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A Disability System for the 21st Century

INTRODUCTION

In the October 2003 report, *The Social Security Definition of Disability*, the Social Security Advisory Board observed that, “The original Social Security disability programs were... designed to serve those who had no realistic expectation of a return to the workforce because of a combination of severity of disability and attainment of near-retirement age.” At that time we also raised the question of whether or not the Social Security definition of disability facilitates an appropriate approach to supporting and enabling persons with disabilities.

During the past 3 years a major activity of the Board has been a review of our Nation’s approach to disability. We have been aided in this task by the many thoughtful parties who have generously shared their perspectives and expertise with us. We have learned a great deal about the strengths and weaknesses of the disability system. The result has been to confirm our belief that a definition based on inability to work collides with the goals of the Americans with Disabilities Act, which proclaimed that “the Nation’s proper goals regarding individuals with disabilities are to assure equality of opportunity, full participation, independent living, and economic self-sufficiency for such individuals.”

The Board believes we must find a way to revise the Social Security definition of disability in a way that does not undermine the protections afforded by the last resort programs administered by the Social Security Administration but does support an integrated approach that provides and emphasizes an alternate path — one directed to self-support, independence, and contribution that can help those who might, by taking that path, avoid, delay, or minimize their need for dependence on the programs of last resort. We should, in fact, question the idea that there is such a thing as a single “definition of disability.”

...the Nation’s proper goals regarding individuals with disabilities are to assure equality of opportunity, full participation, independent living, and economic self-sufficiency for such individuals...

Americans with Disabilities Act

We continue to view the Social Security disability programs as vital supports that must continue to be available. And we congratulate the Social Security Administration on undertaking important administrative reforms within the adjudication process that will help to address some of the delays, backlogs, and quality issues that needed serious attention. At the same time, we believe that the existing definition of disability that emphasizes inability to work does not represent the proper central approach to providing support to persons with significant mental or physical limitations. An overall uniformly applicable and systematic approach needs to be adopted in which the initial focus is on assessing what individuals can do and helping them to obtain the support services, both financial and nonfinancial, that are needed to maintain or increase expectations that return to work (or, as appropriate, starting work) is a realistic possibility. The determination that an individual cannot work should be the option of last resort, not the first option.

The Board believes that increasing expectations about the ability to work is consistent with the *Americans with Disabilities Act* (ADA) and the desires of most persons with disabilities and their families. The challenge is how to implement a strategy that meets the aspirations of the ADA, fulfills the needs of persons with disabilities, maintains the protections provided by the Social Security disability programs, and is fiscally responsible and sustainable.

I. Background of the Board’s Examination of Disability

Fifty years ago—in August of 1956—Congress expanded the Social Security program to include benefits for workers age 50 and over who had mental or physical impairments of a long lasting nature and a severity sufficient to preclude them from engaging in any substantial gainful activity. Subsequent amendments broadened the scope of this program to include younger disabled workers and to add benefits for disabled widows and for individuals who became disabled prior to age 22 and whose working parent died or became eligible for Social Security benefits. The original requirement of a disability of long lasting and indefinite duration was modified to allow benefits for impairments lasting as little as a year, and health insurance under Medicare was added for those on the disability rolls for 2 years or more. In 1972, a needs-based program of Supplemental Security Income (SSI) was created making available cash assistance, accompanied in nearly all cases by Medicaid eligibility, for both disabled adults and disabled children.

These Social Security disability programs provide important supports for the basic needs of income and health care for millions of America’s most vulnerable men, women, and children. As shown in Table 1, as of June 2006, the Social Security Administration is providing monthly benefits to 6.6 million disabled workers along with 1.7 million dependent spouses and children of such workers. Benefits also are paid to 0.2 million disabled widows, and 0.8 million disabled adult children. Some 5.2 million individuals under age 65 receive Supplemental Security Income based on disability (including 1.4 million who also receive Social Security benefits). As of 2004, federal benefit payments under these provisions totaled \$112 billion.

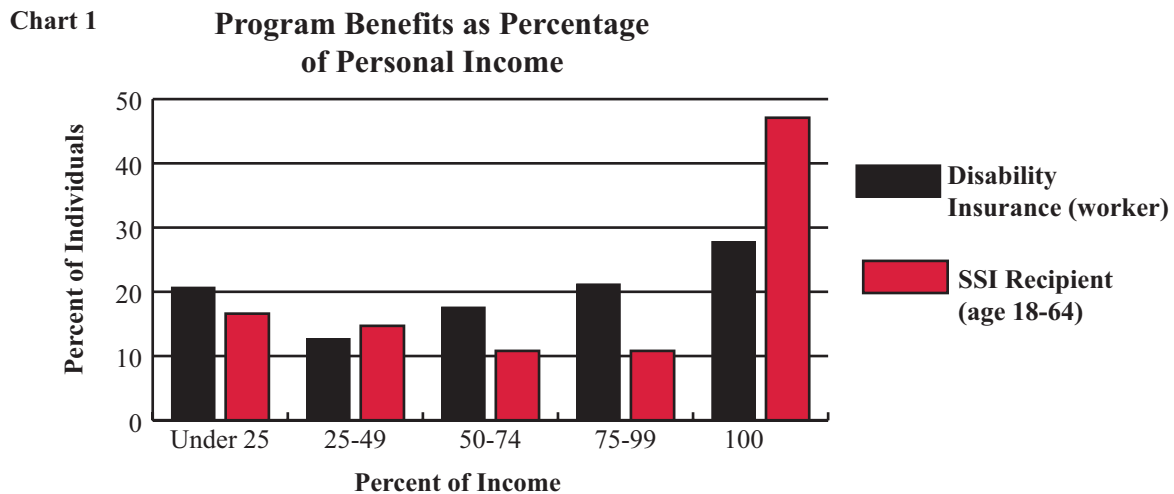
Table 1 Social Security Disability Beneficiaries

June 2006	Thousands
Disabled workers	6,630
Spouses of disabled workers	155
Children (under 18) of disabled workers	1,523
Student children (age 18-19) of disabled workers	51
Disabled widow(er)s	213
Disabled adult children	772
SSI disabled under 18	1,058
SSI disabled 18-64	4,117

(1.384 million of the above receive both SSI and Social Security benefits)

Sources: SocialSecurity.gov (*OASDI Monthly Statistics, SSI Monthly Statistics, Monthly Statistical Snapshot*) and unpublished SSA data.

According to SSA statistical reports on the Disability Insurance (DI) and Supplemental Security Income (SSI) programs, 28 percent of DI worker beneficiaries depend on those benefits for 100 percent of their income; 47 percent of working age (18-64) SSI recipients get 100 percent of their income from SSI. In both programs, the benefits represent more than three quarters of total income for a majority of such beneficiaries. (See Chart 1.)



Source: *Annual Statistical Report on the Social Security Disability Insurance Program, 2004* and the *SSI Annual Statistical Report, 2004*.

The importance of these Social Security programs and their impact on the lives of people with disabilities led the Board to focus much of its attention on disability over the ten years since it first began to carry out its mandate to examine the Nation’s Social Security systems. In our reviews, we found many administrative issues that needed attention, and many of the Board’s reports contain recommendations about how the operations of the program can be strengthened. We expressed concerns about the lengthy processing times in many parts of the program, the unexplained geographical inconsistencies in disability determinations as well as at different levels of adjudication. The need for stronger quality management and policy development capabilities has been noted as well. But, as we examined these essentially administrative and resource issues, we were continually confronted with questions about how well the programs were aligned with the Nation’s fundamental disability policy goals as enunciated over 15 years ago in the *Americans with Disabilities Act*. We also discovered that there is something about these programs that was antithetical to another basic need—the need to pursue independence and a sense of contributing to one’s own self support and to the good of society.

In examining these apparent conflicts, the most obvious and frequently cited suspect was the Social Security definition of disability. The Social Security Act equates disability with inability to do any substantial work. This core definition is as old as the program itself. It was adopted at a time when attitudes about the capabilities of people with disabilities were markedly different than they are today. As the Board pointed out in the 2003 report, *The Social Security Definition of Disability*, the definition was adopted for a program that was limited to individuals approaching retirement age, and the program was explicitly viewed as representing a kind of early retirement. It was adopted by a Congress that could not have foreseen the great advances that would take place over the next fifty years in medical science, adaptive technology, and rehabilitative practice and therapy.

In looking at the Social Security definition of disability, many of those with whom the Board consulted pointed out the apparent contradictions between a program definition that rewards applicants for proving that they cannot work and a national disability policy that emphasizes independence and encourages individuals with significant limitations to make as much of a contribution to society and their own self support as possible. A 2003 Government Accountability Office report placed the Social Security and other federal disability programs on the GAO “high risk” list. In doing so, it characterized them as “mired in concepts from the past and...poorly positioned to provide meaningful and timely support for Americans with disabilities.”

Most of our public policy was originally developed on the assumption that disability was life-long, helpless, hopeless and eternal dependency. And I am sorry to tell you that model is very much alive and well...

Roundtable participant, Washington, D.C.

Still, in the extensive study the Board has undertaken since 2003, the Board has also heard concerns expressed about what it would mean to modify the definition of disability used for Social Security programs. Changing the definition could result in narrowing eligibility in ways that would exclude individuals who have no alternative but to depend upon the benefits those programs provide or could result in broadening eligibility so as to increase the costs of the program and provide benefits to individuals beyond the currently intended scope. We recognize the validity of these concerns. It is our purpose in this report to suggest neither that the existing disability programs should provide coverage more broadly nor that they should be contracted to prevent individuals who are unable to engage in substantial work from receiving their benefits. The problem that we see is in the way in which those programs are, or rather are not, integrated into an overall approach to disability that supports the aspirations of people with disabilities to achieve their maximum potential. Correcting this problem will require a statutory change to define disability in a way that encompasses such an integrated approach.

The Social Security disability programs have been described by many as “programs of last resort.” This seems to us to be an appropriate description. It will, of course, remain true that many of those with severe impairments may need access to those programs on a virtually immediate basis, and such access must remain available. However, the first alternative to be explored must be how to enable persons with work incapacities to avoid, postpone, or minimize their need for dependence on the programs of last resort while assuring that those programs and the important protection they provide remain in place. The first question society poses to those with significant impairments should not be, “Can you prove you cannot work?” The first question should be, “What type of assistance do you need in order to achieve your maximum possible contribution to your own well being and to the good of the community?” If we do not find a way to make that the first question, we will be endorsing and fostering a culture of pessimism and dependency.

In the remainder of this report, we will describe our vision of a 21st century disability system that is founded on a culture of encouraging and supporting economic self-sufficiency, independence, and the personal rewards that come from being able to make a contribution. We acknowledge that the implementation of such a vision will involve much detailed planning that

is beyond the scope of this report. In our work over the past few years, we have found that a great deal of thought and study that could support such a vision is already underway by many individuals and organizations. Policymakers will, therefore, find a wealth of thoughtful material to work with.

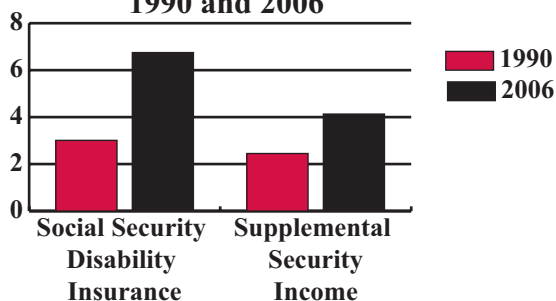
As will be discussed in more detail later in the report, we are aware that the budgetary situation constrains the ability of policymakers to adopt new spending initiatives. However, we have heard widespread agreement that the current overall approach to disability is harmful to people with disabilities, is contrary to basic societal values, and, in particular, contradicts the policies and values of the *Americans with Disabilities Act*. We concur in that judgment. We believe that it is necessary to establish a clear, if broadly drawn, vision of what our national disability system should look like and to take whatever steps we now can to move toward that goal. The new system will be a foundation for a national culture that integrates people with disabilities into society as important and contributing members.

