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# Bridging Silos, Part II: DI, SSI, Medicare, and Medicaid Issues and Initiatives

Karen Matherlee, Consultant

**OVERVIEW** — The second of two papers on the general topic of public disability and health benefits, this background paper lays out some key issues confronting the Social Security Disability Insurance, Supplemental Security Income, Medicare, and Medicaid programs. It also discusses major initiatives to address those issues, in light of growing administrative, fiscal, and other problems. (The first paper, "Bridging Silos, Part I," addresses the linkages among the DI, SSI, Medicare, and Medicaid programs and the effects on the programs of the Ticket to Work and Work Incentives Improvement Act of 1999 and other legislation.)



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National Health Policy Forum 2131 K Street NW, Suite 500

Washington DC 20037

202/872-1390

202/862-9837 [fax]

nhpf@gwu.edu [e-mail] www.nhpf.org [web]

**Judith Miller Jones** *Director* 

Judith D. Moore

Co-Director

**Sally Coberly** *Deputy Director* 

Michele Black

Publications Director

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# Bridging Silos, Part II: DI, SSI, Medicare, and Medicaid Issues and Initiatives

The interlinked Social Security Disability Insurance (DI), Supplemental Security Income (SSI), Medicare, and Medicaid programs raise numerous policy issues, among them the four programs' current and future solvency, the administrative challenges of running the complex and intricate DI and SSI programs, the barriers to shifting disability beneficiaries from income support to the world of work, and the significant differences between the Medicare and Medicaid (as well as among individual state Medicaid) programs.

In striving to address these issues, the federal and state governments, while generally striving for coordination and cooperation, often have competing interests, particularly in terms of who, at times, foots the bill. Because of the uneven way in which the four programs were established and have evolved over time, administering them for growing numbers of beneficiaries is daunting for the public agencies who operate them and frustrating for the recipients they serve. While various initiatives are in process to make the programs more effective—or to experiment with making them work better—the jury is still out on whether the efforts will be successful.

# PROGRAM SOLVENCY: MAKING SURE THE MONEY IS THERE

Budget realities cast a shadow over federal and state initiatives for persons with disabilities who receive DI, SSI, Medicare, and/or Medicaid, although the shadow is longer for some than for others. In terms of the DI program, the Old-Age and Survivors Disability Insurance (OASDI) trustees say that, within the next 10 years, the OASI and DI trust funds will have adequate funding (that is, equity between assets and projected outgo for a given year). In the long term, however, the trustees expect the OASDI cost rate to exceed the income rate for the first time around 2018. In contrast, the SSI program, dependent upon general revenues, is expected to show modest growth during the rest of this decade and the next two decades. Federal expenditures are projected to increase by about 1.1 percent per year through 2027.

For Medicare, the 2003 combined trustees' annual report of Medicare HI (Hospital Insurance) and SMI (Supplemental Medical Insurance) presents different projections, because HI (Part A) is based on a payroll tax and

SMI (Part B) is dependent upon general revenues and beneficiary premiums. The HI trustees indicate that HI meets the financial adequacy test in the short term. However, in the long term, they are pessimistic.

The HI cost rate is projected to exceed the income rate by a rapidly growing margin after 2012. By the end of the 75-year period, HI costs would be more than three times the level of scheduled tax revenues—a very substantial deficit by any standard.<sup>3</sup>

The trustees expect SMI income and expenditures to increase at an average annual rate of about 7 percent through 2012. In the long term, "annual SMI expenditures would grow from about 1 percent of gross domestic product (GDP) in 2002 to 2 percent of GDP within 25 years and to more than 4 percent" by the end of 75 years.<sup>4</sup>

Medicaid, funded by the states with federal matching dollars, seems particularly vulnerable at a time of rising state and federal budget deficits. Although states received \$20 billion "extra" in federal money—half of it slated for Medicaid—as a result of 2003 federal tax-cut legislation, the National Conference of Legislatures indicates that states face "a collective \$53.5 billion budget gap for FY 2004."<sup>5</sup> A state fiscal survey conducted by the National Governors Association and the National Association of State Budget Officers shows that 37 states reduced budgets they had already enacted by nearly \$14.5 billion in 2003, the largest spending cut in the 27-year-old survey's history. Medicaid was singled out as exerting "severe strain on state budgets," with 28 states anticipating "Medicaid shortfalls in the current fiscal year." The organizations conclude that increasing costs for pharmaceuticals and rising enrollments in the program mean that states will have to cover fewer people.6 States have a strong stake in the outcome of current congressional efforts to enact a Medicare prescription drug benefit, in terms of the potential shift of pharmaceutical costs from Medicaid to the Medicare program for "dual eligibles" (those who are eligible for both programs).

# ADMINISTRATIVE CHALLENGES: MAKING THE DISABILITY PROGRAMS WORK

DI and SSI are experiencing significant administrative problems, both individually and through their linkages to Medicare and Medicaid, and strenuous efforts are under way to address them. In administering DI and SSI, the Social Security Administration (SSA) indicated early this year that it is committed "to identifying process and systems improvements, implementing needed changes, and increasing agency efficiency."<sup>7</sup> Its major initiatives include improving employment supports and outreach, making progress on claims processing and appeals, and reducing overpayments, all of which have some bearing on beneficiaries' access to and use of Medicare and Medicaid benefits.

