

**BARRIERS TO WORK FOR INDIVIDUALS RECEIVING  
SOCIAL SECURITY DISABILITY BENEFITS**

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**HEARING**  
BEFORE THE  
**COMMITTEE ON FINANCE**  
**UNITED STATES SENATE**  
ONE HUNDRED TENTH CONGRESS  
FIRST SESSION

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JUNE 21, 2007  
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RECEIVING SOCIAL SECURITY  
DISABILITY BENEFITS**

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**THURSDAY, JUNE 21, 2007**

U.S. SENATE,  
COMMITTEE ON FINANCE,  
*Washington, DC.*

The hearing was convened, pursuant to notice, at 10:07 a.m., in room SD-215, Dirksen Senate Office Building, Hon. Max Baucus (chairman of the committee) presiding.

Present: Senators Salazar, Grassley, Snowe, and Bunning.

**OPENING STATEMENT OF HON. MAX BAUCUS, A U.S. SENATOR  
FROM MONTANA, CHAIRMAN, COMMITTEE ON FINANCE**

The CHAIRMAN. The hearing will come to order.

The Psalmist prayed, "Establish the work of our hands for us. Yes, establish the work of our hands." People have long known the value of work, but for some reason when it comes to people who are receiving Social Security disability benefits, the government makes it hard for people to work. Today we examine those barriers to work. What are they, and what can we do to eliminate them?

The Social Security Administration runs two programs for people with disabilities: Social Security Disability Insurance, or SSDI, which provides wage replacement income for people who have paid payroll taxes and then suffer a disability; and Supplemental Security Income, or SSI, which provides payments to meet basic needs for people with disabilities who have little or no income.

But the government has structured these programs so that they discourage work. For example, in 2004 only 6 out of every 1,000 SSDI beneficiaries left the program to work. Why do so few people go back to work? One barrier is fear. Some fear that they will lose their health insurance coverage. Some fear that the government will ask them to repay over-payments of benefits. Social Security sometimes requires repayment because it does not have enough staff to process earnings reports.

Some fear that it would take a long time to return to the program if their health worsened again. Some fear that the government might use a successful period of work against them if they needed to return to the program.

Another barrier to employment is health. Applicants for SSDI or SSI often have to wait several years before they can get on the program. SSI beneficiaries then get health coverage under Medicaid—that is, in most States.

But SSDI beneficiaries are eligible for Medicare only after waiting 2 more years on the program. During the time that people are waiting for coverage, a medical condition can worsen, and that can make it harder to return to work.

Another barrier to work is the lack of rehabilitation services. State vocational rehabilitation agencies have limited openings, and these agencies are not required to give Social Security disability beneficiaries any priority.

The Ticket to Work program that Congress enacted in 1999 gives beneficiaries a voucher to get rehabilitation services from approved providers, but only 1 in every 61 of these tickets were assigned to a service provider. Something is not working here.

Another barrier is the number and complexity of work incentives in the law. Beneficiaries do not understand the rules, and beneficiaries face heavy documentation burdens.

The law creates barriers to work, with restrictions on earnings and assets. For SSDI, after 9 months of working, if beneficiaries earned more than \$900 in a month, they lose their entire cash benefit. There is no gradual reduction in SSDI as there is in SSI.

And under SSI, the amount that a beneficiary can receive in earnings or other benefits before losing SSI benefits has not been changed since 1974. Beneficiaries can hold no more than \$2,000 in assets, and that has not changed since 1989. These asset limits make it impossible to save for education that might help a beneficiary get a job.

There is so much here that we need to change. I look forward to hearing recommendations from witnesses on how we can reduce these barriers to employment. Let us recognize the value of work. Let us remove barriers between beneficiaries and the workforce, and let us make it easier for people with disabilities to establish the work of their hands.

Senator Grassley?

**OPENING STATEMENT OF HON. CHUCK GRASSLEY,  
A U.S. SENATOR FROM IOWA**

Senator GRASSLEY. Thank you very much, Mr. Chairman. Welcome to everybody.

I wanted to say ahead of time so everybody understood, if I was not here very long, that in about 15 minutes I have to go participate in some other activity on the Hill that is scheduled, including being on the floor.

We all know that in order to receive disability benefits under current law, an individual must have a condition that prevents him or her from working for at least a year.

From the perspective of most disability beneficiaries, the thought of going back to work after spending 2 or 3 years convincing the Social Security Administration that they cannot work might be a frightening prospect.

Technically, the ability to work is defined as “engaging in Substantial Gainful Activity.” Under this definition, it is possible to earn up to \$900 a month, or \$1,500 for the blind, and still remain eligible for disability insurance benefits.

Under certain circumstances, it is possible to earn an unlimited amount for a limited period of time, which is called a “trial work

period.” Those receiving disability through the Supplemental Security Income program, SSI, are subject to different limits.

Despite the fact that persons receiving disability benefits can work a limited amount without losing their benefits, very few beneficiaries choose to do so. For example, according to the latest available data, about 6 percent of SSI beneficiaries are reported as working.

