on the conceptualization of supported employment has been the work of Robert Drake and Deborah Becker in the development of the Individual Placement and Support (IPS) model (Becker and Drake, 1993, 2003). The IPS model is now regarded as synonymous with evidence-based supported employment for individuals with psychiatric disabilities. The following are the key principles that define IPS (Becker and Bond, 2002; Bond, 1998, 2004a):

- (1) **Services are focused on competitive employment.** The agency providing supported employment services is committed to competitive employment as an attainable goal for its consumers with psychiatric disorders, devoting its resources for rehabilitation services to this endeavor rather than to intermediate activities, such as day treatment or sheltered work.
- (2) **Eligibility is based on consumer choice.** No one is excluded who wants to participate.
- (3) **Rapid job search.** Supported employment programs use a rapid job search approach to help consumers obtain jobs directly, rather than providing lengthy preemployment assessment, training, and counseling.
- (4) **Integration of rehabilitation and mental health.** The supported employment program is closely integrated with the mental health treatment team.
- (5) **Attention is paid to consumer preferences.** Services are based on consumer preferences and choices rather than provider judgments. Staff and consumers find individualized job placements based on consumer preferences, strengths, and work experiences.
- (6) **Time-unlimited and individualized support.** Follow-along supports are individualized and continue indefinitely.
- (7) **Benefits counseling is provided.** Consumers are given specific and timely guidance tailored to their unique circumstances.

Evidence-based supported employment (i.e., the IPS model) has been described in detail in a practice manual (Becker and Drake, 2003) and an implementation resource kit (Becker and Bond, 2002). A well-validated supported employment fidelity scale has been developed (Becker, Smith, Tanzman, Drake, and Tremblay, 2001; Bond, Becker, Drake, and Vogler, 1997; Bond, Vogler, Resnick, Evans, Drake, and Becker, 2001).

Using the most stringent requirements for level of evidence, all the recent reviews of supported employment for clients with psychiatric disabilities point to the conclusion that it should be considered an evidence-based practice (Bond, 2004b; Bond, Becker, Drake, Rapp, Meisler, Lehman, Bell and Blyler, 2001; Bond, Drake, Mueser, and Becker, 1997; Crowther, Marshall, Bond, and Huxley, 2001; Heyman, Turton and Schneider, 2002; McLaren, 2004; Moll, Huff, and Detwiler, 2003; Ridgway and Rapp, 1998; Twamley, Jeste, and Lehman, 2003).

Research Question 4

Which factors ensure that documented and evidence-based practices could be adapted/adopted by SSA and other entities that seek to ensure the employment of people with disabilities? Which factors prevent adaptation/adoption?

Over the past decade, SSA has devoted considerable resources to promoting employment and return to work among DI and SSI beneficiaries. The agency has implemented a number of new initiatives authorized under TWWIIA, such as the Ticket to Work and Self-Sufficiency Program; the Benefits Planning, Assistance, and Outreach program; and the protection and advocacy program for Beneficiaries of Social Security. It has modified program rules to provide increased work incentives to beneficiaries, such as the expedited reinstatement and protection from continuing disability review provisions of TWWIIA, indexing the SGA threshold, and increasing the level of earnings allowed during the trial work period. The agency has also launched, or is planning to initiate, a number of demonstrations that will test the efficacy of early intervention services, new modifications to work incentives in the DI program, and services targeted toward youth with disabilities.

While SSA has taken steps to improve its return-to-work services, the agency faces a number of challenges as it implements its reform initiative. The definition of disability in the current SSA eligibility process is based on a 50-year-old conceptualization of disability that is in direct conflict with the premises of more recent federal policies and programs. The present eligibility determination process fails to recognize the difference between the presence of a disability and total work incapacity. It does not acknowledge the concepts of partial disability or temporary disability. Rather than facilitating early intervention services by making rehabilitation services

available to individuals early in the disability process, it delays eligibility for the rehabilitation and medical services and supports that might enable individuals to return to work and avoid lifelong dependence on disability benefits.

SSA is a vast federal agency that implements program rules in an attempt to ensure that millions of individuals with disabilities receive the financial support they need to care for their basic needs and maintain independence. However, the culture of SSA is not geared toward providing rehabilitation services and returning individuals to work. The complexity of the system thwarts the efforts of many beneficiaries who would like to receive rehabilitation services and return to work. The complexity of program rules, coupled with the inability of the agency to accurately track and record post-eligibility earnings, frequently penalizes beneficiaries who attempt to enter or reenter employment.