The president's 2004 budget proposal assumes that SSA will administer a \$535 billion operation with administrative expenses at less than 2 percent

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of its total outlays. The budget reflects "an increase of 7.5 percent over the FY 2003 President's budget." SSA's goal is to improve its productivity by at least 2 percent a year. Although DI and SSI benefits account for less than 20 percent of SSA's total benefit payments, the two programs consume nearly 55 percent of SSA's annual administrative resources, so the agency's staff effort is considerable.

#### **Disability Program Modernization**

The General Accounting Office (GAO) has done a series of reports on the administrative challenges SSA faces in addressing program complexities, responding to applicants and recipients in a more timely way, and improving service delivery, among other issues. GAO, in a comprehensive report issued in January 2003, *Major Management Challenges and Program Risks*, comments on the rapid growth of both DI and SSI and adds modernizing the two programs to its 2003 high-risk list.<sup>10</sup> (GAO has a performance and accountability series on federal departments, agencies, and the U.S. Postal Service that looks at their capacities and capabilities for transforming government operations and addressing fiscal needs. Those at high risk are particularly vulnerable to fraud, abuse, waste, and mismanagement are are challenged relative to economics, efficiency, and effectiveness.)

In GAO's view, SSI "poses a special challenge for SSA because, unlike DI, it is a means-tested program" that requires the agency to "collect and verify information on income, resources, and recipient living arrangements" not only to determine initial eligibility but also to monitor continuing eligibility for benefits. <sup>11</sup> GAO is concerned about the SSI program's living arrangement and in-kind support and maintenance policies, which it considers to be "complex, prone to error, and a major source of overpayments." GAO also recognizes the challenge to SSA of balancing prompt decision-making with protection against fraud and abuse.

GAO, in urging SSA to adopt several reforms to update its disability programs, indicates that the statutory and regulatory design of the programs is outmoded and that the programs do not reflect current theories on the relationship between disability and the ability to work. Moreover, GAO sees SSA as struggling "to provide timely and consistent disability decisions to program applicants." The agency has recommended that SSA update the criteria used to evaluate disability claims to reflect not only medical advances but also changes in the labor market relative to work skills and work settings.<sup>13</sup>

# **Dramatically Increasing Workload**

In the long term, service delivery looms as a special problem for SSA, as baby boomers, born between 1946 and 1964, enter their so-called disability-prone years. Even now, the agency seems to be overwhelmed by the sheer number of applicants. SSA estimates that, overall, the number of

GAO indicates that the statutory and regulatory design of SSA disability programs is outmoded.

persons applying for disability benefits increased by 22 percent between 1999 and 2004 and will continue to rise dramatically due to the aging of the population.

Even as SSA experiences a dramatically increased workload, it will incur significant turnover in its workforce. The agency is predicting that 37 percent of its employees will retire by 2010, with a higher percentage of retirees—more than 70 percent—at the supervisory or managerial levels. The turnover will be exacerbated by technological, cross-cultural competency, and other demands on SSA staff.<sup>14</sup>

Former Rep. Hal Daub (R-NE), chairman of the Social Security Advisory Board, summarized SSA's administrative challenges for the House Ways and Means Committee Social Security Subcommittee last year:

In recent decades, disability policy has come to resemble a mosaic, pieced together in response to court decisions and other external pressures, rather than the result of a well-thought-out concept of how the programs should be operating. Compounding the problem, the disability administrative structure, now nearly a half century old, has been unable to keep pace with the increasing demands that have been imposed upon it. Policy and administrative capacity are dramatically out of alignment in the sense that new and binding rules of adjudication frequently cannot be implemented in a reasonable manner, particularly in view of the resources that are currently available. <sup>15</sup>

## **Sluggish Claims and Appeals Processes**

The DI and SSI disability claims and appeals processes draw numerous complaints from consumers and commentators alike, with SSA Commissioner Jo Anne Barnhart admitting that the agency has "a long way to go to provide the kind of service the American people expect." Applicants whose claims are denied, whether at the initial level or for reconsideration, have the right to appeal to an administrative law judge and to the SSA Appeals Council. According to Barnhart, SSA had 593,000 initial disability claims pending at the end of 2002 and reduced them to 15,000 by July 2003; the agency took an average of 447 days in 2001 to get a decision on a hearing appeal, as opposed to 259 days by July 2003. Holdups tend to be due to backlogs, waits for additional evidence, and applicant delays. The Social Security Advisory Board has a series of graphs on disability decision-making that includes percentages of beneficiaries' successful appeals at each level.

While SSA disability decisions draw considerable complaints about the "modernity" of the agency's definition of disability for adults—objections that increased as a result of passage of the Americans with Disabilities Act of 1990—there are also criticisms regarding the decisions' consistency and fairness. The state agencies that make the initial determinations vary significantly in the claims they allow. According to Daub, "in 2001, the percentage of disability applicants whose claims were allowed by a state

agency ranged from a high of 66 percent in New Hampshire to a low of 27 percent in Tennessee." The advisability of federalizing the disability determination process has been debated for years. <sup>20</sup> The links between eligibility for the cash payment programs and eligibility for Medicare and/or Medicaid make the variance even more inequitable, according to some critics.

