



Highlights of a
FORUM

Convened by the
**Comptroller General of
the United States**

**Modernizing Federal
Disability Policy**

August 2007

GAO-07-934SP



Highlights of [GAO-07-934SP](#), a GAO forum.

Why GAO Convened This Forum

Economic, medical, technological, and social changes have increased opportunities for persons with disabilities to live with greater independence and more fully participate in the workforce. In addition, social and legal changes have promoted the goal of greater inclusion of persons with disabilities in the mainstream of society. However, GAO's reviews of the largest federal disability programs indicate that such programs have not evolved in line with these larger societal changes and, therefore, are poorly positioned to provide meaningful and timely support for persons with disabilities. Furthermore, program enrollment and costs for the largest federal disability programs have been growing and are poised to grow even more rapidly in the future. For these reasons, GAO added modernizing federal disability to its high-risk areas in January 2003.

GAO convened this forum to address some of the key issues related to modernizing federal disability policy. The forum brought together a diverse array of experts, including employers; advocate groups, researchers, and academia; and federal officials. Comments expressed do not necessarily represent the views of any individual participant or the organizations they represent, including GAO. However, GAO does make some concluding observations.

www.gao.gov/cgi-bin/getrpt?GAO-07-934SP.

To view the full product, including the scope and methodology, click on the link above. For more information, contact Daniel Bertoni at (202) 512-7215 or bertonid@gao.gov.

HIGHLIGHTS OF A GAO FORUM

Modernizing Federal Disability Policy

What Participants Said

Forum participants were asked to discuss over three sessions, what's working well and what needs to be improved in federal disability programs, how to strengthen partnerships and coordination for modernizing programs, and ways to modernize measures of program success. Participants also considered the next steps to achieving a 21st century disability policy.

(1) What's Working Well and What Needs Improvement?

- Some partnerships and collaborations are helping to improve services such as income replacement, health care, and work assistance, as well as research on disability issues.
- There is no federal system for disability that coordinates the many different disability programs and services, and no comprehensive lifetime picture of the needs of individuals with disabilities.

(2) Strengthening Partnerships and Coordination

- More coordination and leadership of disability programs are needed.
- Partnerships with and incentives for the private sector are needed to offer and maintain employment for individuals with disabilities.
- States and localities are key partners in delivering services to individuals with disabilities.

(3) Modernizing Measures of Success

- Disability populations and definitions vary.
- Data collection on people with disabilities needs to be improved.
- Multiple indicators are needed to measure economic success as well as quality of life for people with different disabilities.

Participants suggested a number of steps that could be taken by stakeholders to inform the debate to help move current policy toward achieving a 21st century disability policy. Some participants suggested evaluating work incentives and disincentives and the coordination efforts between public and private sector disability entities; others suggested developing a definition of disability and standard language that could be shared across related programs; and many suggested establishing various program outcome indicators and data reporting requirements to track them.

Concluding Observations

To the extent that federal disability programs are aligned with 21st century realities, benefits can be achieved for individuals with disabilities, business, and government. Solutions are likely to require fundamental changes, including regulatory and legislative action. Without federal leadership at this critical time to lead this transformation, there could be fewer options in the future available to policymakers seeking to improve federal disability programs. As the country moves forward, the fiscal implications of any new actions—as well as the cost of keeping the status quo—must be considered.

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Abbreviations

ADA	Americans with Disabilities Act
DI	Disability Insurance
DOD	Department of Defense
SSA	Social Security Administration
SSI	Supplemental Security Income
TIRR	The Institute for Rehabilitation and Research
VA	Department of Veterans Affairs
VR	Vocational Rehabilitation
WIA	Workforce Investment Act

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United States Government Accountability Office
Washington, DC 20548

Introduction from the Comptroller General of the United States

Economic, medical, technological, and social changes over the past several decades have increased opportunities for individuals with disabilities to live with greater independence and more fully participate in the workforce. For example, the economy has shifted toward service- and knowledge-based jobs that may allow greater participation for some persons with physical limitations. Also, advances in medicine and assistive technologies—such as improved treatments for mental illnesses and advanced wheelchair design—afford greater opportunities for some persons with disabilities. In addition, social and legal changes have promoted the goal of greater inclusion of persons with disabilities in the mainstream of society, including adults at work. For example, the Americans with Disabilities Act (ADA) supports the full participation of persons with disabilities in society and fosters the expectation that persons with disabilities can work and have the right to work. In 2001, the President announced the New Freedom Initiative, a set of guiding principles and initiatives aimed at improving the integration of persons with disabilities in all aspects of society, including employment.