It is suggested that we need to modernize the disability program to reflect advances in medicine and technology. However, advances in medicine and technology should make it easier for those receiving disability benefits to go back to work. It should not increase the share of the population receiving disability benefits.

Improving Social Security Disability Insurance is obviously a very important goal. A program as old as that program, needs to be looked at constantly by Congress to see how it can be updated and improved.

However, we must be careful to ensure that the legitimate desire to encourage those receiving disability benefits to return to work does not turn into an unsustainable policy of extending disability benefits to those who are able to work well beyond the “Substantial Gainful Activity” level.

Thank you, Mr. Chairman.

The CHAIRMAN. Thank you, Senator.

Now I will introduce our witnesses. I might say, the Senate’s scheduling is sometimes very difficult to predict. On the floor today there is an amendment to strike a major portion of the bill that this committee reported out yesterday, and I will have to go to the floor to defend the committee position around 10:35, around there somewhere. I very much regret that I will not be able to be here for most of the hearing.

However, Senator Salazar from Colorado has very kindly agreed to chair the hearing, so I want you to know that everybody is going to be hearing—I will be hearing, even though not personally, but indirectly through Senator Salazar and my staff and others—everything you are saying, so do not feel that you are being short-changed just because the Senate schedule is forcing me now to be on the floor during most of this hearing.

Right now, I would like to introduce our witnesses. First, is Ms. Sue Suter, who is Associate Commissioner for Employment Support Programs at Social Security.

And it is a real honor to introduce Jim Brown from Montana. Jim is on SSDI and he wants to work more, but there are some restrictions that are preventing him from doing all that he wants to do. Jim, thanks for coming here today. It is a great distance to come from Montana, and thanks for explaining to this committee what needs to be done so that you can do what you want to do, that is, work. I know I need not tell you this, but the old Montana spirit: just let ’er rip; say what is on your mind. But thank you very much for coming.

We also have Mr. Al Jensen. Al Jensen is from George Washington University. Thank you, Mr. Jensen. Your reputation precedes you. You have done a lot of work in this area, and we thank you very much for your contribution.

The same with Dr. David Stapleton from Cornell. Thank you, Dr. Stapleton, for all that you have done as well.

So let us begin with you, Ms. Suter. We would like to have each person speak about 5 minutes. Your entire testimony obviously will be included in the record, but if you could just summarize your statement and hit the high points and let us know what you want us to hear.

**STATEMENT OF SUE SUTER, ASSOCIATE COMMISSIONER FOR  
EMPLOYMENT SUPPORT PROGRAMS, SOCIAL SECURITY AD-  
MINISTRATION, BALTIMORE, MD**

Ms. SUTER. Thank you, Mr. Chairman and members of the committee. Thank you for the opportunity to discuss the Social Security Administration's efforts to address the barriers that make it difficult for beneficiaries with disabilities to return to work.

I come to you today as a person with a disability since age two, and someone who has worked in the field for a number of years as Director of the Illinois Department of Vocational Rehabilitation, Illinois Department of Public Aid, Illinois Department of Children and Family Services, Commissioner of the Rehab Services Administration, and president of the World Institute on Disability. I very much appreciate that you are highlighting this extremely complex and critical issue.

Assisting beneficiaries with disabilities has been one of the most challenging issues facing Social Security for over 50 years, and assisting individuals to take advantage of employment opportunities remains one of our highest priorities.

Our efforts can generally be placed in two categories: employment services under the Ticket to Work program and the State Rehabilitation program, and Work Incentives for those who are ready for employment and need assistance in transitioning off the disability rolls.

Congress established the Ticket program in 1999 to provide beneficiaries with disabilities choice in obtaining the services and support they need to find, enter, and maintain employment. The Commissioner issues a ticket to beneficiaries who have the option of using the ticket to obtain services from an Employment Network (EN) or from State VR agencies. Upon agreement with the beneficiary, the EN will supply without charge various employment support services. When the beneficiary achieves certain work outcomes, we pay the provider. The Ticket program was implemented in phases beginning in February of 2002, completing the roll-out in September of 2004.

We have learned a number of lessons from the Ticket program over the past few years and are changing accordingly. We are recruiting and establishing partnerships in developing successful business models for Employment Networks and community providers. We have an outreach program for ENs in marketing and outreach messages geared to beneficiaries and potential ENs.

We are providing information to beneficiaries via work incentive seminars, bringing together beneficiaries, ENs, and other partners on the community level. Ten events will be conducted this fiscal year.

We know outreach is not enough. Changes are needed to increase participation by both beneficiaries and ENs to improve outcomes. In September of 2005, we published a Notice of Proposed Rule-making (NPRM) proposing the kind of changes that would significantly enhance access and choice for beneficiaries and improve the likelihood that they will return to work.

The proposed changes are intended to increase payment rates to ENs to increase their participation, to better coordinate services provided by State VR agencies and ENs, and to allow more beneficiaries to be eligible for the Ticket.