While SSA has sought to address the complex, multilayered, and slow decision-making apparatus that characterizes the disability determination and appeals process, it acknowledges that it needs to step up its efforts. According to GAO, "In some cases, the plans were too large and too complex to keep on track, and the results of many of the initiatives that were tested fell far short of expectations." SSA currently is administering a demonstration program, known as Prototype, to test modifications in the disability determination process in 10 states. The agency made some midcourse corrections in the program after early data showed the program would not only boost the number of initially correct awards, but also increase the number of appeals on claims that were denied.<sup>21</sup>

### **Protection against Overpayments**

SSA has two ways of helping ensure that only eligible persons receive DI and SSI benefits and that the benefits are in the correct amounts. For both programs, as already indicated, SSA conducts continuing disability reviews, a check "that only those who continue to have disabilities continue receiving benefits." For SSI only, the agency conducts SSI nondisability redeterminations, a check on whether recipients continue "to meet the financial eligibility requirements" or have experienced a change of circumstances that would affect their monthly benefit amounts.

For example, youth receiving SSI benefits must undergo redetermination at the age of 18 and qualify based on adult criteria, while adults may be reviewed any time between three months and six years after eligibility is determined. The process consists of written notification by the person's local Social Security field office that redetermination is under way, an interview at the field office (with forms completed on the person's disability and functioning and permission sought to interview providers, teachers, and others familiar with individual cases), and review by the state Disability Determination Service of the severity of disability and ability to work.<sup>22</sup> For every \$1 spent on continuing disability reviews, the agency receives about \$9 in savings; for every \$1 spent on SSI redeterminations, it recoups approximately \$7.<sup>23</sup>

The Foster Care Independence Act of 1999 gave SSA added authority to combat SSI overpayments. The legislation provided SSA with

additional tools to obtain applicant income and resource information from financial institutions; impose[d] a period of ineligibility for applicants who transfer assets to qualify for SSI benefits; and authorize[d] the use of

credit bureaus, private collection agencies, interest levies, and other means to recover overpayments. SSA also obtained separate legislative authority in 1998 to recover overpayments from former SSI recipients who currently receive OASI or DI benefits and has recently begun the process of recovering overpayments from Social Security benefits of individuals no longer on the SSI rolls.<sup>24</sup>

In addition, SSA has undertaken some internal steps, such as using tax refund offsets to collect SSI overpayments; utilizing data maintained by the Office of Child Support Enforcement to check wage, hire, and unemployment insurance data; and matching data on SSI recipients in nursing homes and other institutions.<sup>25</sup> SSA also is in the process of putting in place an SSI corrective action plan that involves preventing overpayments due to unreported wages and assets. For example, prior to starting payments, the agency will review at least 50 percent of favorable SSI disability decisions.

#### **Piloting of Electronic Claims Process and Other Strategies**

SSA's largely paper-driven claims process will begin to move to electronic processing in January 2004. SSA plans to start by implementing an electronic claims intake pilot program in one of its regions. It aims to enhance claims processing at state disabilities determination service agencies and support hearing and appeals processing operations. Under the electronic system, SSA would like each applicant eventually to have an electronic folder that can transmit data from one site to another.<sup>26</sup>

SSA is also seeking to reduce average case processing time and the backlog of cases that is waiting to be processed. Some of the short-term strategies adopted include "new formats and software to facilitate the issuance of favorable decisions, guidelines for the issuance of favorable bench decisions, and awarding of contracts to speed the assembly of hearing files." Faced with a backlog of continuing disability reviews for beneficiaries already receiving disability benefits, the agency has opted instead to put more emphasis on initial applications. <sup>28</sup>

SSA has indicated that, in adopting an electronic claims process, it should become more efficient. In its FY 2004 budget overview, the agency says that it "will recommend and implement strategies during the next two years to significantly improve the disability claims process." It also states that it is exploring "ways to improve the accuracy rate of hearing decisions." However, it expects the accuracy level to remain level for the time being.<sup>29</sup>

Prior to FY 2004, SSA was responsible for Medicare administrative law judge hearings for persons with disabilities. However, the Medicare Regulatory and Contract Reform Act of 2001 transferred the responsibility to the Department of Health and Human Services (DHHS) effective no sooner than July 1, 2003, and no later than October 1, 2003. While this lightens the administrative load of SSA, it can involve coordination and communication problems.

SSA's largely paperdriven claims process will begin to move to electronic processing in January 2004.

# EMPLOYMENT SUPPORT AND OUTREACH: TESTING THE CONCEPT

There is little doubt that the federal government would like to reduce its disability and health care rolls by providing incentives for persons with disabilities to work, and SSA has a large stake in the eventual success of the Ticket to Work and Work Incentives Improvement Act of 1999 (TWWIIA) provisions that the agency is developing. (See "Bridging Silos, Part I," for a description of TWWIIA.) Success depends, however, upon various factors, not the least of which is the marketplace's receptivity to and accommodation of persons with disabilities.