However, GAO's reviews of the largest federal disability programs indicate that such programs have not evolved in line with these larger societal changes and, therefore, are poorly positioned to provide meaningful and timely support for persons with disabilities. Furthermore, program enrollment and costs for the largest federal disability programs have been growing and are poised to grow even more rapidly in the future, contributing to the federal government's large and growing long-term structural deficit. For example, from 1996 to 2006, the number of persons with disabilities receiving benefits under the Social Security Administration's (SSA) Disability Insurance (DI), and Supplemental Security Income (SSI) programs and the Department of Veterans Affairs' (VA) Disability Compensation and Pension program increased by 42 percent, 16 percent, and 7 percent respectively. At the same time, the total inflation-adjusted cash benefits for these programs increased by 63 percent, 18 percent, and 44 percent, respectively. Moreover, these disability programs are poised to grow even more as baby boomers reach their disability-prone years. This program growth is exacerbated by the low rate of return to work for individuals with disabilities receiving cash and medical benefits. In addition, the projected slowdown in the growth of the nation's labor force has made it more imperative that those who can

work are supported in their efforts to do so. In 2003, GAO designated modernizing federal disability programs as a high-risk area because of challenges such as these.¹

GAO identified over 20 federal agencies and almost 200 federal programs that either wholly or partially serve persons with disabilities. These programs provide a wide range of assistance such as employment-related services, medical care, and monetary support. Multiple agencies run programs that provide similar types of assistance, but these programs often serve different populations of persons with disabilities because of varying eligibility criteria.

GAO convened this forum on April 17, 2007, to address issues related to modernizing federal disability policy. The forum brought together a diverse array of experts, including federal officials; representatives from advocacy groups, researchers, and academia; and employers. Forum participants discussed what is working well in federal disability programs and what should be improved, explored issues we identified as critical based on prior work such as how to strengthen partnerships and coordination for modernizing disability programs and how to modernize measures of program success, and closed with a discussion on where to prioritize the next steps to achieving a 21st century disability policy. (See app. I for a list of forum participants and app. II for the forum's agenda.) This forum was designed for the participants to discuss these issues openly, without individual attribution, in order to facilitate a rich and substantive discussion of these issues.

This report summarizes the ideas and themes that emerged at the forum, the collective discussion of participants, and comments received from participants based on a draft of this report. The forum comments summarized in this report do not necessarily represent the views of any individual participant or the organizations that these participants represent, including GAO. However, GAO does make some concluding observations about the need to modernize federal disability policy.

I want to thank all the forum participants for taking the time to share their knowledge, insights, and perspectives. We at GAO will benefit from these insights as we carry out our work for the Congress and the country.

¹*High Risk Series: An Update*. [GAO-03-119](#). Washington, D.C.: January 2003.

I look forward to working with the forum's participants on this and other issues of mutual interest and concern in the future.

A handwritten signature in black ink, appearing to read "D. M. Walker", with a long horizontal line extending to the right.

David M. Walker
Comptroller General
of the United States

August 3, 2007

What Is Working Well and What Should Be Improved?

The forum opened with the Comptroller General asking the participants what they thought was working well in federal disability programs and what they thought needed to be improved. In response to the question about what was working well, some participants stated that some partnerships and collaborations were helping to improve services such as income replacement, health care, and work assistance, as well as research on disability issues. Some of these partnerships involved federal programs working together to help individuals, while others involved federal and local entities or federal and private sector entities. In response to areas needing improvement, some participants stated that there should be a federal system for disability that coordinated the many different disability programs and services, and that there was no comprehensive lifetime picture of the needs of individuals with disabilities. Also, many participants agreed that there was a need for more and better indicators to measure the success of disability programs. Participants made individual comments on aspects they believed were working well in federal disability programs and aspects that need improvement, as shown in tables 1 and 2. The tables list individual comments and as such, neither represent a group consensus nor the full range of what is working well or what should be improved in federal disability programs.