SSA is not and should not be solely responsible for providing all the services and supports necessary to enable beneficiaries to enter employment or return to work. The agency has worked closely with the Department of Education (ED), the Centers for Medicaid and Medicare Services (CMS) of the Department of Health and Human Services (DHHS), and the Department of Labor (DOL) to provide beneficiaries with access to the direct employment services and indirect employment supports necessary for employment success. While these efforts are laudable, coordination and collaboration across multiple federal and state agencies remain a significant challenge for the agency. Increased efforts are necessary to ensure consistency across eligibility criteria and program rules, thereby allowing beneficiaries to access and benefit from all necessary services and supports. In addition, SSA needs to expand its collaboration efforts by working more closely with the business community and with public and private insurance providers.

The previous chapters have identified a number of recommendations to modify SSA disability programs to make them more work-oriented. Each of the recommendations has been identified through a review of all available published and unpublished literature, considered and supported at a consensus validation conference attended by representatives of a large number of groups, and described and justified earlier in this report. The 38 recommendations are organized into

three categories: Beneficiary Perspective and Self-Direction, Income Issues and Incentives, and Coordination and Collaboration across Multiple Public and Private Systems.

Beneficiary Perspective and Self-Direction

Customer Service

- (1) SSA should develop and implement a plan to improve the architectural and programmatic accessibility of SSA field offices and Web sites.
- (2) SSA field office personnel functions, staffing patterns, and work assignments should be redesigned to prioritize activities that assist beneficiaries attempting to work.
- (3) SSA should continue and expand its efforts to automate processing of work reports and increase coordination of work reporting across the SSI and DI benefit programs.
- (4) SSA should significantly improve outreach efforts to beneficiaries to inform them of the existence, advantages, and reporting requirements of various work incentives.

Ticket to Work Program

- (5) Congress should expand Ticket eligibility to include beneficiaries whose conditions are expected to improve and who have not had at least one continuing disability review, childhood SSI beneficiaries who have attained age 18 but who have not had a redetermination under the adult disability standard, and beneficiaries who have not attained age 18. It is important to note that if Congress were to adopt this recommendation, there would be additional costs associated with its implementation and therefore, by Office of Management and Budget (OMB) rules, there would be a requirement to provide an offset to pay for the change.
- (6) SSA should review and modify the TTW regulations to ensure that Ticket assignment practices do not violate the voluntary nature of the program and beneficiary rights to grant informed consent.
- (7) SSA should design and implement a strong national marketing program that will expand and intensify its efforts to inform beneficiaries about the TTW and other SSA programs.

Facilitating Beneficiary Choice

- (8) Congress should authorize and direct SSA, RSA, CMS, HUD, and the DOL's Employment and Training Administration (DOLETA) to develop and implement an integrated benefits planning and assistance program that coordinates resources and oversight across several agencies, enabling beneficiaries to access benefits planning services within multiple federal systems.
- (9) SSA should consider changes to the existing BPAO initiative to improve the accuracy and quality of services provided to individual beneficiaries.

Reducing SSA Overpayments to Beneficiaries

- (10) SSA should expand its efforts to increase the use of electronic quarterly earnings data and automated improvements to expedite the processing of work activity and earnings that affect eligibility and benefits.
- (11) SSA should pilot the creation of centralized work continuing disability review (CDR) processing in cadres similar to Plan for Achieving Self-Support (PASS) and special disability workload cadres.
- (12) Congress should direct SSA to enhance its efforts to educate beneficiaries on reporting requirements, the impact of wages on benefits, and available work incentives.

Eliminating the Marriage Penalty

- (13) Congress and SSA should undertake a complete review of the SSI program and make program modifications that eliminate the financial disincentive to marriage inherent in the present program.
- (14) Congress should amend the current Title XVI disability legislation to modify the manner in which 1619(b) eligibility is applied to eligible couples.

Income Issues and Incentives

Easing the SGA Cash Cliff for DI Beneficiaries

- (15) Congress should modify the current Title II disability legislation to eliminate SGA as a post-entitlement consideration for continued eligibility for Title II disability benefits.
- (16) Congress should modify the current Title II disability legislation to provide for a gradual reduction in DI cash benefits based on increases in earned income.
- (17) Congress should modify the current Title II disability legislation to establish a system of continuation of program eligibility for DI beneficiaries through the creation of a beneficiary nonpayment status.