**Recognition of Infrastructure Barriers** 

Under contract to DHHS, the Urban Institute in 2001 completed a report on persons with disabilities and employment. Entitled *Barriers to and Supports for Work among Adults with Disabilities: Results from the National Health Interview Survey—Disability*, the report looked at how government programs can better support the 11.3 million working-age adults with disabilities and what the differences are between the 37 percent of adults with disabilities who are working and those who are not. (Rather than following the SSA's definition of ability to engage in substantial gainful activity, the survey relied on "self-reports of specific activity limitations, supplemented by difficulty seeing or hearing or mobility limitations.") The report focused on job search, work accommodation, and access to and use of transportation. Its findings were, as follows:

- Difficulties in looking for work are widespread, encountered by more than half of non-working adults with disabilities.
- One-third of non-workers report needing some type of accommodation to work.
- While a greater proportion of non-workers need accommodations than workers, the types of accommodations most frequently needed are similar.
- Overall, need for accommodations limits employment prospects among adults with disabilities.
- Although public transportation and special transit systems are widely available, use among adults with disabilities is low.
- $\blacksquare$  Low use of transit systems is for the most part not because of health or disability-related reasons.  $^{30}$

TWWIIA, enacted before release of the Urban Institute study, contained provisions to establish infrastructure to support employment and return-to-work initiatives, so that states would be able to set up necessary systems to implement the law's provisions. For example, the statute provided for a Medicaid infrastructure grant program, underwriting funds for states to build critical intergovernmental and public-private partnerships. The partnerships, described in Part I, have been undertaken in 36 states to address problems such as those identified by the Urban Institute.

SSA has a large stake in the eventual success of the TWWIIA provisions that the agency is developing.

#### **Attempts to Overcome Employment Barriers**

To help DI and SSI recipients overcome barriers that may prevent them from working, SSA offers specific employment supports to recipients in both the DI and SSI programs, to recipients of DI only, and to recipients of SSI only. These supports appear in Table 1. Several of the programs included in Table 1 are demonstration programs being conducted by SSA. For example, the Disability Program Navigator, undertaken in conjunction with the Department of Labor (DOL) for both DI and SSI recipients, is designed to facilitate workforce participation. Now winding down, the demonstration has provided resources to One-Stop Career Centers to help persons with disabilities gain access to services to facilitate their entry or reentry into the workforce. Services include transportation, housing, health care, and assistive technologies.

Another program, conducted in cooperation with DOL, the Department of Education's Rehabilitation Services Administration, and DHHS' Center for Mental Health Services, is the State Partnership Initiative. The project, now entering the evaluation stage, has funded 12 states to develop innovative ways of helping persons with disabilities enter or reenter the workforce.

For DI applicants, the Early Intervention Project is getting under way to offer various kinds of assistance, including cash and health benefits as well as employment supports. These are designed to help them return to work and thereby prevent their future dependence upon government programs.

For DI recipients in danger of losing their entire benefit as a result of work earnings, there is a "two for one" sliding-scale benefit offset program that is intended to reduce, but not eliminate, the benefit according to an offset formula. The purpose of the demonstration, mandated by TWWIIA, is to see if DI recipients might accept a reduction in their benefits as an incentive to work, with the fluctuating benefit supplementing their perhaps unpredictable earnings.

Finally, for youth who receive or are likely to receive SSI benefits, a Youth Transition Process Strategy demonstration involves aiding young people ages 14 to 25 to transition from SSI benefits to work. It also provides incentives for youth under 18 who are likely to become eligible for SSI at 18 to pursue further education or gainful employment instead.

## **Research and Survey Initiatives**

In addition, SSA is involved in several research and survey efforts:

■ The Disability Research Institute—A partnership between SSA and the University of Illinois at Urbana-Champaign, the institute is engaged in research, information exchange, training and education, and facilitation of data usage. It is primarily focusing on advancements in technology, work requirements, and the DI and SSI programs and persons with disabilities.

# TABLE 1 Employment Supports for DI and SSI Recipients

#### **Both DI and SSI Recipients**

- Impairment-related work expenses (e.g., attendant care services and medical devices)—deductions of engaging in substantial gainful activity.
- Subsidy and special conditions—supports received on the job.
- Unincurred business expenses for selfemployed persons with disabilities contribution to self-employment effort by someone else, deducted from earnings when substantial gainful activity decision made.
- Unsuccessful work attempt—effort to do substantial work stopped or below substantial gainful activity level after six months or less due to impairment or removal of special conditions, with earnings not counted.
- Continued payment under a vocational rehabilitation program (known as Section 301)—even with medical improvement in disabling condition, continuation of benefits until vocational rehab program ends.
- Disability program navigators\*—establishment of navigators in one-stop career centers in selected states to facilitate access to programs and services that affect workforce success, such as housing, transportation, health care, and assistive technologies.
- State partnership initiative\*—cooperative agreements with 12 states to develop innovative projects to assist persons with disabilities to enter or reenter the workforce.