Table 1: Individual Responses to “What Is Working Well in Federal Disability Programs?”

Partnerships and Coordination

- Federal partnerships that result in agreement on policy and pooling of resources.
- Programs such as The Department of Labor’s New Freedom Initiative Award that get private sector and other leaders together to commit to more hiring of persons with disabilities and to discuss issues.
- Programs such as the National “School to Work” joint initiative between Labor and Education, which pooled funding resources and created a database for research.
- Research demonstration projects that collaborate with other organizations.
- The practice of using states as a laboratory for innovative programs.

Program Design and Benefits

- Change in public policy paradigm over last 10-15 years that emphasize equality of opportunity, self-determination, economic self-sufficiency and independent living.
- DI and SSI programs provide needed income replacement and Medicare and Medicaid provide needed health care.
- The annual adjustment of substantial gainful activity earnings amounts for inflation.
- VA’s new process and standardized criteria for rating disabilities at discharge.
- Medicaid, home- and community-based services linking independent living and work assistance.

Work Facilitators

- SSA’s program to help individuals with benefits planning and accessing return to work programs.
 - Two science-based best practices: (1) on-the-job training and (2) school-based work for transitioning youth from school to jobs.
 - Assistive technology.
 - Higher education.
-

Table 2: Individual Responses to “What Needs Improvement in Federal Disability Programs?”

Program Orientation

- There is no federal system for disability to ensure that policy, services, and support are in sync and come from all levels of government.
- We need a paradigm shift from models that focus on programs and policies, to a model that focuses on the needs of individual customers.
- Earlier intervention for youth with disabilities to prepare them for the workforce.
- Consideration for how to handle often chronic and frequently variable conditions such as mental illness.

Program Design and Benefits

- Better work incentives are needed for individual beneficiaries and employers.
- Explore eliminating the linkage between health care and cash benefits. Many people are attempting to get on disability because they need health care.
- Programs lack a return-on-investment orientation. Also, they do not allow for investment or accumulation of assets, and so people are kept at the same level of economic security.
- The transition from the Department of Defense (DOD) to VA is layered in bureaucracy.

Evaluation Information

- Return-to-work models do not look at how to help people remain at work.
 - We need a comprehensive picture of individual needs for persons with disabilities—a picture that covers an individual’s life span and differs by age group.
 - Need more and better indicators and disability outcome data. Without it, evidence-based approaches are not possible. The federal government has established data requirements from state and local entities, but neither collects or reports on the data.
 - More input from people who are on these programs (SSI and DI) themselves to know what is working well or not.
-

Strengthening Partnerships and Coordination

Forum participants pointed out that maintaining partnerships and coordinating services to persons with disabilities is critical to success. Key challenges to achieving these goals are the absence of a coordinated government disability policy, the need to establish public-private partnerships with incentives for the private sector, the current role of the Vocational Rehabilitation (VR) Program, and providing education where appropriate to prevent work incapacity according to the participants.

Coordinated Government Disability Policy Needed

While participants noted that many departments achieve good outcomes, they also acknowledged that there is fragmentation and duplication, and cited the need for more coordination among disability programs. One participant said we do not have a federal system for disability and insufficient thought has been given to what the future system should look

like. Disability issues are complex and cut across public domains, including transportation, housing, assistive technology, and community-based services, and only integrated services make functioning possible, according to one participant. Similarly, a participant suggested the need for someone to be responsible for the big picture. Another participant thought coordination should aim to create a federal, state, and local system to ensure that policy, services, and supports are synchronized. This system would require strong leadership, and also needs one nexus in the executive branch and one committee of jurisdiction in Congress or else it would be impossible to manage. Currently, the participant further argued, there are too many congressional committees involved in this issue.

Another participant added that there is a need to understand how well state and federal programs work together, and another cautioned that the goal should not be to federalize all disability programs. In fact, some participants underscored the importance of working with the state and localities. While one participant took issue with the use of state employees and state agencies to determine eligibility for federal benefits, others noted that states are critical to helping facilitate services to local communities, which in turn get services to individuals. One participant said that some local communities have found ways to manage the plethora of federal and state program requirements to address transportation and other needs of the elderly. Some best practices have been identified by the National Council on Disability, including a partnership called Creating Livable Communities.