II. Trends in Disability Expenditures and Number of Beneficiaries

Not only is there impetus for change because the existing national approach to disability is antithetical to both the interest of the disabled population and to basic American societal values, there are also very strong economic reasons why the approach to disability needs to be reexamined. We are, as a Nation, already spending a huge amount of public dollars on programs for people with disabilities, the great bulk of which is being expended for those who are currently dependent upon Social Security’s disability programs. A recent Cornell University study estimates that federal and state spending on programs for the working-age disabled came to \$276 billion in 2002 or 2.7 percent of the Gross Domestic Product. Ninety-six percent of those expenditures were for income security and health care and three-quarters of the total expenditures were for cash and health benefits for beneficiaries of the Social Security disability programs

These costs, however, are not static, but growing. As Chart 2 shows, the number of disabled workers drawing Social Security Disability Insurance has more than doubled since 1990 from 3 million to 6½ million. In the past 15 years, the working-age population of our Nation has grown by 18 percent. During that same period, the number of persons receiving Social Security Disability Insurance benefits has increased by 117 percent, and the number of disabled working-age SSI recipients has grown by 66 percent.

**Chart 2 Working Age Disability Beneficiaries
1990 and 2006**



Sources: SSA *Monthly Statistical Snapshot*, July 2006; *2006 Annual Report of the Supplemental Security Income Program*, *2006 OASDI Trustees' Report*

The projected long-range costs of the Disability Insurance program grew by over 38 percent during the last 15 years. Benefit costs in constant (2005) dollars have increased since 1990 from \$42 billion to \$86 billion and the Disability Insurance Trust Fund is already paying out more than its statutory share of program tax income and is projected to reach exhaustion in less than 20 years. If we can find ways to keep enough individuals in productive employment to reduce long-range disability insurance costs by as little as 10 percent, the present value of reduced benefits would be \$555 billion. This would eliminate roughly two-thirds of the 75-year deficit in the DI program, reducing it from 0.33 percent of payroll to about 0.1 percent. Moreover, facilitating the ability to remain in active employment can enhance an individual's own well-being and can provide an improved standard of living. Add to this the contribution such individuals would make to economic productivity and tax receipts, and it becomes clear that a national cohesive disability policy offers important opportunities for constructive change.

Even apart from their impact on the growing cost of the disability programs themselves, the coming demographic shifts will place severe pressure on our economy's ability to maintain standards of living for the working-age and retired population. Our society has entered the era where the aging baby boom generation is concentrated in its disability-prone years. Since 2000, there has been a steady increase in the disability incidence rate in the baby boom population, and it is expected to continue to grow over the next several years. It is therefore crucially important that we do not needlessly increase program costs and waste human capital by failing to enable individuals with impairments to make some contribution to our national workforce. Unfortunately, there is a lack of strong research that would permit reliable estimates of how much added productivity and reduced benefit costs might be attainable. We recognize that in the absence of such evidence, the argument can be made that it is impossible to know if long-term savings will offset short-range costs that can accompany change. The Board recognizes the uncertainty inherent in any new bold initiative, but we believe that there are strong arguments in favor of acting now. The long-range costs of failure to act are clear from the continuing growth of the programs under existing policy and the meager results of current efforts to support work activity. We find broad agreement on some of the major reforms that would be necessary to transform the system in ways that can reduce the growth of dependency and provide the necessary encouragement and support to achieve a substantial increase in the economic contributions that people with disabilities can make.

As the Board examined the issue of whether the Social Security disability programs are appropriately aligned with national disability policy, we found broad agreement that they are not. However, concern was also expressed that our focus on this lack of alignment may be interpreted as a signal to cut back on the support provided through the programs administered by the Social Security Administration. We do not intend such a result, nor do we believe that direct reductions in the assistance provided by these programs are either feasible or desirable. However, we are convinced that the absence of a coordinated and integrated national system to support increased participation of people with disabilities in the workforce has contributed substantially to the continuing rapid growth of the costs and caseloads of the Social Security disability programs. And we believe that, in the long run, the adoption of such a coordinated and integrated system will not only enable people with disabilities to have a life that is more fulfilling and more economically rewarding but will also lessen the overall level of dependence on—and therefore the cost of—those programs.

One question that might arise is whether such decreased expenditures or possible savings, or much of them, could be achieved by doing a better job of screening applicants for disability benefits so that those who have the ability to work do not become beneficiaries in the first place. Similarly, will doing a better job of rehabilitating those on the rolls so that they stay on for a shorter period result in large savings? Although these are logical questions, the answer to both is no. Certainly, every effort should be made to make initial eligibility determinations accurately. And, certainly it is worthwhile to try to support and encourage rehabilitation efforts by those who do find themselves on the disability benefit rolls. However, past experience has shown that these approaches are largely ineffective and are likely to remain so. The reason is that by the time an individual applies for disability benefits and, even more so, by the time he or she is actually placed on the benefit rolls, the best opportunity for restoring or retaining the capacity for self-support has already been lost. In the absence of a disability system designed to manage toward self sufficiency, the realistic possibilities of someone with a work limitation remaining productive begin to fade. The process itself tends to make an individual who might have been able to work at an earlier point in time less and less capable of doing so. Attachment to an employer, the maintenance and improvement of skills, the sense of belonging to the workforce, the mindset that work is possible—the loss of all of these factors, combined with the passage of time and with the program requirements that reward inability to work, conspire to transform a person from an “impaired individual” with potential into an individual who, in fact, has come to meet the definition “unable to work.”

The Board does not believe there is a single magic answer. There has been research on ways to encourage return to work done in the past; however, much of it has been inconclusive, and certainly there is no substantial body of evidence-based research that shows clearly what specific changes would work with what population. Additional research has been undertaken recently by the Social Security Administration but the implementation of such research and demonstration projects has proceeded slowly. It is impossible to predict in advance how significant the results will be. And, in any case, usable results will not be available possibly for several years. While the Board strongly believes that this evidence-based research is important, it does not preclude rethinking the approach to disability supports and services now.

While disability policy differs in many respects from welfare policy, there are certain parallels. Prior to the development of welfare reform, the then current programs created widespread dissatisfaction on the part of both the public and those they aimed to serve. Program costs and caseloads were on the rise. Attempts to improve the standard of living and create incentives to work were largely ineffective. Evidence-based research demonstrated, however, that effective change could be made, but only when there was a fundamental cultural shift away from a presumption that work was out of the question and toward a presumption that recipients did have the ability to work. While the disability program has not been subjected to the extent of experimental research that AFDC had been, the research that has been done thus far shows that our current disability system presumes that work is not feasible and thus, effectively locks beneficiaries onto the rolls once they get past the initial disability determination.

The Board is aware that existing budgetary processes impose constraints that make it difficult to fund near-term investments which have the potential of achieving significant savings in the longer run. Nonetheless, we believe it is our responsibility to make the recommendations in this report because we are convinced that the current lack of an integrated disability system is a disservice to all members of society. The models we propose in this report can serve as a goal to be discussed and adopted now and to be fulfilled as resources allow.

III. Return-to-Work Demonstration Projects and the Ticket to Work Program

Over the past 20 years SSA has engaged in a variety of research and demonstration projects designed to increase employment of beneficiaries. These activities began in 1985 with the Transitional Employment Training Demonstration, which tested new methods of delivering vocational rehabilitation services to SSI beneficiaries with IQs in the 40-70 range. Project NetWork, in 1991, was SSA's first large-scale interaction with private rehabilitation providers and marked the first time that the agency provided services directly to beneficiaries to help them enter the labor force. The State Partnership Initiative, which focused predominantly on providing benefits counseling, was fielded in 11 states from 1998-2004. These large-scale voluntary programs targeted specific populations and had participation rates averaging only in the 4-5 percent range. This should not be too surprising, given that the programs were offered after beneficiaries had proven satisfactorily to SSA that they could not work.

The projects all had some valuable lessons. The more successful programs had the flexibility to tailor services to the needs of the individual and offered an array of services, including benefit planning and counseling, work assessments, psychological counseling, physical and occupational therapy, job training and search assistance, and other employment services. The findings from the most recent of these demonstration projects, the State Partnership Initiative, indicate that benefits counseling and employment services increased employment rates among the beneficiaries who participated in the program. Other demonstrations, as well, showed some positive impact on employment rates (and earnings), but these effects were small and seemed to diminish over time.

SSA also established other employment programs that targeted disability applicants. Research demonstration projects were funded in the mid-80s that offered rehabilitation services to SSDI applicants (rather than to those whose claims had already been approved). Disability research experts have suggested that the outcomes from these demonstrations provide some indication that higher participation may be possible if the intervention is targeted to applicants. They also conclude that the strongest predictor of program participation is recent work experience.

While these demonstration projects had some positive outcomes that encouraged and supported steps toward economic self-sufficiency, focusing all of the return-to-work efforts inside the structure of the disability program seems to be too late for many individuals. In order for the intervention to be effective, it needs to occur before the individual comes to SSA, before he applies for SSDI or SSI, and before the attachment to the workforce is lost. What is strikingly clear is that the policy of waiting until an individual has established entitlement to SSDI or SSI and has effectively removed himself from the workforce for at least 12 months seems to be at odds with optimal timing for return to work interventions.

Ticket to Work Program

In the legislation adopted in 1999 that created the *Ticket to Work and Self Sufficiency Program*, Congress noted that individuals with disabilities have greater opportunities for employment than ever before, yet despite such opportunities and the motivation of disability recipients to work and support themselves, fewer than one-half of one percent of SSDI and SSI beneficiaries return to work and leave the benefit rolls. The Ticket program has been designed

to address that lack of participation in return to work efforts by improving beneficiary access to rehabilitation and employment services and by improving the quality of those services. It has incorporated several features from earlier demonstrations, most notably benefits counseling and the use of private service providers as an alternative to state vocational rehabilitation services. The legislation also creates a different payment for services plan that is meant to induce more providers to enter the return-to-work market and create more choice for beneficiaries.

Tickets are offered to most beneficiaries, with a notable exception – individuals who have impairments that are expected to medically improve in a year and have not gone through the continuing disability process are not eligible for a Ticket.¹ The program was phased in for current beneficiaries between February 2002 and September 2004; Tickets to new beneficiaries have been mailed out monthly since then. As of August 2006, of the 10 million Tickets that have been mailed out, approximately 144,000 beneficiaries have entered the program. The most recent available data on the number of Ticket participants who are actually working is from the 2004 National Beneficiary Survey, which is part of the Ticket program evaluation. This early data from the first phase of the Ticket rollout, showed that 10,000 of the 21,000 Ticket holders were working. Participation rates in the Ticket program have been found to be higher for beneficiaries who were allowed at the initial determination level. This seems to suggest that those individuals with a more recent attachment to the labor force may be more likely to respond to return to work initiatives.

Even though the Ticket to Work program has helped some individuals regain employment, its success, when measured against the number of people coming onto the disability rolls, is quite limited and the reason is clear. The intervention process comes too late in the process – after the individual’s connection to employment has been severed and frequently after that individual has undergone a lengthy process of proving inability to work.

IV. Vision for the 21st Century

Throughout the Board’s existence, we have spent many hours studying the disability programs, talking to consumers, employers, and disability experts. In all of these conversations, there have been many recurring themes about the shortcomings of the current system. We heard that current public policy is based on the concept that disabilities are lifelong and hopeless and that society still has barriers in place that constrain self-fulfillment. The country’s disability programs do not, generally, recognize the cyclical nature of some disabilities and the concomitant impacts on work capacity. Navigating the hundreds of programs which are frequently uncoordinated can often be an insurmountable challenge. Moreover, conflicting rules for eligibility among the programs can often lead to unintended consequences. The current disability program provides a vital aspect of our country’s social protection system but it has remained basically the same for more than 50 years, even though the environment in which it operates has changed significantly. Scientific advances and economic and social changes have redefined the relationship between impairments and the ability to work. Advances in medicine and technology have reduced the limitations imposed by some medical conditions and individuals experience greater independence and function more productively. Social and legal changes have promoted the goals of inclusion and participation by people with disabilities into

¹SSA published a notice of proposed rule making on September 30, 2005 that seeks to eliminate this exception.

the mainstream of society. The labor market has changed as the national economy has moved toward service and knowledge-based employment.

At a minimum, a 21st century disability system should be one that is responsive to the changing demographics that will shrink the labor force. Over the next 45 years, the over age-40 population will dramatically increase. More people will be entering their disability prone years and could potentially exit the labor force. The Nation's disability system needs to continue to provide essential support to those who need it, but it must also establish a mechanism that maintains a worker's ability to stay in active employment.

We believe that it is time to set aside old paradigms and look more broadly at what is possible. Clearly, a shift in public policies is needed to sustain the employment of people with disabilities. It is time to reexamine our national disability programs with a view to investing in human capital – our most valuable asset. A new disability system must incorporate elements that embrace change and:

- provide assistance and support to individuals and strive to maximize employment outcomes to the extent of each individual's capabilities;
- facilitate a culture shift within society to establish the expectation that individuals with disabilities can and should work to the extent of their capabilities and that society should assist individuals with disabilities in that endeavor;
- recognize and accommodate the dynamic nature of disability and its sometimes cyclical impact on work capacity; and
- facilitate rehabilitation and employment by coordinating and integrating the various sources of assistance and support that are now inconsistently provided by multiple uncoordinated programs.