#### **Recipients of DI Only**

- Trial work period—test of ability to work for at least nine months.
- Extended period of eligibility—automatic start-up of benefits stopped because of work at substantial gainful activity level.
- Continuation of Medicare coverage—93 consecutive months of Medicare Part A and B for people who work, even if cash benefits end.
- Medicare for people with disabilities who work—option to buy continued Medicare coverage if premium-free coverage ends. (Medicaid may pay premiums for some people with low incomes and limited resources.)
- Early intervention project\*
  —job training, placement, and referral demonstration in WI, NM, and VT and later in other states providing one-year cash stipend, three years of Medicare benefits, and access to state Medicaid buy-ins to

encourage recipients to realize full employment potential.

■ Sliding scale benefit offset\* test of a benefit offset under which normal disability benefits would be reduced by a certain amount for each amount earned above a threshold, such as the substantial gainful employment amount.

#### **Recipients of SSI Only**

- Earned income exclusion—most of earned income not counted in figuring SSI benefit.
- ■Student-earned income exclusion—for students under age 22 and not married or head of household, monthly exclusion of \$1,340 (up to \$5,410 annually).
- ■Blind work expenses (such as service animal, transportation to and from work)—earned income to meet expenses not counted in deciding SSI eligibility and payment amount.
- Plan for achieving self-support (PASS)—permission to set aside income and/or resources for a specified time for a work goal.
- Property essential to selfsupport—some resources essential to means of self-support not counted toward SSI eligibility.
- ■Special SSI payments for people who work (Section

- 1619[a])—eligibility for SSI cash payments, even if earned income is at substantial gainful activity level.
- Special benefits for people eligible under Section 1619 (a) or (b) who enter a medical treatment facility—SSI cash benefit for up to two months while in a Medicaid facility or public medical or psychiatric facility.
- Reinstatement of eligibility without a new application—start-up of SSI cash payments and/or Medicaid coverage if ineligible for SSI benefit for 12 months or less for any reason other than medical recovery.
- Youth transition demonstration\*—design, implementation, and evaluation of approaches to improve the transition from school to work of youth ages 14–25 who receive SSI benefits and of youth under 18 who are likely to become elibible for SSI benefits at age 18.

Source: Social Security Administration, 2003 Red Book.

<sup>\*</sup>Demonstration project.

- Mental Health Treatment Study—Given dramatic growth in the numbers of persons with mental illness on the DI and SSI rolls, a study is just getting under way to explore the effects of better access to treatment and rehabilitation services on medical recovery and functioning as well as employment and receipt of disability benefits.
- National Survey of SSI Children and Families—This initiative involves the collection of data on children and young adults who currently are or have been SSI recipients. It includes data on SSI experience, disability and health status, use of health care resources, health insurance coverage, out-of-pocket health care expenditures, education and training, service utilization and costs, employment, income, assets, child care, housing, and transportation. Once the survey is completed, SSA would like to undertake a second survey of the same population.
- Current Population Survey Supplement on Disability—A supplement to the current population survey sponsored by the Bureau of Labor Statistics since 1940, the disability survey is projected for 2004. It would focus on disability in the adult population, looking at prevalence, type, and duration of disability and linking disability to employment data.
- Evaluation of the TWWIIA program—A five-year evaluation is under way, with annual reports projected on the TWWIIA process, program participation, effects and outcomes for participants, beneficiary satisfaction, and adequacy of provider incentives under the program.

#### **GAO's Assessment of Progress**

Because SSA faces numerous barriers in seeking to implement the TWWIIA program, it is no surprise that GAO, in an initial assessment, was negative about its progress:

The ADA supports the premise that people with disabilities can work and have the right to work, and [TWWIIA]...increased beneficiaries' access to vocational services. Indeed, many beneficiaries with disabilities indicate that they want to work, and many may be able to work in today's labor market if they receive needed support. In 1996, we recommended that SSA place a greater priority on helping disabled beneficiaries work, and the agency has taken a number of actions to improve its return-towork practices. But even with these actions, SSA has achieved poor results in this arena and few DI and SSI beneficiaries leave the disability rolls to work.<sup>31</sup>

Two programmatic reasons for the poor results, GAO points out, are eligibility determination wait times and "an either-or disability decision-making process that characterizes individuals as either unable to work or having the capacity to work." The latter reflects members of the disability community's continued frustrations with programs based on an either-or situation: either a person cannot work and therefore is eligible to receive benefits or the person can work and loses or is at risk of losing

benefits. The need for personal care services seems to be at the heart of the frustrations. While TWWIIA strives to address consumer dissatisfaction, achieving an appropriate array of employment supports and other benefits is a tremendous challenge.

At about the same time, GAO reported on the results of a study—required by the TWWIIA legislation—on employer incentives to hire workers with disabilities. Specifically, GAO examined use of a work opportunity tax credit and a disabled access tax credit. GAO concluded, on the basis of Internal Revenue Service data, that few employers used the tax credits to hire, retain, or accommodate workers with disabilities.<sup>33</sup>

#### Tension in the Marketplace

In a U.S. economy characterized by relatively high unemployment—regardless of job-seekers' disability status—making inroads is a daunting task. Important, too, is the diversity of those with disabilities: whether they are seeking employment for the first time, whether they are reentering the job market after a period of disability, or whether they have incurred disability while employed.