Some participants cited the need for better coordination of services for veterans. One participant said the transition from DOD to VA's system is overly layered with bureaucracy, and despite the attempts to educate service members, the transition process has become adversarial. According to this participant, the system needs to be less adversarial and more advocacy-oriented for the service members. Another participant noted the need for better coordination between SSA and VA for veterans as well. There are also incentives for veterans who lose their health care when they transition to retirement to try to remain within the VA health care system, according to one participant. Veterans have the incentive to stay in the health care system, the participant said, because their access to the system gives them access to their prescription drugs. Finally, one participant cited the example of a small DOD program—the Marine for Life-Injured Support Program—that this participant believed has been successful at coordinating services to help seriously injured marines and sailors. The program brings together supports from different federal

agencies and to date has helped 25 seriously injured individuals, according to this participant.

One participant stated that a paradigm shift is needed from a focus on programs and policies to a focus on the needs of individual customers throughout their lives. Fragmentation of services was not necessarily seen as bad by some participants as long as services are focused on the individual. Another advocated a system that is bottom-up, with strong case management, and each individual having an advocate. For example one participant said that Virginia has a “no wrong door” approach, which means that the first contacted agency takes on the role of advocate to get the needed supports for that individual. One participant expressed the need for a comprehensive picture of individual needs for persons with disabilities—a picture that seamlessly encompasses the transitions from childhood to adolescence to young adulthood to adulthood to retirement.

On a similar note, one participant observed that there is a lack of coordination in support of children, even though childhood is where the greatest impact can be achieved within existing laws. This participant said that SSI has many beneficiaries under the age of 21 who have not participated in special education and noted that we have a 21-year spectrum when significant improvements could be made that would affect the entire life of a person with disabilities if the coordination of resources had greater emphasis. More coordination is needed among SSA; Education; and the Early Periodic Screening, Diagnosis, and Treatment Program, the participant said.

Public-Private Partnerships and Incentives for the Private Sector Needed

Many participants noted the need for partnerships with employers. One participant said partnerships can be established by exposing employers to persons with disabilities who are looking for work and exploring career opportunities. At the same time, such partnerships could expose youths with disabilities to mentors to keep their expectations and career aspirations high. A second participant claimed that private insurers have had more success than SSA at helping persons with disabilities find jobs, by building successful relationships with employers, often by adjusting premiums for both small and large employers. The participant suggested that these kinds of changes can be made easily to the existing disability systems. Also, the Department of Labor’s employment and training supports available through the Workforce Investment Act’s (WIA) one-stop system have developed relationships with the business community. This participant noted that there could be a way to enhance the existing system so that more resources are available to provide accommodations. One

participant suggested that the way to encourage businesses to work with persons with disabilities is to give them information about what persons with disabilities and their families want. The business community has such information about teenagers and other groups of consumers, but businesses lack data about consumers among the disability community, according to the participant.

The VA's Compensated Work Therapy Program was cited by one participant as an example of a successful work program. Under this program, the participant said, VA partners with companies to place veterans with disabilities in a competitive work environment and provides incentives for the employer to employ them. Further, the veterans' salaries are not counted against their benefit levels. This participant suggested that this program could be a possible model for providing work incentives for persons with disabilities more broadly if it can be successfully marketed to the wider private sector. Another participant cited the federal government as an example of an employer that could be doing more to employ persons with disabilities. This participant suggested that the federal government test different kinds of work supports to find out what works best. This information could then be disseminated to other employers.

Demographics are creating a pressing need to maintain employment after disability. One participant observed that the baby boomers are approaching the prime age for disability onset and that government needs to provide incentives to employers to keep these employees. Also, one participant contended that after the boomers have retired, the population of workers with disabilities is not going to be severely reduced, as there is still a big population rising to the disability onset age group, due in part to immigration. A second participant agreed with the need for private sector employer incentives because retaining employees during the first 6 weeks of disability is a key concern. By maintaining the work connection, employees are kept in the private disability system and off DI and SSI. Another participant noted that employers have incentives to not retain employees who become disabled. The participant further argued that once that person becomes unemployed, it is very difficult for that person to go back to work and if the person needs health care, he or she may turn to SSI and DI to obtain it. This participant suggested that providing incentives to employers to keep their employees can be done in a way that does not cost a lot.