The new system would recognize that it is not inconsistent to receive supports and work. It will accommodate the continuum of individual abilities and readiness to contribute to one's self sufficiency. It will strengthen and support choice, making the consumer an active partner in designing appropriate services and supports. The interventions will lead to independence, productivity, and community inclusion.

Nobody knows better than me about me and how I can achieve my goals.

Roundtable participant, Washington D.C.

In order for these changes to be effective, there needs to be a larger systemic change that facilitates coordination and integration of services and supports. There needs to be, as someone described it to the Board, a "front end on the stove pipes." This front end is not a barrier to SSDI or SSI, but instead represents a real chance to access tailored services that can enhance return to work efforts. It provides timely intervention before the attachment to the work force is totally lost and the societally imposed culture of having to prove inability to work before benefits and services are offered takes over.

The current disability programs remain in place, and for some people will remain the path of first choice. However, for many others, a coordinated and supported environment in which to access rehabilitation programs and to acquire training and skills that will lead to a productive return to work will be the path of first choice.

As we reflected on the features of prior employment programs and demonstrations and on best practices from public programs and private industry, it seemed that there were some real lessons learned that should be used in designing a new “front end.” The features of this new “front end” include focused case management or service coordination. Working with the individual, the service coordinator arranges for a multidimensional evaluation that will result in a tailored assessment of work potential and the development of a return-to-work plan that is specific to the situation of the individual. This “prescription” or plan will ultimately lead to improved employment readiness and outcomes. Moreover, because there is the acknowledgement that significant limitations can be episodic, the return-to-work prescription needs to be flexible.

Drawing on the findings in research and in employment literature, as well as the extensive experience of private disability insurance providers, we are convinced that people – especially those with recent work history– will participate and will benefit from a coordinated system that provides incentives rather

disincentives to work. Providing a process that facilitates transition from employment through retraining and rehabilitation and back into the work place is the place to start.

The private health industry has incentives to get their claimants back to work and therefore they will move mountains to make that work.

Roundtable participant, Kansas City

V. A Model Disability System for Adults

The population of persons with significant impairments is certainly anything but homogeneous. There are individuals who are born with serious disabilities. There are people who experience their first encounter with serious mental or physical impairment at various stages in their life from childhood through advanced age. Some have strong educational or vocational backgrounds. Others have lower educational levels and limited work histories prior to experiencing a disabling event. Some experience disability as a sudden traumatic event. For others the degree of impairment gradually progresses and becomes more severe over time. Still others have disabilities that are cyclical in nature. A national disability system needs to be flexible enough to appropriately address all of those with disabilities. In this part of the report, we will discuss a basic model for adults, starting with those who experience the onset of disability during the course of an otherwise “typical” work life.

Under current practices, an individual with a disability which is or becomes severe is likely to encounter the national disability system first through a contact with the Social Security

Administration by calling the 800 number, going to a field office, or visiting the SSA website. What such a person will hear can be illustrated by how the Disability Insurance program is now described on the website:

The definition of disability under Social Security is different than other programs. Social Security pays only for total disability. **No benefits are payable for partial disability or for short-term disability.**

Disability under Social Security is based on your inability to work. We consider you disabled under Social Security rules if you cannot do work that you did before and we decide that you cannot adjust to other work because of your medical condition(s). Your disability must also last or be expected to last for at least one year or to result in death.

This is a strict definition of disability. Social Security program rules assume that working families have access to other resources to provide support during periods of short-term disabilities, including workers' compensation, insurance, savings and investments.

This information is accurate, but it clearly sends a message that does not encourage, much less offer support for, attempting to work. If the individual does proceed to apply for benefits, he or she is entering into a system that clearly provides its rewards for proving that doing any substantial work is beyond the applicant's capacity. The eligibility determination process, therefore, is likely to take place only after the applicant has accepted a mindset that significant work is no longer feasible. And the determination process itself has a similar negative objective of establishing inability to work.

The “all or nothing” concept is inherently discouraging to work. People should not be told that you get benefits only if you can do nothing. The program should provide support for people to do as much as they can.

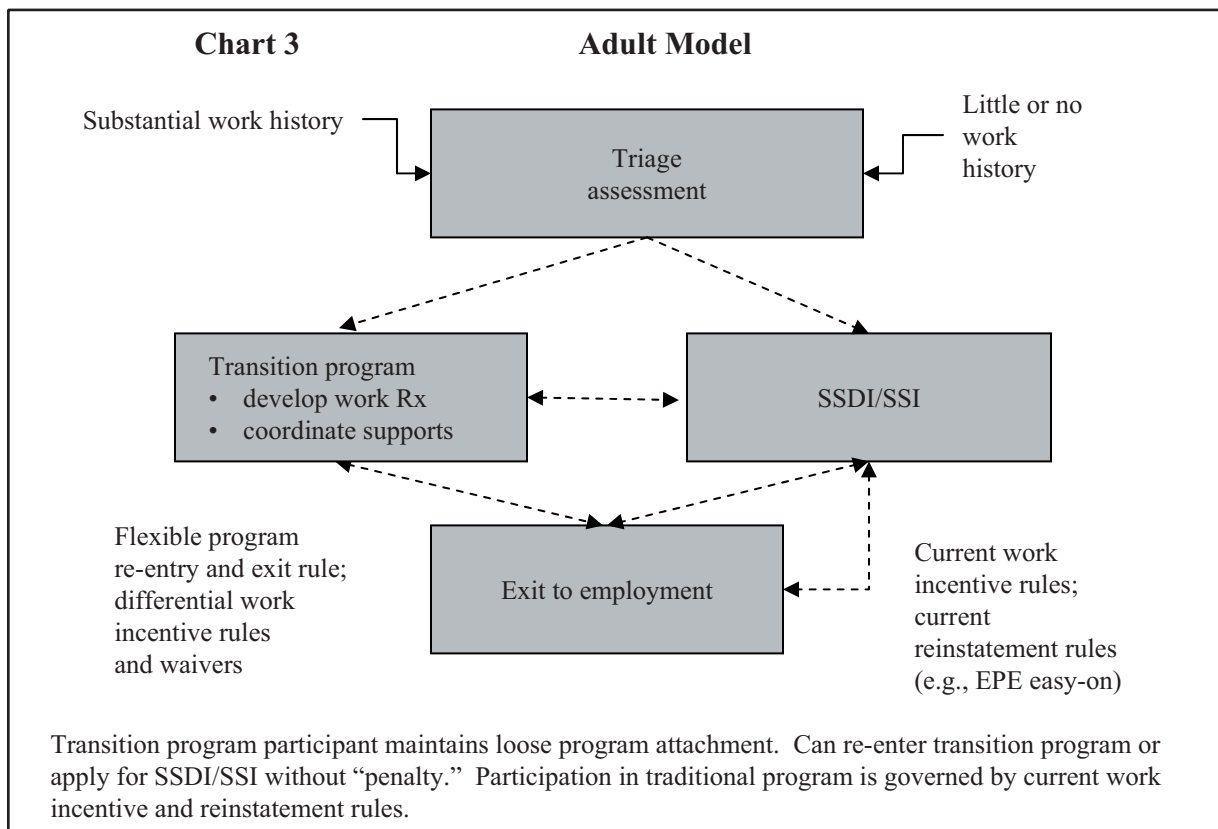
Roundtable participant, Kansas City

One Size Does Not Fit All

Chart 3 diagrams a model that we propose as an alternative to the present system. In that model, the first contact that an impaired individual would have with the “disability system” would involve an assessment that focuses on what resources he or she, and society, have available to make it possible for that individual to retain or regain capacity for self support. This would typically involve some type of functional testing and evaluation to ascertain what residual capabilities the individual has retained and what kinds of supports will be needed to maximize those capabilities.

The model assumes that this assessment would take place very quickly after the onset of the impairment. Depending upon the circumstances and the nature of the impairment, a full assessment might need to be delayed somewhat until the condition stabilizes, but the model assumes that it would take place much earlier than the point at which individuals tend to encounter a disability determination as part of the Social Security application process. For adults who become disabled while employed, the assessment should take place, if at all possible, while the employment relationship is still active.

While the assessment is not envisioned as a Social Security style eligibility determination, it would necessarily involve some elements of triage. Some individuals would be easily categorized as having obviously temporary or minor impairments needing little or nothing in the way of supports beyond what may already be readily available through existing employer health and leave programs. Others may have such clearly severe or traumatic conditions that the logical step would be immediate application for benefits under the existing “last resort” programs, although even those individuals could elect the rehabilitation path, if they chose. They should be assured that doing so would in no way preclude or delay their entry into the Social Security disability programs if or when they find that alternative necessary.



For those who cannot be immediately triaged as being appropriate for immediate referral to the current disability programs or as having temporary or minor impairments, there would be a comprehensive assessment. The nature of the assessment would be essentially the reverse of the Social Security adjudication process which first takes a highly medical approach to see if the severity of the impairment or lack thereof allows a quick decision that the individual is or is not unable to work and, only if that screening process fails, looks to see if a more functional and vocational approach can separate those who are able to work from those who are not.

Under the model that we propose, the objective would be to measure an individual's functional abilities and determine how those abilities could be maximized through an appropriate support environment. This multidisciplinary assessment would be carried out through a nationwide network of public and private medical and vocational experts. This essential expertise exists in many organizations around the country and would be readily available at the local community level. The Social Security Administration has begun to develop a foundation for such a network of medical and vocational experts as part of its Disability Service Improvement plan.

Unlike the Social Security disability determination, the assessment this model envisions is not a "yes/no" eligibility decision. Rather it needs to result in a plan of action prescribing the steps and supports needed to keep the individual on a track to resumption of employment. These can, depending on individual circumstances, include such elements as medical treatment, counseling, transitional income support, rehabilitation therapy, retraining, and other such treatments and services that can facilitate the restoration of self support capabilities.

This type of positive assessment of abilities would go a long way to correcting the culture of inability and hopelessness that is engendered by the existing process. However, a truly effective system should also assist the individual in implementing the plan of action by providing continuing guidance and coordination of the identified support services. Currently, the chances of individuals with significant impairments being appropriately connected with needed supports are haphazard at best. Ongoing access to a coordinator or planner who can monitor the progress of a rehabilitation or self-support plan, put the individual in contact with available supports, and suggest reassessments and course corrections as needed is an essential element in the success of such a plan.

The objective of this model is not to put obstacles in the way of those who need the benefits of the existing Social Security disability programs, but rather to assure that those who have the ability to retain or regain a life of productivity and self support are not unnecessarily abandoned to dependency on those programs. We see this model as ordinarily coming into play at an earlier stage than the point of application for Social Security benefits. Participants in this model would not be barred from applying for Social Security benefits at whatever point they determine that such action is necessary. The outcomes from the assessment and subsequent rehabilitation programs should, if anything, facilitate the eligibility determination for longer-term benefits, since the information developed in the assessment process would be readily available for any subsequent benefits application. While we are convinced that many participants in the model approach will be able to avoid or significantly defer the need for dependence on the Social Security disability programs, we believe that, even for those who ultimately find it necessary to apply for those programs, their participation in the model approach may enable them to enjoy a higher level of independence and sense of contribution than would be the case otherwise.

Learning from Existing Efforts

We understand that some additional work would have to be done to develop the details of how such a model would actually operate. In our study of what now exists and our discussions with a variety of experts, we have found some helpful and impressive examples of existing efforts. These innovative programs could be expanded, coordinated, and utilized to create a culture that clearly states that the contributions of people with disabilities are important and that independence is possible. For example, many businesses participate in programs such as the Business Leadership Network that promotes an understanding by businesses of how they can tap into an underutilized important human capital resource by actively seeking to employ people with disabilities. The Workforce Investment Act (WIA) established a network of locally-based One-Stop Career Centers that bring together in one location public and private resources, including local, state, and federal programs that provide employment services to individuals seeking work, including those with disabilities. Business-led Workforce Investment Boards, funded through WIA, provide training and educational services that prepare workers to reenter the labor force. We also learned that some labor unions, such as the International Association of Machinists, have a long history of operating significant programs to support the return to work of injured or disabled workers.