An example of the challenge in the private marketplace is reflected by a recent survey of employer attitudes to persons who incur disability while on the job. (The results of the survey were widely criticized in the business community.) The survey, conducted by Mercer Human Resource Consulting, involved 723 companies and was featured in the *Wall Street Journal* in July. It indicated that 27 percent of the companies "dismiss employees as soon as they go on long-term disability and that 24 percent dismiss them at a set time thereafter, usually six to 12 months." Only 15 percent of the companies retained (with benefits) employees with disabilities until the employees reached age 65.<sup>34</sup>

An example of the challenge in the public marketplace is reflected in the potential effects of the Bush administration's competitive sourcing initiative on federal employees with disabilities. In 2000, according to the Office of Personnel Management, more than 120,000 persons with disabilities over 7 percent of the workforce—were employees of the federal government. The initiative targets 434,820 jobs, of which 103,412 are under evaluation for possible outsourcing. In one case, scullery workers—all with mental retardation—at the National Naval Medical Center in Bethesda, Maryland, are at risk of losing their jobs unless it is proved—in competing in-house and outsourced bids—that they can do them more effectively and more cheaply than a private contractor. They got the jobs on a provisional basis and became permanent employees after two years of satisfactory performance. The parent of one employee commented to the Washington Post: "Even a White House focused on the bottom line should realize there is little to be gained by contracting out the work. Displaced employees would turn to government entitlement programs, including federal disability payments, Medicaid, and food stamps."35 This anecdote illustrates the tension While TWWIIA strives to address consumer dissatisfaction, providing appropriate employment supports is a tremendous challenge. the federal government faces in implementing employment policies with different goals: on one hand, privatization of jobs, and, on the other, employment of persons with disabilities.

Virginia Commonwealth University's Rehabilitation Research and Training Center maintains an ongoing review of initiatives regarding employer attitudes towards hiring, retaining, and promoting people with disabilities. Its work is contained in the "E-Newsletter: RRTC on Workplace Supports," which can be accessed online.<sup>36</sup>

## MEDICARE AND MEDICAID: ALIGNING DISPARATE PROGRAMS

#### **Program Differences**

Medicare and Medicaid not only have different eligibility requirements but they also have different benefit packages, variations that have great bearing for persons with disabilities. Medicare, as a federal insurance program for eligible persons 65 and older and for younger persons with disabilities who generally have completed a two-year waiting period to qualify for benefits,<sup>37</sup> is oriented to inpatient and ambulatory care, but not long-term services and supports. Moreover, it lacks an outpatient prescription drug benefit, although provision of a benefit is now the subject of a House-Senate conference committee.

Medicaid, as a federal-state program for certain persons and families with low incomes and resources,<sup>38</sup> is obliged to provide medical assistance for certain basic services to most categorically eligible populations. Like Medicare, Medicaid provides inpatient and outpatient services; however, unlike Medicare, Medicaid provides long-term services (in institutional, community, and home settings). A state Medicaid plan may also offer various optional services, chosen from 34 defined by federal statute (with an outpatient prescription drug benefit being a prominent example). Whether the benefits are mandated or optional, states can receive federal matching funds for providing them to beneficiaries.

## **Pathways to Eligibility**

While most persons with disabilities who are on Medicaid have qualified because they are SSI recipients, there are other pathways to eligibility, including Medicaid buy-in. Children with disabilities (as well as those without disabilities), for instance, may receive Medicaid if they are otherwise eligible and in foster care or have special needs and have been adopted (and meet other criteria). In an online publication called "Medicaid Eligibility," the Kaiser Commission on Medicaid and the Uninsured has laid out the various pathways for both children and adults with disabilities to gain eligibility in the program.<sup>39</sup>

The differences in Medicare's and Medicaid's eligibility requirements and benefit packages have great bearing for persons with disabilities.

Medicaid beneficiaries with disabilities are a diverse group ranging in age from very young children to older adults. ... About 50 percent of Medicaid disabled adults have some type of physical impairment or limitation, a quarter have some type of functional limitation on activities of daily living (instrumental or non-instrumental), and almost 40 percent have severe mental symptoms or disorders. (These groupings of disability are not mutually exclusive.)<sup>40</sup>

As discussed in Part I in "The Dual-Eligible Medicare-Medicaid Linkage," the different benefit and eligibility structures have resulted in some persons with disabilities who are Medicare-eligible having full Medicaid benefits, others having supplemental Medicaid benefits, and still others, of course, having no Medicaid benefits because they do not meet state income and asset tests. Through state Medicare access programs, those who qualify for supplemental Medicaid benefits are served through programs targeted at qualified Medicare beneficiaries, or QMBs; specified low-income Medicare beneficiaries, or SLMBs; qualifying individuals, or QIs; and qualified disabled and working individuals, or QDWIs; as well as by separate buy-in programs.