Individuals may also need incentives to maintain work connections. One participant observed that changes are needed to encourage people to continue working past retirement age, and one way to do this would be to

not tax retirement income and allow individuals to draw on retirement while working. Another participant maintained that SSI rules are out of date, noting that the current system may penalize individuals for trying to work by requiring them to make income projections and calculations that are difficult, and then levying overpayment charges on the individual if these calculations are incorrect. Getting assessed with an overpayment bill could be a huge disincentive to find work, and individuals may fear making a mistake, according to one participant. The participant said that SSA needs to remove disincentives and also support persons with disabilities' attempts to work.

Vocational Rehabilitation Program's Role

Participants discussed the role of the VR Program in relation to the WIA. One participant stated that the WIA had contemplated a larger network of federal agencies that included VR, but it never really became incorporated into the WIA system. This participant's earlier work found that services were often misaligned with what people really want and what is needed to create an infrastructure that is responsive to what consumers and employers need. Currently, there are many entrenched bureaucratic cultures with lists of approved or mandated services and supports that may not match up with demand.

Another participant observed that there are misconceptions regarding VR and its integration into the WIA system. Because rehabilitation is generally aimed at those with the most severe disabilities that require longer care, accessibility supports, and accommodations, the participant noted the severely disabled cannot be easily integrated into the WIA one-stop system, which serves persons without as well as with disabilities. This participant advised caution as we move toward integration with WIA to ensure those individuals with severe disabilities are not underserved. On the other hand, one participant was critical of VR, claiming that over time, it had received significant federal funding and served large numbers of SSA beneficiaries with questionable success.

Programs That Provide Higher Education Can Improve Success of Some Persons with Disabilities

Participants agreed that higher education can be an important factor in the success of some, albeit not of all, persons with disabilities. One participant pointed out that the risk that medical issues become work impediments increases with age and also with the lack of education, and that higher education is an effective tool for preventing work incapacity. This participant noted that it is hard to succeed in today's workforce without a college education and that we need programs that help persons with disabilities—including veterans—get to college. Two other participants

also agreed that higher education is an important factor in success but said that it might not be the best choice for everyone in all situations. One of these participants noted that the VA's Vocational Rehabilitation and Employment Program provides veterans with access to higher education benefits but observed that sometimes it is more important to emphasize return to work over education, especially in the first year after the onset of the disability, in part because the individual may be able to pursue education opportunities afterward. The second participant concurred with the importance of higher education to success, but, citing past research on computer skills, education, and other factors on return to work, noted that information technology presents major opportunities for bringing persons with disabilities into the workforce.

Some persons with disabilities may need help getting access to education, and some may be denied access. One participant explained that while veterans with a disability rating of 10 percent or more receive access to vocational rehabilitation services, including higher education, through VA's Vocational Rehabilitation and Employment Program, veterans need more counseling to get through the maze of the benefit system. A second participant said some veterans may also be denied access to education and retraining because of structural issues with the program. For example, according to one participant, the Individual Unemployability Program treats a person with a disability rating of 60 percent and above the same as someone with a 100 percent disability rating and therefore does not offer that person a vocational assessment that could give him or her access to retraining services.

Finally, one participant pointed out that training and education need to be targeted to job opportunities afforded by the new economy. While the relevance of training programs is very important, training someone for a job that is not available in the local economy does not achieve anything for that individual.

Modernizing Measures of Success

Participants generally agreed that new and multiple indicators are needed to measure the success of disability programs, but a number of systemic issues would need to be addressed to achieve that goal. These issues include the differing definitions of disability across programs and the changing nature of disabilities among beneficiaries, the need for better data collection to measure success for persons with disabilities, and the need for multiple indicators to measure both economic as well as quality-of-life outcomes, according to participants.

Disability Definitions Vary

Participants agreed that disability populations and disability definitions varied. One participant pointed out that there is no single definition of disability for all programs—there are definitions, for example, for veterans, older workers, and the general population. Two other participants stated there is a clear difference between veterans programs and programs for individuals whose disabilities are not related to military service. Another participant pointed out that the existence of multiple definitions for disability is not necessarily bad. For example, SSA’s definition is fine for determining need for income supports but does not work for access to medical care or for in-home care and personal assistance.