Reducing Restrictions on Assets for SSI Beneficiaries

- (18) Congress should direct SSA to develop and test program additions and regulatory modifications that will enable SSI beneficiaries to accumulate assets beyond existing limits through protected accounts and other savings programs.
- (19) SSA should change current program rules and work with other federal agencies to modify and expand the value of individual development account (IDA) programs to SSA beneficiaries.

Decreasing the Complexity of the DI/SSI Program Rules Governing Income and Resources

- (20) Congress should direct SSA to simplify regulatory earnings definitions and wage verification processes so they are consistent across the SSI and DI programs.
- (21) Congress should direct SSA to modify regulations related to the treatment of earnings in the DI program by applying the same rules currently applied in the SSI program.

Coordination and Collaboration Among Multiple Public and Private Systems

Health Care System

- (22) CMS and SSA should work together closely to modify existing program regulations in order to uncouple Medicare and Medicaid coverage from DI/SSI cash payments, similar to the way in which Medicare coverage is currently provided to persons with end-stage renal disease or to the Medicaid buy-in program.
- (23) SSA, CMS, and state Medicaid agencies need to work together to identify and eliminate the many employment disincentives currently built into the Medicaid waiver, Medicaid buy-in, and Health Insurance Premium Payment (HIPP) programs.
- (24) SSA and CMS should work collaboratively to examine the Medicare programs for policies that do not promote paid employment or that encourage earlier application for DI benefits.
- (25) SSA should work collaboratively with other federal agencies to expand benefits counseling services to include the full range of financial education and advisement services.
- (26) Congress should direct SSA and CMS to conduct a complete review of the current Medicaid and Medicare programs to identify and correct inconsistencies between the two programs that result in disincentives to employment for beneficiaries.
- (27) Congress should direct SSA and CMS to convene a standing task force composed of representatives of public and private insurance providers, large employers, and small business to design, implement, and evaluate a series of demonstration activities that will test the effectiveness of providing a seamless, uninterrupted public-private insurance partnership in expanding access to health care for individuals with disabilities.

Vocational Rehabilitation System

- (28) SSA should modify TTW program regulations to allow SSA's traditional VR cost reimbursement program to carry on as a parallel program to the Employment Network (EN) outcome or outcome-milestone payment mechanisms.

- (29) SSA should modify the TTW regulations to ensure that an EN is able to accept Ticket assignment from a beneficiary, refer that individual to a VR agency for needed services, and not be required to reimburse the VR agency for those services.

Federal Employment and Training System

- (30) SSA should undertake an analysis of the impact of allowing DOL One-Stop Career Centers to receive cost reimbursement payments for successfully serving beneficiaries under the TTW program.
- (31) Congress should direct SSA and the DOLETA to evaluate the impact of the WIA performance standards on beneficiary participation in WIA programs, and design and test a set of waivers that will assist beneficiaries to access and benefit from WIA core and intensive services, as well as individual training accounts.
- (32) Congress should direct SSA and DOL to evaluate the effect of changing unemployment insurance (UI) policies to all the payment of benefits when combined with vocational rehabilitation or other employment support services, instead of denying UI benefits to individuals who are sick or injured.

Educational System

- (33) Congress should direct SSA to expand the current student earned income exclusion (SEIE) and the Plan for Achieving Self-Support (PASS) to encourage involvement of SSA beneficiaries in postsecondary education and training.
- (34) SSA should work with the Department of Education to ensure that benefits planning and financial management services are available to the transition-aged population.
- (35) Congress should consider a policy change that would disregard all earned income and asset accumulation limits for beneficiaries who are transitioning from secondary education to postsecondary education or employment for at least one year after education or training is completed.

Employers, Business Community, and Private Insurance Industry

- (36) Congress should direct SSA and the IRS to evaluate the possible effects of a disabled worker tax credit as a means of increasing the use of disability management programs in business to prevent progression of injured and disabled workers onto the public disability rolls.
- (37) Congress should direct SSA to collaborate with the Small Business Administration (SBA) and the Rehabilitation Services Administration (RSA) to develop and implement an employer outreach program targeted toward small and mid-size businesses.
- (38) SSA should examine ways to encourage beneficiaries to establish small businesses or microenterprises as an alternative to traditional wage employment.