In addition to the Ticket program, there are a number of other work incentives in place to assist individuals to venture into the workforce. Generally, these provide for continued benefits and medical coverage while working or pursuing an employment goal. I have explained these in detail in my written statement.

In addition to Employment Networks, the Ticket legislation also established an infrastructure that encourages participation and collaboration, and we are working to increase this. We have Work Incentives, Planning, and Assistance (WIPA) grantees who are community-based organizations that assist beneficiaries to understand the work incentives and how they affect their benefits.

These WIPAs are available as resources to ENs and other agencies that assist beneficiaries with disabilities to return to work. Protection and Advocacy (P&A) grantees provide information, advice, advocacy, and other services to beneficiaries.

Within Social Security we have Work Incentive Liaisons (WILs) who work at SSA field offices and receive special training on work incentives. Working with other field office staff, WILs provide personal discussion on how various incentives can work for a specific individual. In turn, the Work Incentive Liaisons are supported by a network of area Work Incentives Coordinators. They assist WILs, coordinate outreach, and help develop training.

In conclusion, Social Security is committed to assisting beneficiaries with disabilities who want to return to work. We will continue our efforts to improve and grow the Ticket Program and remove the barriers with our programs so that every beneficiary with a disability has an opportunity to reach his or her fullest potential.

Thank you. I would be happy to answer any questions.

The CHAIRMAN. Thanks, Ms. Suter, very, very much.

[The prepared statement of Ms. Suter appears in the appendix.]

The CHAIRMAN. All right. Jim Brown, you are up.

**STATEMENT OF JIM BROWN, SSDI BENEFICIARY,  
INDEPENDENT ADVOCATE, BILLINGS, MT**

Mr. BROWN. Mr. Chairman and members of the Committee, over 200 years ago Thomas Jefferson wrote of our inalienable rights: that of life, liberty, and the pursuit of happiness.

At the time, however, the pursuit of happiness did not include the blacks, the Native Americans, or women. It did not, and it still does not, include the disabled. I want to discuss this right of the pursuit of happiness, how the disabled are excluded, and the changes necessary to include us in that right.

Now, the pursuit of happiness may mean great wealth, cars, big houses, maybe the power and prestige of being a big mover and

shaker in the business world. But for others, it simply may be enough to get by on in a little house with a white picket fence, a swing set in the backyard where they watch their kids and grandkids as they grow old together with the love of their life. But whatever the vision, the vast majority of us disabled are left out.

I found this out after I broke my neck on a trip to Hungary. I had no insurance and mounting medical bills, so I had to turn to government assistance for help. I found out I had to sell all of the cows that I had invested in since I was a young boy just to become eligible for the Medicaid program. Medicare, which I had paid taxes into, would not require that sort of a sacrifice, but then it would not help for 2 more years.

When I tried going back to work, I found that my right to the pursuit of happiness was gone. I wanted the prestige of working a full-time job again, and modern technology would make that a possibility.

But then I found if I made more than \$900 a month, according to Social Security I was no longer disabled. Regardless of how much I would make, though, my hands and my legs still will not work and I will still have those disability-related expenses.

Over the course of a lifetime, the personal care, adaptive equipment, and wheelchair-related expenses for a disabled person can total well over \$1 million more than what an able-bodied person faces.

I wanted to work and to make my own money. I did not like the feeling of having to go and be a beggar and to be a burden on society. I would have gladly given up my \$600 Social Security check that I was getting, but I was told I had to stay eligible in order to get the Medicaid assistance for the personal care and other expenses that Medicare does not cover.

I went to work. I got a part-time job, but then I was disheartened when I learned that I would have to give all my earnings, \$540 a month, to Medicaid as a spend-down in order to retain my eligibility.

Still, I loved working with kids. I had a part-time job working with kids, and I just could not even believe I was getting paid to do that, so I kept at it. I was even more disheartened to learn later though that I would have been better off if I had never worked, had never paid into the Social Security system, since then I would be eligible for SSI rather than the SSDI, that SSDI would have allowed me to make more money because the financial assistance would have been gradual rather than the cut-off at \$900, and I would not have had a spend-down for the Medicaid assistance.

So, basically I could have a house, but with the \$2,000 asset limit I could not afford to pay any sort of a down payment, and I cannot afford any sort of a car payment on the \$540 that Medicaid says is all I need to live on.

Basically, I face three choices: either I do not work and I let the government take care of me through SSDI payments, Medicaid, housing assistance, and food stamps; otherwise I could work part-time, but then give my paycheck to the government; or I must somehow find a job with a \$50,000 starting salary so I can pay my own way. The first two options are very discouraging, and the last is just totally unrealistic. There needs to be a fourth option.

It needs to be realized that a disability is a physical or a mental condition, not an economic condition. I realize programs are designed the way they are to discourage people from getting on them, but they do more to discourage those who truly need the help.

We need programs that will bridge the gap between the part-time job and that \$50,000-a-year job, something that will cover the extra \$20,000 to \$30,000 yearly disability-related expenses until we can finally be promoted enough to where we are able to finally pay our own expenses. The entire system would be better off if we were at least working to help pay for it.