In addition to definitional differences, one participant noted the changing nature of disabilities that applicants and beneficiaries were experiencing. VA is seeing that mental disabilities can be more permanently disabling than many physical disabilities and that mental illness related to post-traumatic stress disorder can have a significant impact on earnings and employment of veterans. The participant said even those veterans who may have received a disability rating of 10 percent are experiencing a drop in earnings and employment at age 50. The participant added that VA is just learning about the impact of traumatic brain injuries on today’s soldiers.

Data Collection for Persons with Disabilities Needs to Be Improved

Many participants stated that data are collected, but not in a systematic format, making current data weak. One participant explained there are many sets of data to measure success of specific programs but there is no common data set because all different data sets are program-specific. Also, there is no congressional requirement for one set of data or outcome measures. A second participant agreed, saying that current measures focus on programs and not people, and this is not beneficial. Also, a participant said it is difficult to identify the population of persons with disabilities because current surveys do not capture information about them. Another challenge to identifying this population, according to another participant, is that most major surveys primarily reflect household data, and persons with disabilities may not always live in what is typically defined as a household. Relatedly, another participant noted that Labor’s Office of Disability Employment Policy is working with the Bureau of Labor Statistics to field test questions on disabilities that will be ready in a year and will be reflected in the unemployment data. Another participant observed that the most credible data always seem to be financial data, and that quality-of-life measures are much harder to collect.

One participant asserted that researchers want to push the improvement of data collection forward, but the federal government is lagging. The Bureau of Labor Statistics' Current Population Survey and the Census Bureau's American Community Survey have started to improve data collection regarding disability, but they are going in different directions, according to this participant. This participant also said some work is being performed to develop core survey questions to identify persons with disabilities, and the federal government should adopt these core questions to capture this information. Other participants voiced dissatisfaction with the federal government's role in data collection as well. One participant noted that the federal government has established data requirements for state and local entities, but neither collects nor reports on the data. As a result, this participant argued, good data are not collected or shared, and the data are not helpful across different levels. Another participant observed that many federal agencies have antiquated hardware and particularly software programs that were designed for mainframe computers, and speculated whether funds could be redirected from Government Performance and Results Act activities to improving disability data collection. A third participant stated that without improving electronic medical evidence storage, evidence-based approaches to measure success are not possible.

Finally, one participant disagreed with the other participants' criticisms and suggested that federal and state administrative data are a tremendous source of information about outcomes, but that privacy protection may be a greater impediment to sharing federal data. For example, this participant asserted that SSA collects unemployment data from the states that are the best source of earnings data. This participant saw the need to link more administrative data to survey data.

Multiple Indicators Needed to Measure Success

Most participants agreed that multiple indicators were needed to measure the success of disability programs and that these measures should include not only economic measures such as income and employment, but quality of life measures as well. However, when disaggregating the indicators to the level of individuals with disabilities, some participants cautioned that care should be taken to avoid the creation of perverse incentives that treat persons with disabilities differently from the whole population. Some participants cited the need to determine the indicators of success for the entire population as well as for the subpopulation with disabilities. One participant offered four goals or outcome areas that should be optimized for everyone's status, with the importance of each varying from person to person. They are

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- health and wellness,
 - choices or opportunities for productive activity separate from economic questions,
 - social interaction, and
 - independence or autonomy and control over one's life.

Other participants acknowledged the importance of looking at broader quality-of-life measures beyond employment outcomes. One participant explained that there are many individuals who are very ill or impaired and cannot work, and it is important to avoid the unintended consequences of devaluing these individuals by not measuring their well-being in some other fashion. A second participant concurred, stating that for some people, success is not measured by employment and therefore programs cannot use key indicators for the entire population and apply them to persons with disabilities. Another participant cautioned that we need to determine what outcomes and indicators we want to focus on. If our outcomes are not defined properly, we will see a forced focus on the easier-to-serve populations and neglect the harder-to-serve populations. The participant suggested that a focus on quality-of-life indicators, such as the level of independence enjoyed in daily life, self-determination, and economic security, will allow measurable success for all beneficiaries. While employment is a reasonable outcome measure, not all persons with disabilities are able to return to work, and we should not devalue those individuals in the face of these other goals. Further, another participant noted that if there are going to be goals, stark decisions must be articulated. It is easy to divide people along lines of independent living, but it is harder to define goals for those who cannot live independently. This participant questioned the meaning of success: Is it integration or prevention from relying on the government and programs? Finally, one participant stated that persons with disabilities want self-empowerment and full integration, and therefore a focus on the broader disability community is needed, not just program-specific and employment outcomes as the only proxies. We also must make sure to not talk about only those portions of the disability community that researchers focus on, the participant said.