Employers in Partnership with Insurers

One particular example that is closely aligned with the Board's model is the support offered by private disability insurers. Many employers today provide disability benefits for their workers. While there are many different levels and types of private disability insurance, some of the major plans employ methods quite similar to the model the Board would recommend. A common approach is to provide separate short-term and long-term programs with both programs administered by the same insurer. As soon as an employee qualifies for the short-term benefits, a process is set in motion to identify whether the disability is likely to be protracted and, if so, to provide an assessment of the employee's functional capacity and the probable impact of the impairment on the employee's ability to meet the functional demands of the workplace.

If it appears feasible that the employee could eventually return to the previous job or to other work for the same employer or to other employment, a plan of action is developed to help that employee meet the appropriate employment goal. The work prescription will identify the kinds of supports needed to meet the identified objective. Identified supports could include workplace accommodations, adaptive equipment, rehabilitation services or therapies, and training. A case manager or coordinator is assigned to the individual to assure that the needed supports are provided and to track the progress of executing the plan of action. Greater contact is generally necessary in the early part of the plan, but the coordinator has continuing responsibility to monitor progress and provide any needed intervention. This approach benefits the employee who is enabled to return to productive employment, the employer who maximizes the retention of skilled employees, and the insurer who avoids unnecessary long-term benefit liability.

According to Bureau of Labor Statistics compensation surveys, close to 30 percent of all workers are enrolled in employer sponsored long-term disability programs. Not all of these have the type of early assessment and planning described here. Moreover, the availability of

such plans, at this time, tends to be more likely for larger employers. However, this is a useful working example for the implementation of proposals along the lines the Board suggests as a model.

Bridging the Gap in the Public Sector

The Board also notes that several states already operate short-term disability programs that provide benefits to individuals who have temporary disabilities or who have not yet met the Social Security Disability Insurance program's "waiting period" requirements. In general, these are state-operated programs although some of them allow employers to utilize private insurance programs as an alternative. There is little federal involvement although most of these programs have some connection with the federal-state unemployment compensation program. The existence of these short-term programs is based on a recognition that the unemployment program does not provide coverage for those whose unemployment arises out of their disability.

Except in the limited cases where these state short-term disability programs operate in conjunction with private insurance programs offering short-and long-term benefits, these state programs do not now incorporate the kind of model that the Board is proposing. Since states have no liability for long-term disability costs and the largest part of their caseload will, in fact, have temporary disabilities, there is no built-in incentive for the states to undertake the kind of assessment and coordination of services discussed here. If such incentives could be provided, these state-run programs could be an important element in developing a 21st century approach to disability.

We believe that the development of specific proposals to implement the model that we are proposing should consider ways of providing such incentives. It should aim at taking advantage of the fact that there are already programs operated by businesses, nonprofit employment and rehabilitation organizations, unions, private insurers, the Department of Veterans Affairs, the Department of Labor, state Vocational Rehabilitation agencies, and other state, local, and private agencies that are well positioned to be a part of such a model. Entities like these already have contact with impaired individuals early in their disability and at that crucial point where an employment relationship still exists. In particular, as we will discuss in more detail later, we believe a cooperative project with one or more states to merge short-term disability benefits with the necessary assessment and coordination could be used as a major pre-test of the model we propose.

Such employment-based opportunities offer the most promising avenue for building a model that reaches individuals early in their disability and maintains their motivation and capacities for self support. However, the Board is aware that there are individuals with disabilities who do not have the substantial connection to an employment relationship that could be the basis for efforts to provide the kinds of assessment and supports that are envisioned in our adult model. Some individuals may have limited educational backgrounds and sporadic connection to the workforce. For others, the onset of disability may be early in adulthood while still engaged in education or during a period of unemployment. Still others may have decided to withdraw from the workforce temporarily.

Our model envisions that adults who have a significant limitation but who do not have an ongoing employment relationship would nonetheless have access to assessment and supports that would facilitate the maintenance of their capacity for independent living. Moreover, it is

important not only to have such elements available to those without strong employment relationships, but also to assure that affected individuals are made aware of these resources. An obvious source of such information and referral could be medical providers, but with the exception of occupational medicine, few physicians receive any training in disability assessment and management. This needs to change.

VI. An Integrated Disability System Model for Youth

Disability, as it affects children, differs in many ways from disability in adults. The Social Security Disability Insurance program does not ordinarily provide benefits for children, and the Supplemental Security Income program uses a special definition that primarily looks at the child's functional limitations rather than at the question of ability to work. But those who are disabled in childhood will ultimately move to the adult world and will be measured against the adult disability standards even though they may be at risk and ill prepared to assume adult responsibilities. Too often upon reaching adulthood, they lack education, work skills, and even life skills to fully participate in society. This deficit aggravates the physical or mental limitations that affect their ability to work.

Because children are different from adults, a different disability support model is necessary. Although the details of how such a model would operate will be different, the basic problems are the same. In our discussions with advocates, program administrators, youth with disabilities and their families, and experts on childhood disability, we heard clear messages, including:

- A need for an early, comprehensive, functional assessment.
- A need for a major culture shift that emphasizes expectations of independence, self-support, and participation.
- A need for continuing guidance and management that not only provides planning toward those expectations but also identifies the necessary supports and coordinates the provision of those supports.

We learned that some portion of these strategies exists in theory but either does not exist in practice or is inadequately carried out. Youth with disabilities, like other children, should spend their formative years learning, growing, and planning for a productive and independent future. To do this, families, educational systems, and providers of rehabilitation, training, and other supportive services need to forge an earlier and stronger alliance. And there must be a systematic coordination of these elements.

The lack of an appropriate system for addressing the needs of disabled children can be seen in what happens as they transition to adulthood. The picture of SSI youth that emerges from the National Survey of SSI Children and Families (NSCF) is instructive. Less than half of the youth who are or were on SSI graduate from secondary school. For the young adults (ages 19-23), who are on SSI, nearly 60 percent reported they were not working, going to school, or in vocational training. Of those who had left the SSI program as the result of the age-18 redetermination or for other reasons, just over half were not in school, working, or in a training program. Clearly, the transition to adulthood was not seamless for these youth. This is even more apparent when looking at income. Those who remain on SSI after 18 as well as those who leave the rolls have incomes, on average, only slightly above the poverty line. Youth who come on the SSI rolls before age 18 spend, on average, 27 years on benefits over their lifetime. The

first term of entitlement averages 10 years. The cash benefits of SSI and access to Medicaid are clearly important to the children and their families. But these alone do not prepare the youth for adulthood.

Students in special education, many of whom are SSI recipients, are required by the Individuals with Disabilities Education Act to have an Individualized Education Program (IEP). There are many aspects of the IEP system which represent an excellent approach to addressing the needs of children with disabilities. The IEP system is carried out by schools, which have continuing day-to-day contact with children and have a clear institutional interest in developing the full potential of students. States are required to identify, locate, and evaluate children with disabilities. Requirements include an evaluation designed to identify educational needs and services that will lead to the achievement of specific goals. Progress should be monitored, and the plan must be reviewed at least annually with a triennial reevaluation. Parents, the disabled children, regular and special education teachers, and additional individuals with special knowledge or expertise are expected to be involved in the process. Transition planning is required to be incorporated at least by age 14, and identified transition services must be incorporated into the plan at least by age 16.

Unfortunately, we have heard repeatedly from parents, young people, and disability experts that the quality of the planning as well as the content of the IEP are frequently insufficient or lack meaningful life-skill or knowledge-development benchmarks. The existence of the IEP system certainly is an important advance, and it undoubtedly does provide important help to many individuals. Too often, it appears to represent paper compliance with an ideal that is not actually carried out in a meaningful way. As was pointed out earlier this year in our annual *Statement on the Supplemental Security Income Program*, the Department of Education has found many states out of compliance with the content requirements for IEPs. Examples include schools which essentially used “boilerplate” IEPs with identical goals and objectives and IEPs which did not include goals and objectives to address identified needs.

Moreover, even where the IEP identifies needed services, these services are frequently not in fact provided. The Board has heard, for example, that it is often difficult to get Vocational Rehabilitation agencies to provide services to transition age youth because those agencies are not well equipped to meet the needs of that population. Additionally, many agencies believe that services to such youth will not achieve the kinds of results for which the agencies receive credit, such as quick job placement at a significant earnings level. As a result, an IEP that identifies VR services as a transition need will often be “achieved” by the individual’s placement on a long waiting list.

Our discussion with experts and others concerned with disabled children have also led us to conclude that the IEP system, even if well implemented, has significant limitations. While it is helpful and useful to have evaluations of disabled children in the context of their school attendance, functional evaluations even earlier in life are likely to be able to identify corrective measures that will have major long-term payoffs. Within the IEP process, the provisions for transition planning by age 14 and identification of transition services by age 16 are important, but many of those we consulted believe that planning for the future should generally begin even earlier, perhaps as early as age 8 to 12. Care, of course, needs to be taken not to inappropriately “track” children into vocational goals at the expense of developing and meeting appropriate academic objectives. Children need from an early age to learn the basic life skills and attitudes that will be important in any type of future work life.

Parents are still being told that their kids with severe disabilities will never be able to work. These explicit goals should be written on the wall of every classroom from kindergarten on: “independence,” “productivity,” “community inclusion.”

Roundtable participant, Washington, D.C.

The Board heard time and again, and we concur, that it is essential for children from their earliest years to develop in a culture where the expectations are ones of maximum feasible self support and participation in the life of the community. As we reviewed the IEP guide published by the Department of Education, we see no emphasis—indeed essentially no mention—of this important issue of fostering expectations.

While the IEP system may be a good start, we believe that much more can and should be done. The current situation imposes large costs on the affected children in terms of undeveloped potential for a fulfilling, productive life and on society in terms of foregone productive capacity, as well as significant costs for benefits. Addressing the needs of disabled children is therefore a societal responsibility, regardless of where

From a taxpayer’s perspective, the program with the best return on investment is a timely or early intervention.

Roundtable participant, Washington, D.C.

administrative responsibility may ultimately fall. It is a responsibility that needs to be fulfilled not only for those children currently receiving benefits under the SSI program, but for all children with disabilities including those who, because of parental income, may be ineligible for SSI as children but may become eligible for SSI or other benefits later in life.

Without some type of overarching program that embraces all children with disabilities early in their lives, these young adults may indeed be facing a life of unrealized potential and poverty. It is imperative that a 21st century, integrated disability system assist and support all individuals and that it strive to prepare each person to participate fully in society and maximize their employment outcomes to the extent of their capabilities.

Integrating Services — Changing Lives

We believe that it is time to develop a timely, coordinated, and purposeful approach to evaluating and developing a tailored “life-progression” plan. This should begin with functional assessments at the appropriate times in the child’s development. The assessments should be conducted by competent and well-trained professionals from a variety of disciplines. The child and the family would be referred to a service coordinator who would arrange for a multi-dimensional evaluation. For those children in special education, this evaluation could work in concert with the IEP process and would identify and provide access to the needed services, technologies, supports, education, and training that will help shape a meaningful developmental program. A major role for this system would be the coordination of these services which are now

available on an inconsistent, “stove pipe” basis. The evaluation should not be just another “add on” to the already crowded, and often conflictive, field of required tests, development plans, and educational requirements. But rather, it should be the starting point for marshalling and arraying in a more systematic fashion all of the appropriate services and interventions that would benefit the development of the child.

The evaluation would result in a tailored assessment of abilities and a plan for maximizing the child’s potential and emphasizing expectations. As the child matures, the plan would also mature, shifting its focus over time to more adult-oriented life skills, education, and training. Participation in this additional program would not be conditioned on being enrolled in special education, would be voluntary, and the child would, if eligible, continue to receive any SSI payments and Medicaid coverage. For those who participate, there could be differential program rules. For example, perhaps access to services could be expedited, or periodic reviews could be deferred, or there could be greater flexibility in exiting and reentering the SSI program.

While (as we discuss in more detail in section X) we do not think the Social Security Administration should have administrative responsibility for the service-focused models we propose, it will necessarily have important coordinating responsibilities for the large number of disabled children who are on its SSI benefit rolls. At a minimum, it can provide important medical information obtained in the eligibility determination and redetermination processes (and may participate, administratively, in the early functional assessment proposed). As we pointed out in our 2006 *Statement on the Supplemental Security Income Program*, SSA can also play an important role in making sure that parents of SSI recipient children are informed of the services available through the existing and proposed process and are aware of the differential eligibility requirements their children will face as adults.