Honorable Senators, in Jefferson's day the disabled rarely lived. My condition, a broken neck, was a death sentence. If they did then, they were shut away in homes and forgotten about. But now, 21st-century technology keeps us alive and healthy. We live independently. We can get out into the community.

We should not have to stay at home and stifle our abilities just because something in our brains and our bodies does not work quite right and we need an extra hand. These policies need upgrading so we can truly live, so we can live with hope and dignity, enjoying the right to the pursuit of happiness.

Honorable Senators, I urge you to leave a legacy and help change these policies so we can all get access to that last inalienable right. I thank you for the opportunity to speak with you on behalf of disabled people everywhere, and I will be happy to entertain any questions. Thank you.

The CHAIRMAN. Thank you, Jim, so very, very much. Thank you.

[The prepared statement of Mr. Brown appears in the appendix.]

The CHAIRMAN. Mr. Jensen?

**STATEMENT OF ALLEN JENSEN, SENIOR RESEARCH STAFF SCIENTIST, CENTER FOR HEALTH SERVICES RESEARCH AND POLICY, GEORGE WASHINGTON UNIVERSITY, WASHINGTON, DC**

Mr. JENSEN. Mr. Chairman, Senator Salazar, my name is Allen Jensen. I am with George Washington University's work incentives project. You have a copy of my written testimony, which is presented by myself and on behalf of Bobby Silverstein.

We have worked together for the last 10 years, looking at possible ways to reduce some of these problems that have been described by Jim and in your opening statement, Mr. Chairman.

Of particular emphasis in our research was looking at the interrelationship between SSI, SSDI, Medicaid, and Medicare and trying to figure out how to make this system work better. As indicated by Jim, there are certain areas where we do have pretty good work incentives, but in others, it is very limited.

I want to just talk briefly about some of the key facts, and then some basic themes, and then our recommendations.

First of all, looking at the SSDI and SSI programs, they are definitely programs of last resort. That is, the eligibility requirements are very strict. Less than 55 percent of those who apply for benefits actually receive benefits, and, of those who are denied, 40 percent are out of work for a total of 3 years.

Many of those on SSDI, of course, cannot work even a limited amount because of the extent of their disability. Studies have been

done that show, for a 15-year period, that only 50 percent of the people with earnings in one year had earnings the following years. So, their ability to work was very much intermittent. The whole matter of risking working for a long time was very much the concern.

But there are a significant number of people, a significant minority of beneficiaries, like Jim and others, with mental disabilities and other types of disabilities, who can work if they have the right kind of supports and ongoing assistance as they attempt to work and if there is adequate infrastructure at the Social Security Administration and within State and local governments to provide the services that they need and to enable them to understand the work incentives. Sue talked about the infrastructure that SSA is trying to develop, to develop a way for people to understand the work incentives.

And so our recommendations are based upon the idea that you should have something which provides security, that is simple to understand, and is sustainable with an infrastructure at the State and the Federal Government.

I think that our recommendations are based, again, on our experience with the SSI program and with the Medicaid buy-in program which this committee authorized back in 1999, and prior to that, 1997.

We are suggesting targeted recommendations to reduce barriers to employment. Here again, for much of the population, SSDI and SSI is providing income assistance to enable them to live in the community. As Jim talked about, many years ago, 50 years ago when the SSDI program started, most people with disabilities were in institutions.

So our recommendations. We suggest a continued attachment to the SSDI and the SSI program and Medicaid once a person starts to work and they have earnings, and as long as their disability continues.

We think this is an important part of the security and the ongoing assistance that is needed, that they have, in effect, a safety net that they can return to if there is an exacerbation as far as either physical or mental disability.

In the current program in SSDI, there are, in effect, continued attachments, but they are time-limited. For people with disabilities, their disability is not time-limited.

I think that also on the SSI side, it is earnings-limited. So we are suggesting that there be continued attachment to the program, as long as their disability continues, including when they are in a non-benefit status so they can return to benefits.

As Senator Baucus talked about in his opening statement, these are not situations where you can easily get back on benefits, so there is fear as far as returning to benefits.

The second part of our recommendation is related to that, the idea of a gradual reduction in benefits that is now part of the SSI program. Right now, in the SSI program, the first \$85 for someone only on SSI is disregarded, and then there is a gradual \$1 reduction in benefits for every \$2 of earnings.

This is a provision that has been in SSI since the program began in 1974, and we think this is an important aspect of the work in-

centives that are needed by people like Jim and others with disabilities.

There have been attempts to provide this type of a gradual reduction in SSDI benefits over the last 20 years. I have in my document here a CBO estimate from 1988 that talked about the projected cost, but we think we have devised a package of proposals which would not have that type of cost.

There is also discussion in our written testimony regarding the whole matter of rewarding work by allowing more savings, and we are recommending that there be an increase in the SSI and Medicaid resources test.