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Appendix A: Methodology

Introduction

Between July 2004 and March 2005, a comprehensive qualitative research study was conducted under the direction of NCD that (1) examined efforts of the Social Security Administration to implement its SSI and SSDI disability programs; (2) documented philosophical, programmatic, and regulatory obstacles for SSA beneficiaries to return to work; and (3) identified evidence-based practices that promote the return to work of working-age beneficiaries. The final outcome of the study was the compilation of recommendations for policy changes necessary to facilitate the successful implementation of evidence-based practices.

Research Questions

The specific research questions addressed in the study were:

- (1) What are the evidence-based practices that promote the return to work of working-age beneficiaries of the DI and SSI programs?
- (2) What policy changes are needed, given recent trends in program participation and employment?
- (3) Are there proven and documented practices that work best for some populations of people with disabilities and not others?
- (4) Which factors ensure that documented and evidence-based practices could be adapted/adopted by SSA and other entities that seek to ensure the employment of people with disabilities? Which factors prevent adaption/adoption?

Implementation of the Study

A four-step approach was used to implement the study. First, a comprehensive literature synthesis was completed to identify all information of relevance to the proposed study. Second, 34 detailed structured interviews were conducted with key stakeholders, including federal SSA officials, representatives of other federal agencies, consumer and advocacy organization representatives, service organizations, community service providers, and business representatives. Third, NCD and its researchers developed a preliminary list of findings, evidence-based practices, and recommendations based on the literature review and structured interviews through the development of seven topic papers, and then convened a consensus building conference that allowed individuals with disabilities, advocacy organizations, service providers and policymakers to react to and further develop the proposed recommendations. Fourth, was the development of the comprehensive study report. The information which follows describes the methodology used to implement the process used for the study.

Identification of Evidence-Based Practices

The approach to this task involved the development and synthesis of a research database of studies related to return to work for working-age individuals with disabilities. This database includes studies not only of SSA disability beneficiaries, but any individuals whose disabilities are comparable to those of beneficiaries regardless of their SSA status. The rationale for this higher level of inclusiveness is that it will allow identification of evidence-based practices not only for SSI and DI beneficiaries, but also those designed for nonbeneficiaries that may be applicable or adaptable to the SSI and DI populations.

A thorough and comprehensive search of the existing professional literature was conducted through online bibliographic resources, through Social Security and other governmental resources, World Wide Web searches, and direct communications with the research community. Relevant studies were analyzed and recommendations that were made were identified. This research database will be made publicly available to encourage submissions from the field and to enhance the validity of the effort as well as to benefit various constituencies, particularly federal, state and local disability organizations, policymakers and researchers.

Conducting the Literature Search

Keyword and subject index searches. The initial means of searching for research were through databases available through the researcher's university library system, which included the following: (1) Databases of professional journal citations, including educational, rehabilitation, and policy-related journals; (2) the library card catalog; (3) card catalogs for all public universities and most private universities in the Central Virginia area; and (4) databases of Federal Government documents, including the GPO Monthly Catalog, Government Information Resources, and the Government Periodicals Index.

Table 1 provides a partial list of the educational and social services databases available through the library system. Keywords used to search for relevant studies included "Social Security beneficiaries," "disabilities" and "return-to-work/employment/work."

Table 1 Databases Available Online Through the UNIVERSITY Library System	
• ArticleFirst • Arts and Humanities Citation Index • Directory of Electronic Journals • Dissertation Abstracts Online • Education Abstracts • Education Resources Information Center • Expanded Academic ASAP • FirstSearch Databases • General Science Abstracts • Humanities Abstracts • Lexis-Nexis Universe • PubMed/MEDLINE	• netLibrary • Ovid Web Gateway Databases • PAIS: Public Affairs Information Service • PapersFirst Proceedings Index of Conference Papers and Publications • Project MUSE (Johns Hopkins University Press) • PsycINFO Psychological Abstracts • Social Sciences Abstracts • Sociological Abstracts • Web of Science • WebSpirs Databases

Citation searching. An alternative means of searching for specific articles is to search by citation. This method came into play as studies were suggested by the project's consultants and collaborators, and by those in the field. Citation searching involved searching by researcher names, affiliation, publication dates, journal, or title keywords.