VII. Incentives to Make Work Pay

In the course of our study of this issue, we have heard many suggestions about how incentives might be improved to strengthen and encourage return-to-work efforts. While we are not attempting to endorse specific proposals and are aware of the constraints imposed by short-term budgetary realities, we think it is worth pointing out a number of the areas in which better incentives for a work-friendly culture could be created.

Short-Term Benefits Systems and Tax Incentives

One of the obvious needs during a period of transition from onset of impairment to resumption of self support is some sort of income support. Initially some persons will have private or state short-term disability benefits; others may need to rely on accumulated leave and savings. Development of public policy to bring about wider availability of short-term benefit systems (with an employment connection where possible) would be very helpful. In assessing the possibilities of resuming employment, individuals with impairments will inevitably measure what they can expect to earn against what might be available if they can qualify for one of the major benefit programs.

Measures to help “make work pay” could contribute significantly to deciding to attempt the self support option. The earned income tax credit (EITC) is designed to encourage work by providing an increasing credit as earnings increase up to a point where it begins to phase out. For workers with children, the EITC provides a significant supplement to earnings that begins to phase down at an earnings level around \$14,000 and phases out completely at around \$35,000. For individuals without children (whether or not disabled) the credit is much smaller, grows only until earnings reach somewhat above \$6,000, and is phased out completely at earnings levels around \$12,000. Making a more generous schedule available for workers with disabilities could make work a more attractive alternative.

The tax code already includes some other provisions designed to facilitate the employment of people with disabilities such as the full deductibility of impairment related work expenses (such as attendant care costs), business deductions for the costs of providing access as required by the Americans with Disabilities Act, and the work opportunity credit for hiring individuals participating in vocational rehabilitation programs through state VR agencies or the Department of Veterans Affairs. (Legislation to extend the work opportunity credit for persons hired after 2005 is currently pending in Congress.)

The Board heard a number of suggestions for making tax incentives stronger, more effective, and more widely used. Ideas ranged from simplification and efforts to increase awareness of existing provisions to proposals to provide credits in place of deductions for assistive devices and personal assistants. Additionally, suggestions were made to create new provisions such as tax-sheltered savings specifically designed to enable impaired individuals to accumulate assets that could be used to support employment efforts or new tax credits for employers with strong return-to-work programs.

It is important to look for those things that might influence or motivate an employer to get involved in managing disability. Maybe we should consider giving employers tax credits to intervene.

Roundtable participant, Kansas City

Simplify and Strengthen Work Incentives

In this report, the Board has focused particularly on the need to provide early assessments and supports prior to the point of application for the Social Security disability programs. We are convinced that the primary issue with our national disability system is not to be found in how the current Social Security disability programs are designed and operated but rather in the absence of an adequate culture and methodology to guide and support impaired individuals into a more work-oriented path that could avoid or delay their need to depend on those Social Security programs. We do, however, recognize that there are also changes that could be made in those programs to better encourage work activity. We recognize that there are some ongoing efforts such as the proposed regulatory changes to the Ticket to Work program and the Benefit Offset demonstration project that may lead to somewhat better success in the area of return to work. As we suggested in our 2005 *Statement on the Supplemental Security Income Program*, it should be possible to make changes that would simplify that program and at the same time provide stronger work incentive features.

We also believe that the adoption of a pre-Social-Security assessment and work incentive program along the lines of the model we are proposing might also provide an opportunity to eliminate some of the barriers to work activity for those who do later become eligible for Social Security disability benefits. For example, one of the barriers to attempting a return to work on the part of current beneficiaries is the fear that an attempt to work might result in a benefit termination that would be difficult to reverse if the individual subsequently needed to return to the rolls. While Congress has attempted to reduce these disincentives through provisions aimed at maintaining technical eligibility that would allow a quick return to the rolls and extended Medicare eligibility, many of those the Board has talked with have indicated the fear that benefits will not be available if needed remains a major deterrent to attempting a return to work. The adoption of a system such as we are recommending might make it feasible within reasonable cost constraints to provide a special status for those who participated in the early assessment program and subsequently found it necessary to seek disability benefits such persons might be granted permanent technical entitlement subject only to benefit reduction and payment of Medicare premiums appropriate to their earnings level. Provisions like these could provide strong incentives for participation in the early assessment program and appropriately address the cyclical nature of some disabling conditions.

Social Security has got work incentives for people who are on SSDI to go back to work. Have y'all read those? Have you actually sat down and read them? Because they are so complicated. I am a lawyer, and I looked at them and I said, huh, I don't know; I don't really know if I get this.

Public hearing participant, Dallas

VIII. Health Care

We are addressing the issue of health care separately because it is in many respects both the most important and most difficult part of any model for supporting individuals with severe impairments in their attempt to pursue or return to employment.

How do you encourage people to continue working if they can't get health insurance unless they are found disabled?

Roundtable participant, Kansas City

In the 1960s and 1970s, Congress extended health insurance coverage to disabled individuals under the Medicaid and Medicare programs in recognition of the fact that this population has a critical need for medical and hospital care. In general, eligibility for these health insurance programs is directly tied to eligibility for cash benefits under

the Social Security or SSI disability programs. In the case of Medicare, eligibility is established after fulfilling a 24-month waiting period. However, this waiting period begins after the 5-month waiting period for Disability Insurance Benefits, thus DI beneficiaries must wait up to 29 months before receiving Medicare coverage.

The tie-in to the cash benefits programs and the waiting period provision reflect understandable administrative and fiscal concerns. Only one eligibility determination is needed

for both cash benefit and health insurance coverage. The Medicare waiting period avoids the need for complex reimbursement calculations for the large number of cases where the adjudication period is protracted.² In addition, this waiting period also eliminates the need for public health insurance expenditures during a period when some beneficiaries may still have ongoing group or individual coverage.

While there is some logic for tying health coverage to benefit programs, as well as for the waiting period, this process has resulted in an unintended consequence. Many individuals are driven to establish entitlement to cash benefits in order to obtain what they really seek—health insurance. They apply very quickly for cash benefits in order to begin serving the lengthy waiting period because they want to minimize the gap (and cost) between the end of any employer-sponsored coverage through COBRA or similar plans, and the beginning of Medicare eligibility. Those workers who had employer-sponsored health benefits can continue to participate in those plans for up to 18 months under the COBRA law. However, they may be required to pay the full costs of such coverage. Workers who are found eligible for Social Security disability benefits can qualify for an additional 11 months of COBRA coverage but may be charged 150 percent of the plan costs for those added months.

Many large employers do offer health insurance. However, a Kaiser Family Foundation survey noted that for small firms with fewer than 200 employees, the percentage offering health benefits has declined from 68 percent in 2000 to 59 percent in 2005. Despite the coverage that may be available through COBRA, there remains for a significant number of workers the need to maintain a continuous connection to healthcare coverage at an affordable cost. Establishing eligibility for cash benefits in the hope of obtaining Medicare can be a prime motivator for individuals who are out of work and have significant impairments.

In our discussions with interested groups, program administrators, and academic experts, the Board has heard that securing health insurance coverage is far more important than cash benefits to children and adults with disabilities and their families. The most frequently repeated word in our conversations about this issue is “fear.” When thinking about the possibilities of working as opposed to receiving benefits, the fear of losing healthcare coverage is likely to carry the most weight.

Improving Access to Health Coverage

There is an overwhelming concern on the part of individuals with disabilities to assure access to health care. It also frequently plays a very substantial role in making it possible for them to engage in employment. We are convinced that any model of a national system to encourage individuals with impairments to view work as a viable alternative to benefit dependency must find an effective way to address the need to access adequate and secure health insurance protection. At the same time, we recognize that for the national budget as for private employers, the increasing costs of health benefits are already a huge challenge.

Congress has taken an important step in the direction of addressing this issue by establishing the Medicaid buy-in process. This allows states to provide Medicaid coverage to disabled individuals who would be eligible for Supplemental Security Income (and therefore

²Retroactive Medicare reimbursement may be required if the processing of the disability claim extends beyond 29 months from the first month for which disability benefit entitlement is established.

Medicaid) but for the fact that their earnings take them above the SSI eligibility limits. (For such individuals, states can also waive or increase the asset and unearned income limits.) In providing Medicaid to such individuals, states are able to charge premiums related to income.

This general approach of providing health benefit coverage to individuals with disabilities on a cost-sharing basis and utilizing other coverage that may be available to them through employment or post-employment provisions (e.g., COBRA coverage) provides an appropriate model for assuring that health care is available while limiting program costs to feasible levels. However, at this point, the Medicaid buy-in is quite limited in scope. There are 32 states participating and rules differ from state to state. Some states have only a few participants and nationally the number of participants was just under 80,000 as of March 2005. (See Table 2, which is based on CMS data.)

Table 2 — Enrollments in Medicaid Buy-In Programs – March 2005	
States Participating (32)	Number of enrollees (79,140)
Alaska	214
Arizona	683
Arkansas	444
California	1263
Connecticut	3617
Illinois	700
Indiana	5811
Iowa	8098
Kansas	865
Louisiana	529
Maine	681
Massachusetts	7414
Michigan	176
Minnesota	6339
Mississippi	1460
Missouri	18654
Nebraska	83
Nevada	11
New Hampshire	1319
New Jersey	1436
New Mexico	1241
New York	2864
North Dakota	275
Oregon	585
Pennsylvania	5007
South Carolina	52
Utah	283
Vermont	553
Washington	495
West Virginia	118
Wisconsin	8265
Wyoming	5

One major issue with the current Medicaid buy-in approach is that eligibility is limited to individuals who are disabled under the Social Security programs' current definition of disability. This means that eligibility depends on going through the existing process of proving inability to engage in any substantial work activity. To keep costs within bounds, eligibility would necessarily be limited according to some standard of significant functional limitation, but it should not be tied in this way to the Social Security disability definition.

An appropriate new national disability system should include measures that convincingly assure adults and children with disabilities and their families that secure and continuing adequate health care coverage would not depend on their establishing and maintaining eligibility for Social Security or SSI disability benefits. In addition, the assurance should be there that such coverage would be available as necessary to enhance their efforts to seek independence and self support.

IX. Suggestions for Longer-Term Program Enhancements

Over the course of our discussions with experts, through our public hearings and roundtables, we have heard many ideas that may indeed help realign the current program and set the stage for a 21st century disability system that truly supports the goals of the ADA. Those suggestions include:

- Revise work, earnings, and asset rules

Research shows strong evidence that some beneficiaries substantially restrain their earnings in order to stay below the SSDI and SSI thresholds. Exceeding these limits threatens program attachment and access to health coverage.

Current asset test rules constrain a working beneficiary's ability to save money that can be vital for sustaining employment and maintaining independence.

- Provide lifetime certification for health coverage for beneficiaries with lifelong conditions

We have heard repeatedly that the biggest barrier to work is the fear of losing health coverage. Exploration of access to healthcare coverage that could potentially include public/private partnership should be considered. Assuring people with lifelong conditions access to health care would remove one of the disincentives to work.

Exploration of continued attachment to the program in order to maintain continued eligibility for healthcare benefits through an enhanced buy-in program should be considered.

- Refocus the criteria for the SSI age-18 redetermination of disability

The current criteria assume that there is a bright line between functional limitations that qualify a young person for disability and those that would qualify an adult. Expanding the age-18 assessment criteria to include an overall evaluation that addresses medical, functional, and life-skills readiness should be considered.

- Address the disincentives to employment in an integrated fashion through the creation of system-wide buy-in programs

For many people with disabilities, their ability to work is made possible through the support that they receive from a variety of public programs. As their income increases, they often lose eligibility for some public benefits such as supported housing and medical assistance. These expenses, which have been covered in all or part by these programs, cannot always be completely paid for out of the worker's current earnings.

As a result, individuals will often limit earnings or withdraw entirely from the workforce in order to remain eligible for these essential services. The creation of system-wide sliding scale buy-in programs would allow the person to continue to work and to receive the public services and supports that they need, while at the same time contributing toward the costs of those services.

- Create job preparation trust funds

The SSI program generally limits eligibility to those whose assets are below relatively small thresholds (\$2000 for an individual, \$3000 for a couple) and counts as income, for purposes of calculating benefits, any type of income that is not specifically excluded. The law does include limited exceptions for amounts placed in trust (such as trusts established by family members to provide for special needs). Such trusts can be complicated to establish, are subject to varying state trust laws, and to somewhat different rules between the SSI and Medicaid programs.

The Board supports a more simplified approach that would allow recipients or their families to set up accounts that are dedicated to accumulating the kinds of resources that would support their attempts to undertake employment or self employment.