The last thing I want to say is, we think, in order to make any kind of improvements work, that there has to be a sufficient commitment of resources by the Social Security Administration and support from the other agencies in the Federal Government and by State and local government to have a program which can have an accurate and timely adjustment of benefits as people work.

So I would say that what we are trying to do here is devise a program that sustains people who cannot work, but at the same time provide a system of work incentives that enables people who can work to work up to their ability and not risk the loss of their safety net of income assistance and health care.

Thank you very much.

Senator SALAZAR. Thank you, Mr. Jensen.

[The prepared statement of Mr. Jensen appears in the appendix.]

Senator SALAZAR. Dr. Stapleton?

**STATEMENT OF DR. DAVID C. STAPLETON, DIRECTOR,  
CORNELL CENTER FOR POLICY RESEARCH, WASHINGTON, DC**

Dr. STAPLETON. Thank you. Thank you for inviting me here today.

Like his two predecessors, the Social Security Administration's new Commissioner, Michael Astrue, is giving high priority to improving the unconscionably poor performance of the Social Security Administration's disability determination process.

I was involved in some of the Agency's earlier efforts, and sad to say, very little progress has been made over a period longer than 12 years.

I have become increasingly convinced that the problems with the determination process are more a reflection of larger problems with Federal disability policy than they are with poor process design, poor management, or inadequate resources.

Yes, increased funding and procedural improvements could improve the process, but I believe the process will continue to be very problematic in the absence of successful transformative change to Federal disability policy. I fear that efforts to transform disability policy will take a back seat to efforts that focus on improving the determination process.

Because of time limits, I am going to limit my remarks to the Social Security Disability Insurance program, but different remarks along the same vein apply to SSI and other programs.

It is critical to preserve SSDI for those workers whose physical or mental impairments really prevent them from permanently earning a substantial sum under any reasonable circumstance.

The SSDI program has become unduly burdened because it is trying to meet the needs of significant numbers of workers with disabilities who would be better served by a program that helps them continue to be self-sufficient through work. Current programs serving that purpose are inadequate, and as a result many turn to SSDI for lack of better alternatives. It is a last resort.

Last summer, the Social Security Advisory Board outlined an appealing structure for a 21st-century disability program. This structure includes SSDI as part of an income support program for those who are unable to attain a reasonable standard of living through work for very long periods, or permanently.

The structure also includes two other critical components. The board calls the second component, which is parallel to the income support benefit, a transitional program that would help participants achieve or continue productive and fulfilling lives rather than becoming highly dependent on public benefits, through individualized programs involving various combinations of rehabilitation services, job restructuring, assistive devices, specific health and related services, short-term income support, and perhaps even longer-term earnings subsidies.

The third component of the Advisory Board's structure is a common entry system into the two parallel systems, which the board calls triage assessment. Workers with disabilities would be encouraged to enter triage assessment early, even while they are still employed.

The process would be designed to quickly identify those with very short-term challenges, or with challenges that can readily and reasonably be addressed by their employers, those who are clearly unable to contribute substantially to their own support under any reasonable circumstances for a year or longer, and those in the gray area in between, which I believe is quite large.

The first group would not receive additional services, the second would enter SSDI, and the last would enter the transitional program. Some of the latter group would later enter SSDI, but only after their efforts to pursue their aspirations under the new program were not sufficiently successful.

A draft report written by Bryon MacDonald and Megan O'Neil of the World Institute on Disability also recommends a new program that would parallel SSDI and would serve many workers who might otherwise exit the labor force and enter SSDI. They call it Employment Support Insurance.

There are many differences in the details of the Advisory Board's recommendations and those of the World Institute report, but I think the large area of common ground in these two reports is much more important than the differences.

Each calls for a single employment support program or system separate from SSDI that helps people with disabilities achieve or sustain economic independence as soon as they believe they need help, and before they become heavily reliant on long-term income supports.

Such a program could theoretically both improve the lives of people with disabilities and reduce the burden of disability programs on taxpayers. Current policies waste the considerable productive

capabilities of people with disabilities and undermine their ability to support themselves.

Further, although people with disabilities receive many services under the current system, these services are delivered in a very inefficient manner because financial responsibility is highly fragmented. A well-designed program would help participants make good use of their productive capabilities and might achieve considerable efficiencies through financial and service integration.

I think there is some hope that we can achieve those lofty goals. In the submitted testimony, I talk about a program that is a pilot program in the U.K. called Pathways to Independence, which has shown real promise in reducing the number of people with disabilities who enter their long-term benefit rolls, on the order of 14 percent.

To finish, though, I want to place my remarks in the context of what you have heard from the other speakers. Mr. Brown's story clearly illustrates the harm done by current disability policies, about the poverty trap that they create for people who could, with some assistance, contribute much more to their own support and to our society.

Both Ms. Suter and Mr. Jensen have talked about efforts to help people who are already on the SSDI and SSI rolls increase their earnings, and reduce their dependence on income support. I am involved in some of those efforts myself, and in general I think they are headed in the right direction, but at a pace that is frustratingly slow.