Obtaining copies of published research. In order to assess a study's quality and enter it into the database, abstract alone did not suffice and it was necessary to obtain a hard copy or electronic copy of the complete study. For those studies that are identified as potentially useful which are not available through subscriptions or the university library collections, they were obtained through either purchasing directly from the publisher, or using interlibrary loan and journal article retrieval agreements with other universities within Virginia.

Federally funded research and demonstrations. Most federal agencies have one or more offices that support research and demonstration projects through discretionary grants. As a major part of the search effort, employment-focused research studies were sought that related to individuals with disabilities, including Social Security disability recipients (youth and adults) that have been funded through these offices. Attempts were made to obtain final reports or other research summaries.

Fugitive literature. One of the common oversights in research synthesis is de-emphasizing the so-called "fugitive literature." This term denotes material that cannot be located through traditional, commonly used sources (Rosenthal, 1994). Pursuing the fugitive literature serves as an assurance that the literature search has been exhaustive and that all viable studies are included. The methods used to accomplish this objective included Web browsing, Listserv and USENET browsing, and snowball sampling, which involved personal contacts through research

and demonstration projects, state and local educational agencies, university programs, technical assistance providers, and others.

Analysis of the Literature

Once a relevant study was identified, it was analyzed for its relevancy. The purpose, methodology, and results were summarized and recommendations that were made were identified.

Developing the Research Database

A database of research literature related to employment outcomes for individuals with disabilities, including SSI and DI beneficiaries was developed. This includes a summary of the purpose of the study, methodology, results, and recommendations that were made.

Data Management

A Microsoft Access data table was created, containing the following fields:

Record ID	Primary Author
Additional Authors (up to 7)	Year of Publication
Title of Work Cited	Source
Volume	Pages
Citation is from a book (yes or no)	Book Author/Editor
Publisher	City, State
Purpose	Methodology/Sample
Results	Recommendations
Work Cited is nonempirical (yes or no)	Article Availability (URL)

In addition, a user interface was designed for data entry. Each article's analysis came in the form of a Microsoft Word document so that data entry could be conducted in copy/paste fashion. If necessary, the citations were modified to meet ADA formatting standards before entry into the database. Then, components of the analysis were copied and pasted into the appropriate fields. Each analysis was assigned a unique ID in the database, and the Word filename was edited to contain that ID so that each record in the database will be associated with its corresponding physical Word file.

Database Development and Making it Web Accessible. A copy of the Microsoft Access database was put on a Web server and it was registered as a data source with ColdFusion MX. From there, the search engine functionality was built using ColdFusion MX as well as the integrated Verity search tool that ships with ColdFusion MX. Once the search capability was

running, the Web-based forms were built to allow for the adding of new research literature to the database via a Web browser, as well as the editing of existing literature. A Web page was finally constructed to allow users to view a listing of the research in the database, which can be sorted on a number of fields.

User feedback. The database was made accessible to project consultants and collaborators during its development and they were asked to provide input into its development to enhance quality and usefulness. This allowed users to submit or recommend research or publications not listed to be analyzed and added to the database, allowed users to monitor and critique our quality assessments enhances our coding reliability; as well as modify the database in order to enhance its functionality and user-friendliness.

Key Stakeholder Interviews

The research method used for this part of the study consisted of structured telephone interviews with members of eight targeted stakeholder groups. No more than nine interviews using the same questions was used within each of the targeted groups. Table 2 below identifies the affiliations of the stakeholder who participated in the interviews. A total of 55 individuals were identified as key stakeholders by the NCD Employment Team. Of these, 34 individuals were interviewed between October 2004 and January 2005.