- Establish lifelong certification for disabled worker's tax credit

Similar to the earned income tax credit, establishment of an appropriate schedule for workers with disabilities could make work a more attractive alternative.

- Encourage the expansion of community-based services such as those created by the New Freedom Initiative of 2001

These programs (e.g., "cash and counseling") facilitate community living, consumer choice, and employability.

- Educate physicians on their role in disability assessment

Few doctors, outside of a few specialties, ever receive training in disability assessment and management. Yet, they are routinely asked to determine a patient's ability to participate in the workforce. Training doctors to properly assess functional abilities will allow them to better understand the relationships between physical and mental findings and work related tasks. Furthermore, such enhanced training may reinforce for medical providers the gains that a patient may achieve by going through a rehabilitation program soon after the onset of the work limiting impairment.

- Consider an educational/rehabilitation "sabbatical"

For workers with significant work history, an opportunity to create their own education and rehabilitation plan could be afforded as an alternative to disability benefits. This could be available, for example, to persons who exhausted unemployment benefits prior to applying for disability or who were denied such benefits solely because of their inability to work. Similar to the concepts of "cash and counseling," the worker would receive a lump sum stipend that could be used for income replacement, training, education, etc.

- Consider a partial disability program

One concept that has been brought to our attention is that of establishing eligibility criteria for "partial disability." An example is the program administered by the Department of Veterans Affairs which provides a level of benefits based upon the applicant's degree of impairment.

X. Administrative Responsibility

The Board does not view this report as a detailed blueprint for change, but rather as the establishment of a basic framework that can, we hope, shape the future of a 21st century disability system. When the development of a new structure for integrating and delivering services begins, the issue of administering the new structure will necessarily be a major consideration.

We recognize that there are obvious reasons why the Social Security Administration is likely to be viewed as the appropriate seat of major responsibility in whatever structure is created. It is the agency that has the broadest contact with adults and children with significant limitations. Its workloads and costs will be significantly impacted by the success or failure of a new disability system that offers people with disabilities an alternative path to self sufficiency and independence. And it is an agency that has a well deserved reputation for outstanding public service and excellent administration of the programs entrusted to it.

However, SSA would not be the appropriate entity for implementing the model we are proposing in this report. SSA's primary responsibility is that of processing applications, adjudicating whether or not individuals meet a strict definition of disability that emphasizes the yes/no question of ability to do any substantial gainful activity, and maintaining benefit rolls.

These are, and will continue to be complex administrative tasks. These are tasks that are quite different from the models that we propose. The agency is just beginning to implement a new Disability Service Improvement initiative that offers much promise of addressing the existing backlogs and delays in the disability adjudication process.

Our proposal is based upon creating a national culture shift that emphasizes continuing employment and contribution before the Social Security Administration provides benefits to those eligible applicants who have left the workforce. In our model an “early intervention” step emphasizes, where feasible, (re)training and employment. After this initial step (and for some the last step), SSA would, as it does now, make the ultimate decision on whether or not individuals meet the strict definition of disability. It would be inappropriate and misdirected public policy to add a triage and case management approach to a claims processing organization. SSA will, of course, need to carefully coordinate its role with that of a new and integrated system, and there will need to be extensive sharing of information and data.

The model we are recommending requires a coordinating entity for the early intervention step. There are many existing government agencies that currently have a “piece of the action.” For example, the Department of Education has oversight of the Vocational Rehabilitation system that is primarily administered by state governments; the Department of Labor is responsible for state workforce agencies (including “One Stops”). In fact, the Government Accountability Office has (as shown in Table 3 below) identified 192 different programs operated or overseen by some 20 different federal departments or independent agencies that are designed to provide supports for people with disabilities. In fiscal year 2003, more than \$120 billion in federal funds were spent on programs serving people with disabilities. It is especially noteworthy and disheartening that only 2 percent was spent on employment related programs.

Table 3 – Federally Sponsored Disability Programs

Agencies	Total Number of Programs Supporting People with Disabilities
Department of Health and Human Services	40
Department of Education	33
Department of Veterans Affairs	32
Department of Labor	22
Department of Housing and Urban Development	16
Social Security Administration	10
Department of Agriculture	9
Department of Transportation	6
Department of Justice	5
Equal Employment Opportunity Commission	3
Office of Personnel Management	3
Department of Commerce	2
Department of Treasury	2
Library of Congress	2
Access Board	1
Committee for Purchase from People Who are Blind or Severely Disabled	1
Department of Defense	1
Department of Energy	1
Department of the Interior	1
Railroad Retirement Board	1
Small Business Administration	1
Total number of programs (GAO survey)	192

Source: GAO analysis of survey data from GAO-05-626 Federal Disability Assistance

Again and again, the Board has heard that this uncoordinated, “stove pipe” approach is itself a major part of the problem. To develop a 21st century system for persons with disabilities, there should be a new, single and integrated center of responsibility that can offer people with disabilities a clear and uniform path to finding the support they may need to pursue a path to independence and self support. On the benefit side, we currently have such a clear cut, uniform structure; on the employment support side we have something close to chaos. There are, of course, many different kinds of supports including training, medical care and therapy, assistive technology, counseling and more. A variety of providers reflecting different disciplines will need to be involved, but persons with disabilities should have a single point of entry that can help them, as needed, attain and stay on the path to the supports they need.

XI. Conclusion

In our October 2003 report, *The Social Security Definition of Disability*, we raised the question of whether or not the Social Security definition of disability facilitates an appropriate approach to supporting and enabling persons with disabilities. Since we issued that report, we have, as described in detail in the Appendix, completed 3 years of additional study of our national approach to disability. This study has included regional hearings, public forums, roundtable discussions with experts, administrators, and advocates, and a series of meetings with an expert panel we convened to help us better understand the issues and develop our recommendations.

This study has been very instructive. We have learned much about the strengths and weaknesses of the disability system. Most importantly, we have confirmed our concern that a definition based on inability to work is inconsistent with the goals of the *Americans with Disabilities Act*. That Act proclaims that “the Nation’s proper goals regarding individuals with disabilities are to assure equality of opportunity, full participation, independent living, and economic self-sufficiency for such individuals.”

The current Social Security statutory definition represents a powerful symbol of a national approach to disability that collides with the policy objectives enunciated in the ADA legislation. We need to replace that definition, but must do so in a way that does not undermine the protections afforded by the programs administered by the Social Security Administration. A new system must support an integrated approach providing an alternate path directed to economic self-sufficiency, independence, and community inclusion.

In reshaping our statutory standards for supporting persons with disabilities, we need to recognize all the changes that have taken place over the past 50 years. The nature of work itself has changed substantially as we have moved away from an economy largely dependent on manufacturing jobs. The medical and pharmacological sciences have radically changed the impact of many conditions. There have been great strides made in rehabilitation therapy and the availability of adaptive technology. And, most importantly, there has been a sea change in the attitudes of and about persons with disabilities and their capabilities and rightful aspirations. This has been accompanied by recognition that disability is not a single state but a process—a process that may be inconsistent with the misleading precision of a single definition.

Call for Action

We have attempted in this report to present some general models for what we believe is a more appropriate structure. We have developed these models by drawing on what we have learned about the experience of many existing efforts including those of private disability insurers, state and local programs, the approach of other countries, and the many private and nonprofit organizations that have taken on responsibility for providing supportive services to persons with disabilities. We do not expect or intend that these efforts should be replaced, much less eliminated. Rather we see the need for a better and integrated system to assure that people with disabilities receive timely assessments and coordinated access to the supports they need to maximize their capabilities.

The Board recognizes that disability affects individuals in widely differing ways, and we have accordingly attempted to draw our models broadly and with a view to assuring flexibility. We do not assume that these models answer all questions or can be used as detailed blueprints, but we present them as a goal and vision of a 21st century approach to a new disability system. This is a call for action.

Unified Vision and Management

Our Nation's policymakers need to acknowledge that the current disability programs, though well intentioned, are badly fractured and disjointed. A unifying point of vision, oversight, and management is desperately needed. To rectify this, consideration should be given to the creation by the Administration and the Congress of an entity or entities that can develop and implement detailed legislative proposals for managing and integrating the supports available to people with disabilities in a way that truly offers a coordinated path to achieving community inclusion, independent living, and economic self sufficiency. Detailed legislative proposals to build a 21st century system could include, where appropriate, a realignment of functions and responsibilities that are currently carried out by numerous entities. It is now a decade and a half since our Nation declared its adherence to a disability policy that encourages and supports people with disabilities in their quest to achieve independence and self-support that is within their capabilities. It is time to begin to make the necessary administrative and statutory changes that can make that policy a reality.

We recognize that moving from our broad conceptual models to an actual legislative proposal that can in fact be implemented will require substantial work and coordination by the Administration and the Congress. We believe, however, that the difficulty of that task, while daunting, must not be viewed as a reason for avoiding action. We believe, in particular, that there already exists an important opportunity for carrying out a major pre-test of parts of the adult model we propose in a way that could help to sort out the details of how to make the model work.

Untapped Opportunity: State Short-term Disability Programs

Short-term disability insurance programs currently exist in 5 states and Puerto Rico.³ As was discussed earlier in this report, these programs provide benefits to individuals with temporary disabilities or to those workers who have not yet fulfilled the 5-month waiting period for SSA disability benefits. Generally, these programs do not include any type of assessment or provide rehabilitation or training services.

It seems to us that there is potential here for working with one or more of these states (or other states that might be willing to implement such a program) to develop a pre-test that incorporates the concepts described in the adult model. These programs would afford the opportunity to determine when and how to intervene in order to return people to work. The states would continue to pay their usual benefits. In addition, through a public/private partnership, a wrap-around program that included a multidimensional assessment which leads to

³California, Hawaii, New Jersey, New York, Rhode Island, and Puerto Rico.

the tailored work “prescription” and access to services would be incorporated. Such a pre-test would help determine how the type of intervention that is suggested in this paper can result in a better integrated disability system and whether it can be done in a cost effective way. Greater insight into and understanding of the prospective SSDI applicant pool would be gained as well.

We urge the Congress to seriously consider establishing such a pre-test of a model disability system that can enable our Nation to show that it was serious when it adopted the Americans with Disabilities Act. We acknowledge that many questions remain to be answered, but they will still remain to be answered fifty years from now unless we undertake a serious effort to attain those answers through a real world test such as the Board proposes here.

APPENDIX

How the Board Studied This Issue

Throughout the last 10 years, the Board has devoted considerable time and careful attention to the study of the issues facing the disability programs administered by the Social Security Administration (SSA). Our study took several forms:

- regular monthly meetings at which we have discussed disability policy issues with disability experts in both the public and private spheres,
- research and discussion forums convened by the Board,
- public hearings,
- commissioned studies and other work.

All of these activities shaped our thinking and led to the present report.

Most recently, in 2006 we convened a panel of disability experts to work intensively with a working group of the Board to help inform our development of this report. The combined knowledge, experience and advice of the members of that Disability Expert Panel was also of great assistance to the Board in studying these issues. The Board would like to thank the Panel for its invaluable insights and contributions. We would also like to thank David Barnes, who served as facilitator for the Panel's discussions. This report, however, was produced by the Social Security Advisory Board, and we are solely responsible for its content.

The Early Years: 1996-2002

During the early years of the Board's existence, we began, as mandated by our authorizing statute, to undertake a broad examination of and develop recommendations about the Nation's retirement and disability systems. These are the charges which the Congress has given us:

- analyzing the Nation's retirement and disability systems and making recommendations with respect to how the OASI, DI, and SSI programs, supported by other public and private systems, can most effectively assure economic security;
- studying and making recommendations relating to the coordination of programs that provide health security with SSA's programs;
- making recommendations with respect to policies that will ensure the solvency of the OASDI program, both in the short term and the long term;
- making recommendations with respect to the quality of service that SSA provides to the public;
- making recommendations with respect to policies and regulations regarding the OASDI and SSI programs;
- increasing public understanding of the Social Security system;
- making recommendations with respect to a long-range research and program evaluation plan for the Administration;
- reviewing and assessing any major studies of Social Security as may come to the attention of the Board; and
- making recommendations with respect to such other matters as the Board determines to be appropriate.

As we began examining each of these issues in depth, the Board met with SSA officials both in headquarters and in the field. We met with representatives from the state Disability Determination Services (DDS) and Vocational Rehabilitation (VR) systems, community leaders and consumer advocates, representatives from the private and nonprofit sectors, and program beneficiaries. The Board traveled throughout the Nation, visiting SSA offices, state offices, and demonstration project sites to learn about what works and what does not work. In addition, the Board held a number of public hearings throughout the country to hear directly from experts and the beneficiaries of SSA's programs.