#### **Provision of Nonmedical Services: A Key Factor**

Many persons with disabilities indicate that personal assistance services are vital to their well-being, whether in basic functioning, living independently, and/or being employed. DOL defines such services in this way:

People or devices that assist a person with a physical, sensory, mental, or cognitive disability with tasks that the person would perform for himself or herself if he or she did not have a disability. In general, these may include assistance with dressing, bathing, eating, toileting, and cognitive tasks such as handling money or facilitating communications access with a reader or an interpreter.<sup>41</sup>

Twenty-five states offer personal assistance services through Medicaid state plan options and virtually all of them provide personal assistance services or something very close to such services through home- and community-based waivers. Three states recently enhanced their personal assistance services benefit to target it to employment.<sup>42</sup>

# **Efforts to Improve Benefits and Coordinate Services**

There seems to be growing recognition of the complexities in the DI, SSI, Medicare, and Medicaid programs and in the linkages among the programs. As new provisions are added to any of the programs, the complexities become even more difficult, as enactment of TWWIIA amply demonstrates.

If, for example, a Medicare outpatient prescription drug benefit is enacted, it will affect not only Medicare beneficiaries (including those in the DI program) but also dual eligibles in receipt of Medicaid (including those

Many persons with disabilities indicate that personal assistance services are vital to their well-being.

in the SSI program). Depending upon the final shape of the benefit, full Medicaid and supplemental Medicaid dual eligibles could see their pharmaceutical costs shift to Medicare, reducing the burden on state Medicaid programs.<sup>43</sup>

Various demonstrations are under way at the Centers for Medicare and Medicaid Services to better coordinate services to meet the needs of Medicare and Medicaid beneficiaries, including those with chronic illnesses and disabilities. For example, Evercare Choice provides case management services to dually eligible persons in nursing homes in an effort to improve and monitor quality of care and health outcomes. For another example, a "cash and counseling" demonstration in three states (Arkansas, Florida, and New Jersey) provides consumer direction to Medicaid beneficiaries with disabilities by giving them monthly allowances and counseling help on how to plan their purchases. 44 Jointly funded by the Robert Wood Johnson Foundation and DHHS, the demonstration program has shown positive results in an initial evaluation of Arkansas's IndependentChoices. 45 For a final example, Independence Plus offers states templates for Section 1115 waivers or Section 1915(c) waivers for individual or family services so that persons with disabilities and their families can exert greater control over the personal and community services they receive.

#### CONCLUSION

In bridging the DI, SSI, Medicare, and Medicaid silos, the federal and state governments are seeking to coordinate income support and health benefit programs and, at times, to venture into new types of services. With the passage of the ADA and subsequent linking of disability and health benefits to employment supports, the frustrations of persons with disabilities have led to demands for more effective, better-coordinated programs. While the track record of the federal and state governments, as documented by GAO and other investigators, has not been smooth, the shift in social policy propels the agencies forward, ideally in the interest of the persons with disabilities whom they serve.

#### **ENDNOTES**

- 1. Board of Trustees of the Federal Old Age and Survivors Insurance and Disability Insurance Trust Funds, "Projections of Future Financial Status," 2003 OASDI Trustees Report, March 17, 2003; accessed May 4, 2003, at http://www.ssa.gov/OACT/TR/TR03/II\_project.html#wp105057.
- 2. Social Security Administration. "Highlights," 2003 Annual Report of the SSI Program, 3–4; accessed July 27, 2003, at http://www.ssa.gov/OACT/SSIR/SSI03/Highlights.html.
- 3. Board of Trustees of the Federal Hospital Insurance and Federal Supplementary Medical Insurance Trust Funds, "Financial Status of the HI Trust Fund," 2003 Annual Report, March 17, 2003, 1; accessed July 7, 2003, at http://cms.hhs.gov/publications/trusteesreport/2003/secif.asp.