TABLE 2 NCD SOCIAL SECURITY STUDY INTERVIEWS COMPLETED KEY STAKEHOLDER AFFILIATION	
Social Security Administration Offices Office of Program Development and Research Office of Employment Support Programs TWWIIA Advisory Panel	
SSA Initiatives State Partnership Initiative (SPI) Projects Protection and Advocacy for Beneficiaries of Social Security (PABSS) Benefits Planning, Assistance, and Outreach (BPAO) Projects Employment Networks Youth Transition Initiative Early Intervention Demonstration Projects	
Federal Partners DOE Office of Special Education and Rehabilitation Services (OSERS) HHS Administration on Developmental Disabilities (ADD)	

State and Regional Offices State Protection & Advocacy Services State Vocational Rehabilitation Agencies Workforce Investment Boards Disability Program Navigators State WIG Grants State MIG Grants Governor’s Committee on Employment of Persons with Disabilities
Consumer Organizations National Council on Independent Living (NCIL) Paralyzed Veterans of America Speaking for Ourselves National Association of People with AIDS American Council of the Blind (ACB) National Federation of the Blind (NFB)
Advocacy Organizations Consortium for Citizens with Disabilities (CCD) American Association of People with Disabilities (AAPD) Association of Persons in Supported Employment (APSE) National Association of the Deaf (NAD) Self Help for Hard of Hearing People (SHHH) National Organization of Social Security Claimants’ Representatives The Arc
Service Organizations National Industries for the Blind (NIB) Goodwill
Business Organizations U.S. Chamber of Commerce

Potential respondents were initially contacted by phone or email by the researchers to solicit their participation. A script of the recruitment is attached. If the potential respondent agreed to be interviewed, the staff person coordinating the interview process made sure that the consent statement, a copy of the designated questions, and a one-page description of the study was sent to them for preview. An appointment time for the telephone interview was then set-up.

Interviews were conducted using a three-way teleconference that included (1) the interviewer, (2) the participant, and (3) a note-taker. The interview began with a re-reading of the verbal

consent statement, and a verbal confirmation from the respondent that he/she consented to be interviewed. The verbal consent statement was sent to each respondent prior to the interview. Using the state teleconference provider, each interview was audio recorded, and participants were appropriately informed that they were being recorded prior to the interview taking place.

After each interview, audio recordings and notes were then summarized by the note taker. Interview summaries were emailed by the interviewer to each respondent, who had the opportunity to edit his or her responses for clarification or to remove potentially risky statements. Only participant-edited summaries and verified comments were made available for analysis.

Data were analyzed descriptively, reviewing the interview summaries and notes to identify themes, commonalities, and patterns of responses. The data were then analyzed within respondent categories and across all respondents. These themes and patterns were then organized and used in the development of the topic papers.

Development of Topic Papers

In December, NCD's researchers developed seven topic papers, also referred to as "white papers," that synthesized the findings from the evidence-based practices reviewed to date with the findings from the interviews with the key stakeholders. These topic papers were distributed to invited participants of the Consensus Validation Conference that was convened in late January in Washington, D.C. The purpose of developing the topic papers was to present a written discussion of key issues that affect the employment of beneficiaries so that invited participants could react to the information and identify additional issues that should be prioritized and included in the study report.

The topic papers were authored by the researchers, consultants, and leading experts on the employment of people with disabilities. The titles of the papers and their authors were:

- **Evidence-Based Practices that Promote Employment of People with Disabilities**
Authors: Gary Bond, Paul Wehman, and David Wittenburg
- **Lessons from the Foreign Experience: How Some Other Countries Deal with the Current United States Barriers to Employment of People with Disabilities**
Author: Ilene Zeitzer
- **SSA's Current Efforts to Implement the Ticket to Work and Work Incentive Improvement Act**
Author: John Kregel
- **Post Eligibility Policies and Procedures: Eliminating Disincentives to Employment in the SSA Benefits Program**
Author: Susan O'Mara, JoAnne Malloy, and Tobey Partch-Davies
- **Early Intervention and Diversion Strategies as a Means for Stemming the Growth in Social Security Disability Programs**
Author: Lucy Miller

- **Public and Private Health Coverage for Social Security Disability Beneficiaries who Work**
Authors: Toni Lee Acevedo, Omar Kahn, and Bryon MacDonald
- **Beneficiary Experiences: Entitlement and Return to Work for Social Security Disability and SSI Beneficiaries**
Author: Terri Uttermohlen

Consensus Validation Conference

NCD and its researchers conducted a Consensus Validation Conference as part of the Social Security Study on January 26, 2005 at the National Press Club in Washington, D.C. Of the 103 invited participants, 69 individuals registered to attend the conference, and 64 researchers, policymakers, service providers and consumers, including former and current SSI and DI beneficiaries, attended the one-day conference. This number does not include the NCD Council Members, staff and the research team who were present.