As a result of these many meetings in Washington, D.C., and across the Nation, it quickly became apparent to the Board that high among the significant challenges facing SSA were the administrative and policy-making burdens placed on the agency by the SSDI and SSI disability programs. The Board was growing increasingly concerned that the disability programs—originally envisioned to be small in comparison to SSA's retirement program—were now dominating SSA's workloads, resources, and management capacity. About two-thirds of the agency's annual administrative budget and a growing portion of the time and attention of SSA management and staff at all levels of the agency are spent on disability-related workloads.

Between 1996 and 2002, the Board wrote extensively on issues it encountered in its review of the SSDI and SSI disability programs. We have issued a number of reports in which we raised concerns and made recommendations with respect to:

- timely adjudication and service to the public,
- consistency of decision making,
- work measurement and quality assurance, and
- disability policy development.

The Board also met regularly with the Commissioner of Social Security and with representatives of SSA and the DDSs in order to keep abreast of the many efforts that SSA was undertaking to improve the operation, integrity, and management of these programs—including the design of a new disability adjudication process, a new quality assurance process, and a new budget formulation process focused on service delivery.

While many issues were related to administrative processes and resource constraints, it became increasingly clear to the Board that there also were more fundamental problems with these programs that needed to be addressed. During these early years, we issued a number of reports that continually brought the Board's attention back to the basic question of whether or not the definition of disability—established nearly a half a century ago when the program was first created—continues to be appropriate in a 21st century environment. In our January 2001 report, *Charting the Future of Social Security's Disability Programs: The Need for Fundamental Change*, the Board raised the question of whether or not Social Security's definition of disability was appropriately aligned with national disability policy as reflected, for example, in the *Americans with Disabilities Act*.

2003

As the Social Security Administration worked to develop a new process to improve the adjudication of disability claims, the Advisory Board in 2003 simultaneously undertook a more earnest and in-depth look at the issues facing SSA's disability programs that require more than

administrative or regulatory remedies—issues that will require statutory change in order to address them adequately. The Board devoted about three-quarters of its monthly meetings to the study of SSA’s disability programs. We met with disability experts and adjudicators, including outside experts, representatives from the Government Accountability Office (GAO), and numerous officials from SSA. In May of 2003, the Board made a field visit to Boston where it met with SSA officials from the Boston Region and with representatives from the Massachusetts DDS. In June, we met with representatives from the Council of State Administrators of Vocational Rehabilitation (CSAVR) in Washington, D.C.

As a result of everything the Board heard and discussed in its many meetings and consultations on disability policy to date—and the Board’s growing sense that perhaps the disability programs administered by the Social Security Administration needed to be modernized—in October of 2003 the Board released a report entitled, *The Social Security Definition of Disability*. This report examined the background of SSA’s disability programs and how they have changed, the growing difficulty of appropriately determining who can and cannot work, and the various attempts to build in work incentives. While recognizing that these programs are a large and important part of our national income security system, the Board concluded that the Nation must face up to the contradictions created by the existing definition of disability. The report briefly catalogues some of the alternative approaches that might, in some combination, be incorporated into revised programs while noting that any such changes must be made carefully and with due regard for the importance of these programs to the lives of America’s disabled citizens and to their impact on other elements of national income security. The Board issued this report to focus attention on that issue, and indicated its intent to do additional work in this area in the future.

Disability-Related Board Publications in 2003:

Introducing Nonadversarial Government Representatives to Improve the Record for Decision in Social Security Disability Adjudications, May 2003.

The Social Security Definition of Disability, October 2003.

2004

The Board’s 2003 report on the definition of disability led, in April of 2004, to a discussion forum exploring the Social Security definition of disability and whether or not it is consistent with a national goal of supporting maximum self-sufficiency. At its discussion forum, the Board convened a group of disability experts and these invited experts presented and discussed papers presenting a wide range of views on the future of the disability programs. In 2 separate sessions, the presented papers examined: (1) whether or not the current Social Security disability programs are consistent with a 21st century national vision of disability policy—integrating benefits, services, civil rights, and employment for people with disabilities; and (2) what would be the necessary features of a consistent national disability benefits/supports system should reform be necessary.

The presenters and discussants who participated in the first series of discussions were: David Stapleton of Cornell University; Virginia Reno of the National Academy of Social Insurance; Marilyn Howard, a social policy analyst from the United Kingdom; Robert Anfield of UnumProvident Corporation; Bobby Silverstein of the National Center on Workforce and Disability; Peter Blanck of the University of Iowa; and Tony Young of NISH and the Consortium for Citizens with Disabilities. Gerben DeJong of the University of Florida was the moderator for

this session. The presenters and discussants who participated in the second series of discussions were Monroe Berkowitz of Rutgers University; Bruce Growick of the Ohio State University; Eugene Steuerle of the Urban Institute; Michael O'Brien of the Washington Department of Vocational Rehabilitation; William Kiernan of the Institute for Community Inclusion; and Mark Dakos of BTE Technologies, Inc. Richard Burkhauser of Cornell University was the moderator for this session. David Walker, Comptroller General of the United States, gave the keynote address stressing the large and growing financial impact of the Nation's disability programs and the need for reform.

The presentations and discussion at this all-day forum highlighted the importance, broad scope, and extreme complexity of the problem identified by the Board's report on the Social Security definition of disability. In addition, the forum revealed a range of views on the severity and scope of the problem; the underlying causes; and possible solutions. At the conclusion of the forum, the Board pledged its continued active involvement in this policy arena.

In keeping with its promise, throughout the remainder of 2004 the Board continued to devote considerable time and attention to its examination of the disability programs and the appropriateness of a definition of disability that may not be aligned with 21st century policy and may, in fact, present barriers for people with disabilities in their efforts to contribute to their own economic well being. At its regular monthly meetings, the Board met with representatives from SSA, the GAO, the Department of Veterans Affairs (VA), the Department of Labor (DOL), experts, researchers, and disability advocates. In addition, the Board traveled to Vallejo, California in June of 2004 where it met with representatives of and participants in the California Bridges to Youth Self Sufficiency pilot project designed to provide assistance for youth with disabilities as they transition to adulthood.

2005

Early in 2005, the Board began to outline a specific project to explore these disability issues and develop a set of recommendations. The Board's meeting and research agenda for 2005 was planned in support of this project. Early in the year, the Board met with a group of disability experts to discuss their joint proposal to improve the disability programs. This group consisted of: Deborah Kaplan, Disability Consultant; Bonnie O'Day, Senior Research Associate at the Cornell University Institute for Policy Research; Susan Parker, Director of Policy Program Research in the Office of Disability Employment Policy at the Department of Labor; Sallie Rhodes, External Relations Director for CSAVR; and David Stapleton, Director of the Cornell University Institute for Policy Research. The Board met with representatives from SSA's Office of Disability and Income Security Programs to discuss, among other topics, the definition of disability. The Board met with representatives from the Centers for Medicare and Medicaid Services (CMS) and with representatives from SSA to discuss current and proposed grant and demonstration projects under the *Ticket to Work and Work Incentives Improvement Act*. The Board also met with members and staff of the Ticket to Work and Work Incentives Advisory Panel to discuss the future directions of the Ticket program.

In November of 2005, the Board traveled to Dallas, Texas where it met with SSA managers and staff from the Dallas Region, as well as with representatives from the Texas DDS. On November 15, 2005, the Board held a public hearing in Dallas to hear additional expert opinions on whether or not the definition of disability required modernization. At this hearing, the Board heard from: Dallas Regional SSA Commissioner Ramona Schuenemeyer; Wayne Pound, Vice President of Community Services for the Lighthouse for the Blind of Fort Worth, Texas;

Mary Wolfe, Assistant Commissioner for the Texas DDS; Elise Mitchell, Senior Regional Attorney for Advocacy, Inc.; Carol Schaper, Advocate and Claimant Representative for the National Alliance for the Mentally Ill (NAMI); and Charlotte Stewart, Executive Director of Reach Independent Living Center.

Disability-Related Board Publications in 2005:

Retirement Security: The Unfolding of a Predictable Surprise, March 2005

Board Comments on Ticket to Work Regulations, December 2005

2006

In February of 2006, the Board convened a panel of disability experts in an effort to further the Board's study of the national disability system and assist us in our attempt to lay out, broadly, the parameters that would be necessary for a modernized disability system that better meets the goals of the American people and better serves people with disabilities. This Disability Expert Panel consisted of: Richard Burkhauser from Cornell University; Martha Ford from Disability Policy Collaboration; Allen Heinemann from the Rehabilitation Institute of Chicago; Andrew Imparato from the American Association of People with Disabilities; Kenneth Mitchell from UnumProvident Corporation; and the late Eileen Sweeney from the Center for Budget and Policy Priorities. The Disability Expert Panel met monthly from February through August of 2006, often consulting with additional experts from both the public and private sectors where needed, including MDRC, Virginia Commonwealth University, and Maryland Rehabilitation Services.

In June of 2006, the Board traveled to the Kansas City Region in an effort to further its study of the Nation's disability system. While in Kansas City, the Board met with SSA executives and staff and the Director of the Kansas DDS. Also during this field visit, the Board held a half-day roundtable discussion to learn the views of a diverse cross section of knowledgeable individuals from the Kansas City Region, including university researchers, community and business leaders, legal advocates for people with disabilities, rehabilitation specialists, providers of other services to persons with disabilities, representatives from state and local government programs, and a state legislator. (See table at end of this Appendix.) The roundtable sessions were designed to draw on the wisdom that these individuals have gained in their many years of experience with the Social Security disability programs and the other programs that make up our country's disability system.

Roundtable participants were divided into 5 small groups—each table was hosted by a member of the Social Security Advisory Board. Each table was asked to examine 4 questions and then summarize their discussion back to the larger group. These 4 questions were:

- Our major national disability programs (SSDI and SSI) apply a complex set of evaluation standards in an attempt to separate those who can work from those who cannot work. The questions are: “Does this approach achieve the desired result?”
Would a better alternative be a system that attempts to:
 - evaluate each individual's potential to maintain, attain, or regain the capacity for self support,
 - provide the encouragement, incentives, accommodations, and supports necessary to achieve that self support, and
 - ultimately determine eligibility for long term income support on the success or failure of that attempt?

- Assuming the need for change, there is wide acceptance that effective intervention should be “timely,” for example, while the individual still has a connection to the workforce and, if possible, an employment relationship. What could be done to assure that such timely intervention occurs routinely when an individual suffers a significant impairment? When is “timely” intervention for youth with disabilities?
- There exist in our society a large number of entities providing a variety of supports and services and employment opportunities to individuals with significant impairments, but there is a perception that these are largely uncoordinated and the likelihood of a given individual finding the appropriate combination of supports and opportunities is haphazard. Is this a correct perception and, if so, what would remedy the situation?
- If we need a significant course correction in how we implement our national disability policies, then what major changes not addressed in the above 3 questions would the roundtable participants like to bring to the Board for consideration?

As a result of the Kansas City roundtable discussions, the Board was able to focus on a more narrow set of issues and questions and begin framing a broad outline for a new approach to disability—with one set of parameters specifically designed for adults with disabilities and another set of parameters for youth with disabilities. And in an effort to further refine its outline, on July 19, 2006, the Board held a second all day roundtable discussion forum in Washington, D.C. to examine the Nation’s disability system with a view toward developing a description of a disability system that maximizes economic self sufficiency at a reasonable standard of living. The new system would be consistent with the Americans with Disabilities Act and would facilitate equal opportunity, independent living, and full participation in the labor force to the extent of an individual’s abilities.

Participants for this second set of roundtable discussions included, once again, a broad cross section of public and private sector experts on the Nation’s disability system, including representatives from: The Ticket to Work Advisory Panel; Mathematica Policy Research; the American Council of the Blind; Webility Corporation; the Association of University Centers on Disability; Easter Seals; Abt Associates; the National Council on Disability; the Cornell University Institute for Policy Research; Griffin Hammis Associates, LLC; the Anixter Center; the Office of Students with Disabilities at Gallaudet University; AFL CIO; Daniels and Associates; the Center for the Study and Advancement for Disability Policy; the National Organization of Social Security Claimants’ Representatives; the Integrative Pain Center of Arizona; America’s Health Insurance Plan; the Kennedy Krieger Institute, the Virginia Department of Rehabilitative Services; the National Disability Rights Network; Community Legal Services, IMX Medical Management; ENDependence Center of Northern Virginia; the National Alliance on Mental Illness; and McLendon and Associates. (See table at the end of this Appendix.)