These efforts can potentially help Mr. Brown, given his history, but they are also complementary in many ways with a separate work support program like the sort I have very briefly described.

Such a work support program would be designed to help people like Mr. Brown continue their pursuit of happiness as soon as they experience a potentially disabling condition, so they would never be trapped in poverty and never become so highly dependent on public support.

Such a program also has the potential to address the induced demand problem, the increase in applications and awards for SSDI and SSI that SSA's actuaries and the Congressional Budget Office predict will occur if we replace the SSDI cash cliff with a gradual benefit offset.

Finally, if the new program achieves sufficient success over a very, very long period of time, SSA would no longer need to put such effort into helping SSDI beneficiaries return to work because the only beneficiaries left in the program would be those who could not provide substantial support for themselves through work under any reasonable circumstances.

I urge this committee, other government leaders, and advocates for people with disabilities to promote in general the efforts that are going on, but to pay increasing attention and give very high priority to efforts that would, in fact, reduce the premature exit of workers from the labor force and onto SSDI.

Thank you.

[The prepared statement of Dr. Stapleton appears in the appendix.]

Senator SALAZAR. Thank you. Thank you, Dr. Stapleton.

Let me first, in a matter of introduction as to why I am sitting here as opposed to Senator Baucus or Senator Grassley, we have been working very hard for a long time on a major energy package, and that package came out of this committee this week and is on the floor of the Senate.

Within probably an hour or so, there will be a vote that will determine the outcome of this very, very important work for this committee. Otherwise, it would be Senator Grassley who would be chairing this committee, or Senator Baucus. So, they are working on very important work for our Nation right now.

Let me also just join Senator Baucus in welcoming the witnesses, and thank you for sharing your expertise with all of us. And, in particular, Jim, for your coming across the country all the way from Billings, MT to share your personal story.

There is nothing that tells a story better than someone who has to live through the program the way that you have had to live through the programs that we are talking about here today. So, we appreciate all of you, but we also appreciate you for your courage and your strength in being here today.

Let me also note that we have been joined by Senator Snowe, who is an expert on some of these issues. So, after my 5 minutes, I will turn it over to her for her set of questions.

The Social Security disability programs serve a critical purpose. They give Americans with disabilities an income that they are prevented from earning on their own, as well as access to health care many of them would otherwise receive through their employer.

These programs help millions of Americans. Over 8.6 million Americans today are enrolled in SSDI and 7.3 million in SSI. A critical goal of these programs is to help Americans with disabilities transition back to the workplace. Unfortunately, these programs have been less than successful—and that is an understatement—in this regard.

Return-to-work rates for individuals in the SSDI program are less than 1 percent. Less than 1 percent. For individuals receiving SSI, the rate is only 7 percent. I think that those statistics tell a story that should concern each and every one of us.

Our largest return to work programs, Ticket to Work and Plans for Achieving Self-Support, have shown little success, frankly. Ticket to Work has a participation rate of less than 2 percent, and the PASS program has shown a less than ½ of 1 percent participation rate.

We all have to ask the questions, why are these rates so low and what are the solutions to dealing with these low rates of return to work? In my own experience, the vast majority of individuals with disabilities who are physically able to work want to return to work, but do not seek employment out of fear of losing their disability benefits that they so depend on.

Return to work programs are not the only problems that exist with respect to SSDI and SSI. My office in Colorado assists hundreds of people in Colorado as they apply for these disability benefits and work their way through the appeals process. In fact, it is one of the top three issues that my office in Colorado is contacted about on an annual basis.

Recently, this committee held a hearing on how to best address the backlog in Social Security disability claims, and I look forward to working with my colleagues to address this, and other, critical matters.

Toward that end, I am looking forward to hearing more from the witnesses as I ask some questions that Senator Baucus asked me to ask on behalf of the committee.

I will begin by asking the first of those questions, which is, we know the reality of the problems that we face with the system, so I will ask a question of each one of the witnesses, that is essentially this.

So we have your statements for the record, and I know how hard you worked in preparing those statements. They obviously will be reviewed by staff and will be reviewed by the Senators themselves.

But the question that I would ask each of you, and, if you could just take a minute or so to think about this, if you were to point out the two most important things that we as a committee could do to address these challenges that we face with the disability issues we are talking about this morning, what would they be? The two most important ones. And because of the limit on time, if you will just take a minute in answering the question.

Ms. Suter, we will begin with you.

Ms. SUTER. I think the two most important things, and you have heard today, are to bring the two programs closer together in terms of work incentives and how they are administered, the Supplemental Security Income (SSI) and Disability Insurance (DI) programs: to look at the whole issue of employment supports and health care in terms of supports for people going back to work, and then from our perspective, to extend the demonstration authority to make that permanent for the SSDI program.

Senator SALAZAR. All right. So bringing the two programs together, employment support and health care during the transition, and then continuing on with the demonstration projects.

Mr. Brown?