Proceedings

The agenda for the conference was divided into a number of plenary sessions followed by small group working sessions. There were seven groups, each directly related to the seven topic papers sent out a few days previous to the conference to the participants assigned to each group. Assignment of participants was based on expertise, experience and the desire to have as much diversity in roles in each group as possible.

Each small topic paper group followed the same process with minor modifications being made as accommodations to ensure full participation:

- Identification of key points from the topic paper.
- Identification of findings that should have been in the topic paper but were not.
- Clustering together the identified findings that were similar and assigning a descriptive phrase.
- Voting by each group on the findings in each cluster by coding according to the following color scheme:
 - Red = you agree with the finding and believe that most other individuals in your field would agree as well
 - Green = you agree with a finding but do not necessarily believe it is the consensus of your field
 - Yellow = you agree with the finding but believe it has a long way to go to becoming consensus
 - Leave Blank = you do not agree with the finding

(Note: All findings were read out loud and ranking was done verbally in the small groups for the benefit of participants who had low vision or who were blind.)

After presentation of findings in a plenary session, each individual participant had the opportunity to vote on the single finding, from among all findings, that was felt to be most important. These “consensus findings” were represented by red hearts.

Data Analysis

After the conference, all findings were listed by topic group and categorized according to the cluster in which they were placed. The number of specific codes awarded through **team vote** by group members was recorded as well as whether a particular finding had been prioritized through the **consensus vote** done by all participants. Identification as to whether the finding came directly from the white paper or had been added by the topic group was identified by an asterisk (*).

All findings which received at least one consensus vote were then grouped together according to topic group and according to its assigned cluster. After examination of the findings, themes began to emerge and coding was again used for grouping purposes.

Results

The themes that emerge from the analysis of the consensus validation conference data fall into four trends:

- **Definition of Disability.** There was much diversity in how the small groups identified the issue of definition of disability. Discussion ranged from how the current definition differs from an international perspective of work incapacity to the presumption made by the current definition that beneficiaries have the inability to work. No recommendations were made as to what the definition of disability should be.
- **Coordination/Collaboration Among Systems.** Increased coordination and communication across federal Agencies for policy alignment was discussed. Also identified was the need for SSA to increase coordination with Vocational Rehabilitation Services and employers at all levels within the framework of the Ticket to Work programs.
- **Beneficiary Focus and Control.** Discussion focused on the need for increased individual planning and choice with work incentives. Improved customer focus and simplification of rules that directly affect beneficiaries were recommended.
- **Income Issues and Incentives.** This area was approached in small group discussions at both the systems and individual beneficiary levels. Recommendations were made for specific change to individual incentives, but also recommendations by a number of small groups were made for a comprehensive approach to policy change that would allow for increased earnings without the current penalties encountered by beneficiaries.

All trends but the “Definition of Disability” have a research base as identified in one or more of the topic papers. The strength in the number of participants who identified “Definition of Disability” was unexpected, but is explored in the study report.

Next Steps

NCD has taken the findings from the consensus validation conference and triangulated them with the information obtained from the key stakeholder interviews, the recommendations emanating from the topic papers, and any additional findings from the continuing literature search on evidenced based practices and has used them in the development of the final study report.

Use of NCD Employment Team for Advice and Feedback

Throughout the study's implementation process, there were at least monthly contacts made between the researchers and the NCD Employment Team. The feedback received from Team members and staff was invaluable for the implementation of the study. A monthly conference call was held with the Employment Team, and communication occurred with NCD staff multiple times in any given week.

It was the researcher's intent to include the Employment Team in every step of the study's process so that Team members were fully aware of any issues that were encountered and could provide advice in how to address any issues that were encountered. This proved to be especially helpful in addressing concerns that arose from SSA during the key stakeholder interview phase of the study. Also Team members provided names and contact information of a number of key stakeholders who were interviewed as part of the study.

Appendix B: Results of Literature Review to Identify Evidence-Based Practices

Topic Papers Used for Discussion at the Consensus Validation Conference

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Results of the Literature Review

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Balkus, R., and S. Wilschke. (2003/2004). "Annual wage trends for Supplemental Security Income recipients." *Social Security Bulletin* 65 (2): 51–53.

Barnhart, J.A. (2003). Hearing on the Social Security Administration's Management of the Office of Hearings and Appeals, September 25, 2003. Retrieved May 27, 2005, from www.ssa.gov/legislation/testimony_092503.html.