Roundtable participants were divided into 4 groups. Each group discussion was hosted by a member of the Social Security Advisory Board and a member of the Disability Expert Panel. Participants were provided with the broad parameters, as outlined by the Board, for a hypothetical adult model and a hypothetical youth model. As in Kansas City,

each group was asked to examine and discuss a series of questions for each of the models. These questions were:

For Adults with Disabilities:

- Is this model worth pursuing?
- What would the initial evaluation look like, when would it happen, and who would do it?
- Should there be a temporary program that provides services before an individual is determined eligible for the Social Security disability benefits and, if so, what would it look like?
- How should existing programs be improved or strengthened to assure successful outcomes?
- What other issues or concepts need to be considered?

For Youth with Disabilities:

- Is this model worth pursuing?
- What would the initial evaluation look like, when would it happen, and who would do it?
- What would the transition-to-adulthood phase look like, when would it begin, what would be the incentives, and how would it be financed?
- Would there be a post-transition phase and, if so, what would it look like and how would it be financed?
- How should existing programs be improved or strengthened to assure successful outcomes?
- What other issues or concepts need to be considered?

This present report represents the culmination of all that the Board has learned about the Nation's disability system, and how it can be improved, over the past decade.

Other Disability-Related Board Publications in 2006:

Disability Decision Making: Data and Materials, revised edition, May 2006

**SOCIAL SECURITY ADVISORY BOARD
DISABILITY ROUNDTABLE PARTICIPANTS**

**Participants at the roundtable in
Kansas City, Missouri June 21, 2006**

David Barnes, Advanced Policy Solutions
Clay Berry, Alphapointe Association for the Blind
Martha Blue-Banning, University of Kansas
William Craig, Lakemary Center
Shannon Crane, Kansas Legal Services
Janis DeBoer, Kansas Department on Aging
Gary Enyard, Full Employment Council
Jean Hall, University of Kansas
Jerry Henry, Kansas State Representative, Achievement Services of Northeast Kansas
Susan Herrin, The Whole Person Independent Living Center
Jack Hillyard, University of Iowa Health Care
Robert Hull, Cerebral Palsy Research Foundation
Alen Ighedosa, Osalen Services
Shannon Jones, Statewide Independent Living Center of Kansas
Leonard Matheson, Washington University
Jeanine Schieferecke, Kansas Department of Social and Rehabilitation Services
Teresa Nianga, Missouri Vocational Rehabilitation Services
Theresa Shively, Kansas Legal Services
Kelly Sloan, Jewish Vocational Services
Sheila Stoeckel, Iowa Workforce Development
Jessica Sulzern, The Helping Hand of Goodwill Industries
Jeff Wilson, Missouri Business Partnership Initiative
Chris Zuercher, Prairie View Hospital

**Participants at the roundtable in
Washington, D.C. July 19, 2006**

Day Al-Mohamed, American Council of the Blind
Berthy De La Rosa Aponte, Ticket to Work Advisory Panel
David Barnes, Advanced Policy Solutions
Stephen Bell, Abt Associates
Allan Bergman, Anixter Center
Richard Burkhauser, Cornell University
Winthrop Cashdollar, America's Health Insurance Plan
Tom Croghan, Mathematica Policy Research
Susan Daniels, Daniels and Associates
Marty Ford, The Arc and UCP Disability Policy Collaboration
Elizabeth Genovese, IMX Medical Management
David Hammis, Griffin-Hammis Associates, LLC
Cheryl Bates-Harris, National Disability Rights Network
Allen Heinemann, Rehabilitation Institute of Chicago
Jill Houghton, Ticket to Work Advisory Panel
Andrew Imparato, American Association of People with Disabilities
John Lancaster, National Council of Independent Living
Eric Levey, Kennedy Krieger Institute
Brad Turner-Little, Easter Seals
Gina Livermore, Cornell University Institute for Policy Research
David Long, Abt Associates
Michael McLendon, McLendon and Associates
Djuna Parmley Mitchell, ENDependence Center of Northern Virginia
Katherine Beh Neas, Easter Seals
Bonnie O'Day, Cornell University Institute for Policy Research
Edgar Palmer, Gallaudet University
Jane McDonald-Pines, AFL-CIO
Jeff Rosen, National Council on Disability
James Rothrock, Virginia Department of Rehabilitative Services
Rhoda Schulzinger, Association of University Centers on Disabilities
David Siktberg, Webility Corporation
Randy Soohoo, Integrative Pain Center of Arizona
Andrew Sperling, National Alliance on Mental Illness
Craig Thornton, Mathematica Policy Research
Richard Weishaupt, Community Legal Services
David Wittenburg, Mathematica Policy Research
Ethel Zelenske, National Organization of Social Security Claimants' Representatives

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Social Security Advisory Board

Establishment of the Board

In 1994, when the Congress passed legislation establishing the Social Security Administration as an independent agency, it also created a 7-member bipartisan Advisory Board to advise the President, the Congress, and the Commissioner of Social Security on matters relating to the Social Security and Supplemental Security Income (SSI) programs. The conference report on the legislation passed both Houses of Congress without opposition. President Clinton signed the Social Security Independence and Program Improvements Act of 1994 into law on August 15, 1994 (P.L. 103-296).

Advisory Board members are appointed to 6-year terms, made up as follows: 3 appointed by the President (no more than 2 from the same political party); and 2 each (no more than 1 from the same political party) by the Speaker of the House (in consultation with the Chairman and the Ranking Minority Member of the Committee on Ways and Means) and by the President pro tempore of the Senate (in consultation with the Chairman and Ranking Minority Member of the Committee on Finance). Presidential appointees are subject to Senate confirmation.

Board members serve staggered terms. The statute provides that the initial members of the Board serve terms that expire over the course of the first 6-year period. The Board currently has 2 vacancies. The Chairman of the Board is appointed by the President for a 4-year term, coincident with the term of the President, or until the designation of a successor.

The Chairman of the Board is appointed by the President for a 4-year term, coincident with the term of the President, or until the designation of a successor.

Hal Daub, Chairman

Hal Daub is currently a partner in the law firm of Blackwell Sanders Peper Martin in Omaha, Nebraska and Washington, D.C. Previously, he was President and Chief Executive Officer of the American Health Care Association and the National Center for Assisted Living. He served as Mayor of Omaha, Nebraska from 1995 to 2001, and was an attorney, principal, and international trade specialist with the accounting firm of Deloitte & Touche from 1989 to 1994. Mr. Daub was elected to the U.S. Congress in 1980, and reelected in 1982, 1984, and 1986. While there he served on the House Ways and Means Committee, the Public Works and Transportation Committee, and the Small Business Committee. In 1992, Mr. Daub was appointed by President George H.W. Bush to the National Advisory Council on the Public Service. From 1997 to 1999, he served on the Board of Directors of the National League of Cities, and from 1999 to 2001, he served on the League's Advisory Council. He was also elected to serve on the Advisory Board of the U.S. Conference of Mayors, serving a term from 1999 to 2001. From 1971 to 1980, Mr. Daub was vice president and general counsel of Standard Chemical Manufacturing Company, an Omaha-based livestock feed and supply firm. A former U.S. Army Infantry Captain, he is a Distinguished Eagle Scout, 33rd Degree Mason, is active in the Salvation Army, Optimists International and many other charitable and philanthropic organizations. He is the current chairman-elect of the Community Health Charities of America. Mr. Daub is a graduate of Washington University in St. Louis, Missouri, and received his law degree from the University of Nebraska. Term of office: January 2002 to September 2006.

Dorcas R. Hardy

Dorcas R. Hardy is President of DRHardy & Associates, a government relations and public policy firm serving a diverse portfolio of clients. After her appointment by President Ronald Reagan as Assistant Secretary of Human Development Services, Ms. Hardy was appointed Commissioner of Social Security (1986 to 1989) and was appointed by President George Bush to chair the Policy Committee for the 2005 White House Conference on Aging. Ms. Hardy has launched and hosted her own primetime, weekly television program, “Financing Your Future,” on Financial News Network and UPI Broadcasting and “The Senior American,” an NET political program for older Americans. She speaks and writes widely about domestic and international retirement financing issues and entitlement program reforms and is the co-author of *Social Insecurity: The Crisis in America’s Social Security System and How to Plan Now for Your Own Financial Survival*, Random House, 1992. A former CEO of a rehabilitation technology firm, Ms. Hardy promotes redesign and modernization of the Social Security, Medicare and disability insurance systems. Additionally, she has chaired a Task Force to rebuild vocational rehabilitation services for disabled veterans for the Department of Veterans Affairs. She received her B.A. from Connecticut College, her M.B.A. from Pepperdine University and completed the Executive Program in Health Policy and Financial Management at Harvard University. She is a Certified Senior Advisor and serves on the Board of Directors of Wright Investors Service Managed Funds, and First Coast Service Options of Florida. First term of office: April 2002 to September 2004. Current term of office: October 2004 to September 2010.

Barbara B. Kennelly

Barbara B. Kennelly became President and Chief Executive Officer of the National Committee to Preserve Social Security and Medicare in April 2002 after a distinguished 23-year career in elected public office. Mrs. Kennelly served 17 years in the United States House of Representatives representing the First District of Connecticut. During her Congressional career, Mrs. Kennelly was the first woman elected to serve as the Vice Chair of the House Democratic Caucus. Mrs. Kennelly was also the first woman to serve on the House Committee on Intelligence and to chair one of its subcommittees. She was the first woman to serve as Chief Majority Whip, and the third woman in history to serve on the 200-year-old Ways and Means Committee. During the 105th Congress, she was the ranking member of the Subcommittee on Social Security. Prior to her election to Congress, Mrs. Kennelly was Secretary of the State of Connecticut. After serving in Congress, Mrs. Kennelly was appointed to the position of Counselor to the Commissioner at the Social Security Administration (SSA). As Counselor, Mrs. Kennelly worked closely with the Commissioner of Social Security, Kenneth S. Apfel, and members of Congress to inform and educate the American people on the choices they face to ensure the future solvency of Social Security. Mrs. Kennelly served on the Policy Committee for the 2005 White House Conference on Aging. Mrs. Kennelly received a B.A. in Economics from Trinity College, Washington, D.C. She earned a certificate from the Harvard Business School on completion of the Harvard-Radcliffe Program in Business Administration and a Master’s Degree in Government from Trinity College, Hartford. Term of office: January 2006 to September 2011.

David Podoff

David Podoff was a senior advisor to the late Senator Daniel Patrick Moynihan on Social Security and other issues while serving as Minority Staff Director and Chief Economist for the Senate Committee on Finance. While on the Committee staff he was involved in major legislative debates with respect to the long-term solvency of Social Security, health care reform, the constitutional amendment to balance the budget, the debt ceiling, plans to balance the budget, and the accuracy of inflation measures and other government statistics. Prior to serving with

the Finance Committee he was a Senior Economist with the Joint Economic Committee and directed various research units in the Social Security Administration's Office of Research and Statistics. He has taught economics at the Baruch College of the City University of New York, the University of Massachusetts and the University of California in Santa Barbara. He received his Ph.D. in economics from the Massachusetts Institute of Technology and a B.B.A. from the City University of New York. Term of office: October 2000 to September 2006.

Sylvester J. Schieber

Sylvester J. Schieber is Vice President/U.S. Director of Benefits Consulting at Watson Wyatt Worldwide, where he specializes in analysis of public and private retirement policy issues and the development of special surveys and data files. From 1981 to 1983, Mr. Schieber was the Director of Research at the Employee Benefit Research Institute. Earlier, he worked for the Social Security Administration as an economic analyst and as Deputy Director at the Office of Policy Analysis. Mr. Schieber is the author of numerous journal articles, policy analysis papers, and several books including: *Retirement Income Opportunities in An Aging America: Coverage and Benefit Entitlement*; *Social Security: Perspectives on Preserving the System* and *The Real Deal: The History and Future of Social Security*. He served on the 1994 - 1996 Advisory Council on Social Security. He received his Ph.D. from the University of Notre Dame. First term of office: January 1998 to September 2003. Current term of office: October 2003 to September 2009.

Members of the Staff

Joe Humphreys, Staff Director

Katherine Thornton, Deputy Staff Director

Joel Feinleib

Beverly Rollins

George Schuette

Jean Von Ancken

David Warner