One participant explained that it is not surprising that there are no key measures for success for Americans with disabilities because other countries do not have them either. A second participant noted that the problem with measures is that they focus on programs and not people. Another participant said that there must be a relationship between the purpose of the disability program and the indicators used to measure success. When discussing key indicators, a fourth participant pointed out

that it is important to understand the distinction between the extent to which these systems make a difference in the quality of life for persons with disabilities and what is good public policy.

In discussing key national indicators as a measure for success, one participant suggested taking a life path approach for different age groups. In other words, determine what defines success for individuals from the general community at different stages of their lives and contrast it with what constitutes success for those individuals with disabilities to see if there is a difference. A second participant stated that the National Indicators Project has quality-of-life indicators and that the United States' effort came about as a result of a GAO forum on key national indicators.² The need for disability indicators is an important subset of the overall need for key national indicators. Another participant maintained that national indicators should also include income and assets, but the current disability support system does not allow for income or asset accumulation. Establishing economic security is key for persons with disabilities, the participant argued, including making benefits adequate and protecting these individuals from discrimination in the workplace. The goal should be for programs to make people better off and not just provide subsistence, the participant continued. A fourth participant agreed that economic security, including asset accumulation, is key and faulted the disability support system for not providing lifelong financial planning.

In evaluating current disability programs, one participant acknowledged that disability programs score lower on the Office of Management and Budget's Program Assessment Rating Tool than other programs. The participant said, however, that these evaluations create a framework to measure improvement going forward and suggested that overall, there needs to be the political will to manage this problem. Another participant cautioned that there can be a problem if agencies are held responsible for outcomes they were not created to achieve. A final participant stated there was enough cumulative knowledge among the forum participants to create a national plan to measure success. However, what was lacking was an action plan and someone responsible for implementation of that plan.

²GAO, *Forum on Key National Indicators: Assessing the Nation's Position and Progress*. [GAO-03-672SP](#) (Washington, D.C.: May 1, 2003).

Suggested Next Steps for Achieving a 21st Century Disability Policy

Individual participants suggested a number of steps that could be taken by stakeholders to inform the debate to help move current policy toward achieving a 21st century disability policy. These include the following:

- talk with people receiving disability services to find out what is working well, what is not, and what additional services they need to succeed;
- develop a definition of disability and a standard language that could be used across related programs;
- develop a comprehensive picture of individual needs for persons with disabilities—a picture that covers an individual’s life span and is different for each age group;
- identify barriers to coordination of programs;
- identify best practices that could be shared across programs;
- evaluate work incentives and disincentives and the coordination efforts between public and private sector disability entities;
- evaluate both the short-term and long-term services for all veterans with disabilities while recognizing both the projected increase in the number of veterans filing for disabilities and the changing nature of the injuries being reported;
- establish various program outcome indicators including quality-of-life indicators, to measure success and establish data-reporting requirements to track those outcomes; and
- focus on providing services to youth with disabilities in order to help them transition into the workforce.

Concluding Observations

Changes in society, technology, and the economy have increased opportunities for individuals with disabilities to more fully participate in the workforce. At the same time, the growth in the size and costs of major federal programs not only contributes to the federal government’s long-term structural deficit but also creates a strong business case for reexamining our current federal disability programs and identifying workable solutions to leverage change. To the extent that federal disability programs are aligned with 21st century realities, benefits can be achieved for individuals with disabilities, business, and government. Notably, recent attention to injured service members returning from the global war on terror offer opportunities to better serve veterans. This forum brought forth many of the challenging issues facing the federal government as it modernizes federal disability policy to better meet the abilities and needs of individuals with severe disabilities. Amongst these issues, the articulation of clear and coordinated policies, the development of strong and meaningful partnerships between all stakeholders, the use of targeted

incentives to achieve desired results, and a reliance upon appropriately defined outcomes were noted. Clearly, as the country moves forward, the fiscal implications of any new actions—as well as the cost of keeping the status quo—must be considered. Solutions are likely to require fundamental changes, including regulatory and legislative action. Without strong federal leadership at this critical time to lead this transformation, there could be fewer options in the future available to policymakers seeking to improve federal disability programs. As with the GAO forum, policymakers can benefit from bringing together multiple stakeholders to seek common solutions.