Mr. BROWN. Yes. Actually, we have a group, Voices for Work, that met in Atlanta and discussed a lot of these issues. They are all Social Security beneficiaries. We did a poll among our group and had agreed that the number one recommendation was that we needed to raise the SGA amount, the Substantial Gainful Activities, because the amounts of that are so low, we are forced to work only part-time in order to be eligible for the medical benefits that we still need.

All those costs are so high that there is just no way to afford that on a normal income, so we need that help. So, it would sure be helpful if we raised the amount so we could go to work full-time.

Also, to allow us to work and maintain those health care benefits. If there was a way to bridge that gap between our part-time and our full-time employment, then we would have the benefits of insurance through the companies that we would be working for then, where that would take over and pay a lot of those until we could get to where we afforded our other personal care and that sort of thing that private insurances do not cover.

Senator SALAZAR. Thank you, Mr. Brown.

Mr. Jensen?

Mr. JENSEN. I think I want to follow up on what Sue and Jim have talked about: increase the similarities between the SSI and SSDI programs. That is a key part of our recommendations, that is, you have in the SSI program a gradual reduction in benefits as people have earnings, and then you also have the ability—in Montana I think it is \$27,000—to stay attached to Medicaid, and also if you have your earnings reduced you can return to SSI. So, it is a continued attachment and a gradual reduction.

Those are kind of the basic core of the work incentives in SSI. If SSDI was similar to that, then I think that we would be able to have people like Jim work up to a higher amount and not lose their health care protection under Medicaid. But also, as you talked about, as you increase your earnings and you move toward full-time employment, you are more likely to have employer-based health insurance.

Senator SALAZAR. All right.

Mr. JENSEN. So I think that is what we are learning in that regard.

Senator SALAZAR. Thank you, Mr. Jensen.

Dr. Stapleton?

Dr. STAPLETON. Yes. Two things. One, I have already indicated. That is, I think this committee really needs to pay attention to efforts to design and develop a front-end program, a transitional program, or an employment support program that is separate from SSDI and one that would help people with disabilities as soon as they experience disability and help them avoid getting on SSDI in the first place.

The second, though, is related to a remark I made about the frustratingly slow efforts for reform of the disability programs themselves, and specifically SSDI. I have to disclose, as I did in my written remarks, that I have been involved very substantially in these efforts, including currently working on the design of the benefit offset demonstration which came out of the one-for-two demonstration that was authorized by Congress under the Ticket Act in 1999. Also, I have been involved in evaluation of Ticket to Work.

Senator SALAZAR. So you know a lot about it. So what is your second recommendation?

Dr. STAPLETON. Yes. So my recommendation is, I cannot tell you a lot about what we have been doing, but I can tell you that it has been very slow. I think this committee needs to take actions, whatever actions it can, to move the process along more quickly.

Senator SALAZAR. So you are urging us to act.

Dr. STAPLETON. Right. Right.

Senator SALAZAR. I appreciate that very much.

Senator Snowe?

Senator SNOWE. Thank you very much, Mr. Chairman. I thank all our witnesses here today. In just listening to the testimony, and obviously being familiar with some of the problems that are challenging the disability programs, it makes me think about how logical it would be to have these programs work to the benefit of those who are disabled and want to go back to work. These programs should produce a win-win situation and not be so challenging and complicated and bureaucratic for the beneficiaries.

As you probably know, back in 1999 we attempted to fix this program with the Ticket to Work program—Ticket to Work with incentives like health care. Obviously, based on the results of that program since it became law, it truly has not worked.

So far few beneficiaries have taken advantage of this program. In fact, according to the CRS report, only 1.7 percent of the eligible SSDI and SSI beneficiaries have participated in Ticket to Work programs since its inception.

So I would like to start with you, Ms. Suter. Can you explain to me, what are the problems? We obviously should be learning by example. This program has been in place for roughly 8 years. And we should be able to learn from our experience and address those problems. So, please, can you tell me, why are there so few people involved? Why are so few using this program?

Ms. SUTER. Thank you, Senator. We certainly agree that the numbers are very low. We have put programs in place, and we are improving the program. I think you have heard a good example today of some of the challenges in the program. We have to, number one, alleviate the fears. We send a very mixed message to individuals with disabilities.

On the one hand, we say, if you need cash assistance or medical help, you have to prove you cannot work. And then we say—and this is in the big picture—oh, by the way, you can work. So we have to work with individuals, with beneficiaries to alleviate that fear. We have four things in place to be able to do that.

We have a new proposed Ticket regulation that looks at some of the EN payment structure and encourages more outreach. It also gets to Jim's point about how we need to include more people who can work part-time, or want to work part-time and gradually return to work. We have included that in the new regulations.

We are doing much more aggressive outreach and marketing, where we have 104 programs out in the country to provide benefits planning and assistance to beneficiaries to help them navigate this very, very complex system.

We also have protection and advocacy agencies out in the country to work with individuals. We are doing messaging for beneficiaries and potential Employment Networks on how to get involved in the program, and how to use the program.