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Appendix C: Mission of the National Council on Disability

Overview and purpose

The National Council on Disability (NCD) is an independent federal agency with 15 members appointed by the President of the United States and confirmed by the U.S. Senate. The purpose of NCD is to promote policies, programs, practices, and procedures that guarantee equal opportunity for all individuals with disabilities regardless of the nature or significance of the disability and to empower individuals with disabilities to achieve economic self-sufficiency, independent living, and inclusion and integration into all aspects of society.

Specific duties

The current statutory mandate of NCD includes the following:

- Reviewing and evaluating, on a continuing basis, policies, programs, practices, and procedures concerning individuals with disabilities conducted or assisted by federal departments and agencies, including programs established or assisted under the Rehabilitation Act of 1973, as amended, or under the Developmental Disabilities Assistance and Bill of Rights Act, as well as all statutes and regulations pertaining to federal programs that assist such individuals with disabilities, to assess the effectiveness of such policies, programs, practices, procedures, statutes, and regulations in meeting the needs of individuals with disabilities.
- Reviewing and evaluating, on a continuing basis, new and emerging disability policy issues affecting individuals with disabilities in the Federal Government, at the state and local government levels, and in the private sector, including the need for and coordination of adult services, access to personal assistance services, school reform efforts and the impact of such efforts on individuals with disabilities, access to health care, and policies that act as disincentives for individuals to seek and retain employment.
- Making recommendations to the President, Congress, the Secretary of Education, the director of the National Institute on Disability and Rehabilitation Research, and other officials of federal agencies about ways to better promote equal opportunity, economic self-sufficiency, independent living, and inclusion and integration into all aspects of society for Americans with disabilities.
- Providing Congress, on a continuing basis, with advice, recommendations, legislative proposals, and any additional information that NCD or Congress deems appropriate.
- Gathering information about the implementation, effectiveness, and impact of the Americans with Disabilities Act of 1990 (ADA) (42 U.S.C. § 12101 et seq.).
- Advising the President, Congress, the commissioner of the Rehabilitation Services Administration, the assistant secretary for Special Education and Rehabilitative Services within the Department of Education, and the director of the National Institute on Disability and Rehabilitation Research on the development of the programs to be carried out under the Rehabilitation Act of 1973, as amended.

- Providing advice to the commissioner of the Rehabilitation Services Administration with respect to the policies and conduct of the administration.
- Making recommendations to the director of the National Institute on Disability and Rehabilitation Research on ways to improve research, service, administration, and the collection, dissemination, and implementation of research findings affecting people with disabilities.
- Providing advice regarding priorities for the activities of the Interagency Disability Coordinating Council and reviewing the recommendations of this council for legislative and administrative changes to ensure that such recommendations are consistent with NCD's purpose of promoting the full integration, independence, and productivity of individuals with disabilities.
- Preparing and submitting to the President and Congress an annual report titled *National Disability Policy: A Progress Report*.

International

In 1995, NCD was designated by the Department of State to be the U.S. government's official contact point for disability issues. Specifically, NCD interacts with the special rapporteur of the United Nations Commission for Social Development on disability matters.

Consumers served and current activities

Although many government agencies deal with issues and programs affecting people with disabilities, NCD is the only federal agency charged with addressing, analyzing, and making recommendations on issues of public policy that affect people with disabilities regardless of age, disability type, perceived employment potential, economic need, specific functional ability, veteran status, or other individual circumstance. NCD recognizes its unique opportunity to facilitate independent living, community integration, and employment opportunities for people with disabilities by ensuring an informed and coordinated approach to addressing the concerns of people with disabilities and eliminating barriers to their active participation in community and family life.

NCD plays a major role in developing disability policy in America. In fact, NCD originally proposed what eventually became ADA. NCD's present list of key issues includes improving personal assistance services, promoting health care reform, including students with disabilities in high-quality programs in typical neighborhood schools, promoting equal employment and community housing opportunities, monitoring the implementation of ADA, improving assistive technology, and ensuring that people with disabilities who are members of diverse cultures fully participate in society.

Statutory history

NCD was established in 1978 as an advisory board within the Department of Education (P.L. 95-602). The Rehabilitation Act Amendments of 1984 (P.L. 98-221) transformed NCD into an independent agency.

National Council on Disability
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