- 4. Board of Trustees of the Federal Hospital Insurance and Federal Supplementary Medical Insurance Trust Funds, "Financial Status of the SMI Trust Fund," 2003 Annual Report, March 17, 2003, 1; accessed July 7, 2003, at http://cms.hhs.gov/publications/trusteesreport/2003/secig.asp.
- 5. National Conference of State Legislatures, "State Lawmakers Applaud Economic Recovery Compromise," *NCSL News*, May 23, 2003, 1; accessed July 15, 2003 at http://www.ncsl.org/programs/press/2003/pr030523.htm.
- 6. National Governors Association, "Tough Economic Times Remain for States," press release, June 26, 2003, 1–3; accessed July 28, 2003, at http://www.nga.org/nga/newsRoom/1,1169,C\_PRESS\_RELEASE^D\_5631,00.html.
- 7. Social Security Administration (SSA), "Limitation on Administrative Expenses," *The Fiscal Year 2004 Budget Press Release*, February 3, 2003; accessed June 17, 2003, at http://www.ssa.gov/budget/print2004.html#LAE.
- 8. SSA, "Limitation," 11-15.
- 9. U.S. General Accounting Office (GAO), *Major Management Challenges and Program Risks: Social Security Administration*, GAO-03-117, Washington, DC, January 2003, 13; accessed June 10, 2003, at http://www.gao.gov/pas/2003/d03117.pdf.
- 10. General Accounting Office. Major Management Challenges and Program Risks, 3.
- 11. GAO, Major Management Challenges, 4.
- 12. GAO, Major Management Challenges, 5-6.
- 13. GAO, Major Management Challenges, 8.
- 14. GAO, Major Management Challenges, 18.
- 15. Hal Daub, "Reforming the Disability Insurance and Supplemental Security Income Disability Programs," statement before the House Ways and Means Committee, June 11, 2002, 1; accessed May 4, 2003, at http://www.ssab.gov/DaubJune11.pdf.
- 16. Jo Anne Barnhart, Social Security Administration, "Testimony before the Subcommittee on Social Security of the House Committee on Ways and Means," September 25, 2003; accessed October 31, 2003, at http://waysandmeans.house.gov/hearings.asp?formmode=view&id=761.
- 17. Barnhart, "Testimony."
- 18. Office of Management and Budget (OMB), "Social Security Administration," *Budget of the United States Government, Fiscal Year 2004*, Executive Office of the President, Washington, DC, 291–293; accessed June 10, 2003, at http://www.whitehouse.gov/omb/budget/fy2004/pdf/budget/ssa.pdf.
- 19. Social Security Advisory Board, "Allowance Rates/Awards," *Disability Decision Making: Data and Materials*, Part 1A, January 2001; accessed June 19, 2003, at http://www.ssab.gov/chartbookA.pdf.
- 20. Daub, "Reforming," 2.
- 21. GAO, Major Management Challenges, 13-14.
- 22. WorkSupport.com, "Supplemental Security Income and Age 18 Redetermination," *Key Facts*, I, no. 2 (February 2003); accessed October 9, 2003, at http://www.worksupport.com/Archives/age18Redetermination.asp.
- 23. OMB, "Social Security," 295.
- 24. GAO, Major Management Challenges, 4–5.
- 25. GAO, Major Management Challenges, 5.
- 26. GAO, Major Management Challenges, 16.
- 27. GAO, Major Management Challenges, 15.

- 28. U.S. General Accounting Office, Social Security Disability: Reviews of Beneficiaries' Disability Status Required Continued Attention to Achieve Timeliness and Cost Effectiveness, June 2003, 8, 10; accessed October 10, 2003, at http://www.gao.gov/.
- 29. OMB, "Social Security," 293.
- 30. Pamela Loprest and Elaine Maag, "Executive Summary," Barriers to and Supports for Work among Adults with Disabilities—Results from the NHIS-D, U.S. Department of Health and Human Services; accessed October 9, 2003, at http://aspe.hhs.gov/daltcp/reports/barrses.htm.
- 31. GAO, Major Management Challenges, 10.
- 32. GAO, Major Management Challenges, 10.
- 33. U.S. General Accounting Office, Business Tax Incentives: Incentives to Employ Workers with Disabilities Receive Limited Use and Have an Uncertain Impact, GAO-03-39, Washington, DC, December 2002; accessed October 13, 2003, at http://www.gao.gov/atext/d0339.txt.
- 34. Joseph Pereira, "To Save on Health-Care Costs, Firms Fire Disabled Workers," Wall Street Journal, July 14, 2003, 1.
- 35. Christopher Lee, "In Bethesda, Hiring Policy, 'Competitive Sourcing' Clash," Washington Post, October 14, 2003, A21.
- 36. Rehabilitation Research and Training Center, "E-Newsletter: RRTC on Workplace Supports," Virginia Commonwealth University; accessed October 28, 2003, at http://www.vcu.edu/rrtcweb/cyberu/enewsletter.html.
- 37. Persons with end-stage renal disease and Lou Gehrig's disease are eligible for Medicare sooner.
- 38. For a chart showing states' asset limits, see Corporation for Enterprise Development, "Asset Limits for Public Assistance"; accessed November 6, 2003, at http://sadrc.cfed.org/.
- 39. Andy Schneider, Risa Elias, and Rachel Garfield, "Medicaid Eligibility," *The Medicaid Resource Book*, Kaiser Commission on Medicaid and the Uninsured, Washington, DC, January 16, 2003; accessed October 9, 2003, at http://www.kff.org/content/2003/2236/2236chapter1.pdf.
- 40. Schneider, Elias, and Garfield, "Medicaid Eligibility," 18.
- 41. Office of Disability Employment Policy, "Personal Assistance Services in the Workplace," U.S. Department of Labor, Washington, DC; accessed October 9, 2003, at http://www.dol.gov/odep/pubs/ek97/personal.htm.
- 42. Michael Cheek, Lewin Group, e-mail communication with author, October 26, 2003.
- 43. See Jennifer Ryan and Nora Super, "Dually Eligible for Medicare and Medicaid: Two for One or Double Jeopardy?" Table 1, Issue Brief 794, National Health Policy Forum, Washington, DC, September 30, 2003, 20; available at http://www.nhpf.org.
- 44. Mathematica Policy Research, Inc., "Evaluation of the Cash and Counseling Demonstration," Princeton, NJ; accessed October 11, 2003, at http://www.mathematica-mpr.com/3rdLevel/cashcounseling.htm.
- 45. Leslie Foster, Randall Brown, Barbara Phillips, Jennifer Schore, and Barbara Lepidus Carlson. "Improving the Quality of Medicaid Personal Assistance through Consumer Direction," *Health Affairs* Web Exclusives, January–June 2003, W3-162–W3-175.