Appendix I: List of Participants

Moderator

David M. Walker Comptroller General of the United States
U.S. Government Accountability Office

Participants

Gale P. Arden Director, Disabled and Elderly Health Programs Group
Centers for Medicare and Medicaid Services

Daniel Bertoni Director, Education, Workforce, and Income Security Issues
U.S. Government Accountability Office

Robert C. Brostrom Special Assistant, Office of Disability Employment Policy
U.S. Department of Labor

Judith A. Cook Professor and Director, Center on Mental Health Services Research
and Policy, Department of Psychiatry
University of Illinois at Chicago

Col. Marsha Lee Culver Director
Secretary of the Navy Council of Review Boards

Susan M. Daniels Daniels & Associates

Cynthia M. Fagnoni Managing Director, Education, Workforce, and Income Security Issues
U.S. Government Accountability Office

Marty Ford Chair
Consortium for Citizens with Disabilities

Lex Frieden Senior Vice President
The Institute for Rehabilitation and Research (TIRR) and Director of
TIRR's Independent Living Research Utilization Program

Martin Gerry Former Deputy Commissioner, Disability and Income Security Programs
U.S. Social Security Administration

Margaret Giannini Director, Office on Disability
U.S. Department of Health and Human Services

Martin Gould	Director of Research and Technology and Co-Acting Executive Director National Council on Disability
John H. Hager	Assistant Secretary, Office of Special Education and Rehabilitative Services U.S. Department of Education
Dorcas R. Hardy	Member Social Security Advisory Board
Andrew J. Imparato	President and CEO American Association of People with Disabilities
Patricia A. Jonas	Assistant Deputy Commissioner for Disability Operations Office of Disability and Income Security Programs U.S. Social Security Administration
John M. Kamensky	Senior Fellow IBM Center for the Business of Government
Thomas J. Pamperin	Deputy Director, Compensation and Pension Service Department of Veterans Affairs
Virginia Reno	Vice President, Income Security National Academy of Social Insurance
Samuel B. Retherford	Deputy Director for Policy, Officer and Enlisted Personnel Management, Office of the Under Secretary of Defense for Personnel and Readiness
Robert J. Shea	Associate Director for Management U.S. Office of Management and Budget
Robert Silverstein	Director Center for the Study and Advancement of Disability Policy
David C. Stapleton	Director Cornell University Institute for Policy Research
Ray Wilburn	Executive Director Veterans' Disability Benefits Commission

Appendix II: Agenda

8:30 a.m.	Continental Breakfast
9:00 a.m.	Opening Session <ol style="list-style-type: none">1. Welcome and Introductions2. Overview of Agenda3. Why the Need to Modernize
9:30 a.m.	Session I: Modernizing Federal Disability Programs— What’s Working Well, and What Should be Improved?
10:00 a.m.	Break
10: 15 a.m.	Session II: Strengthening Partnerships and Coordination for Modernizing Disability Programs
11:45 p.m.	Lunch with Film and Discussion: <i>2005 ESPY Arthur Ashe Courage Award to Emannual Ofosu Yeboah and Jim MacLaren</i>
1:00 p.m.	Session III: Modernizing Measures of Success of Disability Programs
2:00 p.m.	Hill Perspective
2:30 p.m.	Session IV: Prioritizing Next Steps to Achieving a 21st Century Disability Policy
3:15 p.m.	Summary and Closing Remarks
3:30 p.m.	Adjournment

Appendix III: Contacts and Staff Acknowledgments

GAO Contact

Daniel Bertoni (202) 512-7215 or bertonid@gao.gov

Staff Acknowledgments

In addition to the contact above, Brett Fallavollita, Assistant Director, and Kevin Kumanga, Analyst-in-Charge, managed all aspects of the work, and Krista Anderson, Anna Kelly, Scott Purdy, and Charles Willson made important contributions to organizing the forum and producing this report.

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