We are having local work incentive seminars where we bring in people who have received a Ticket and they are scared and they do not know about the program because it is so complex. We bring them in to a community provider, a community partner who has credibility with that individual and we talk to them about the work incentives and we link them up with partners in the community.

Getting a Ticket in the mail from us saying, "Here is your Ticket," after we have put people through what we put them through, is not good enough. So we know we have to get people at the community level with people that they trust.

Finally, the partnerships. We have improved our business process, the red tape in paying Employment Networks. So, we have four aggressive things that we are doing to improve the program and to increase the numbers. We want to increase the numbers as well.

Senator SNOWE. Well, are there changes that Congress should work on with respect to this program? Do you have any specific changes in the statute?

Ms. SUTER. I think that I mentioned before the extension of the demonstration authority. That is how we look at some of these transitional and early interventions. I think what you could do is support us in terms of the Ticket regulation coming out.

Again, we have been frustrated—everybody has been frustrated—with the pace of this. But I think with these measures that we have in place, I think we can address a number of these issues.

Senator SNOWE. Do you have enough staff?

Ms. SUTER. As I think you know very well, our resources in Social Security are spread extremely thin. We can always use more resources. I think, from my perspective in terms of return to work, it is not an either/or issue.

Of the issues that affect people with disabilities on a daily basis, as Jim has pointed out, the backlog is very important. You should not have to wait long to find out if you are eligible.

By the same token, you should be able to have the supports you need to return to work. So, we are spread very thin in the Agency and, as I said, resources are always helpful. You all have been extremely supportive of that, and we appreciate that very much.

Senator SNOWE. Well, the reason why I asked about the staff is because, obviously in the President's budget, it was significantly under-funded. Senator Kerry and I, along with Senator Baucus and more than 40 Senators, have written to the Appropriations Committee, as well as the Budget Committee during the budget process, for an additional \$430 million for administrative costs. This amount is essentially the minimum that is required in order to address these disability claims and the backlog.

Right now in the State of Maine it takes an average of 469 days to deal with a specific claim in the backlog. Additionally, the average claimant could wait as long as 3 years for the resolution of a claim. These are disturbing numbers, to say the least, for those who certainly need the support of the Agency. We have to do better, and we have to figure out, what is it going to require to produce better results?

I realize that more money and more staffing overall are needed to address the problems here. It will also take the commitment to making sure that this program can work and serve the people it is intended to serve.

It is unacceptable for waiting times to exceed 3 years. The more than half a million disability claims that have been in the system and the backlog simply do not make sense.

We have to figure out how we can make the system better for those like Mr. Brown, who have gone through such an ordeal. The income limits are something else that we need to address. It should be a win-win in that sense, and working and receiving support from the government when you are disabled should not be mutually exclusive goals.

Thank you, Mr. Chairman.

Senator SALAZAR. Thank you, Senator Snowe, for those excellent questions and comments.

This is a question to Mr. Jensen. Mr. Jensen, under current law, SSDI beneficiaries lose all of their cash benefits when they earn over \$900 a month. They also lose their Medicare benefits after about 8 years.

The \$900 a month is commonly referred to as the "cash cliff." You have come up with a proposal to try to address the cash cliff. Can you describe how your proposal eliminates the cash cliff, and what are the other significant features of your proposal?

Mr. JENSEN. We propose that, first of all, our first priority, our first option would be that you have a gradual reduction beginning at that SGA, that cash cliff. As I talked about a moment ago, during the past 20 years, the actuaries and CBO have indicated that that would be a costly provision. We do not necessarily agree with that estimate they have made.

We have come up with another option which, in effect, here again, tries to deal with the matter of making similar the SSI and SSDI programs so that people would have, in effect, a choice: they can stay with the current program which helps a lot of people and they could work up to the SGA, or they could decide they are going to go this other approach, which says that we will have a beginning reduction of benefits at one-half of the SGA amount. But the trade-off then is that they would stay continually attached to the SSDI program and they could come back onto the program.

We are also suggesting that the SSI Initial Earned Income Disregard, which is now \$85 before you have the reduction, that that be increased up to that half of SGA. That has not been increased since 1974, when the SSI benefit level was about \$150.

So we think that increasing that amount—if you just had a COLA on the initial disregard, it would be more like \$250. So that is the basic approach that we are using, to say that if you believe you can sustain work—and this is a choice people can make on a periodic basis.

This does not necessarily simplify the program, but it, in effect, would require a certain level of resources for Social Security—and in answer to the question to Sue Suter, yes, Social Security needs more resources. You cannot starve, in effect, the work incentive program and have people working. You are going to have over-payments and those kinds of concerns.

That is the basic approach that we have in our program, which we think would result—and we have made estimates based on experience in the SSI program—that perhaps 150,000 to 300,000 people, we think, on SSDI would have substantial earnings if we did that.

In the experience in the SSI program, in any one month there are 330,000 people who have earnings. I think that that is a very significant number. A number of those people, like 75,000 in any one month, are not receiving any SSI. They are just still connected to the SSI program, but they are getting Medicaid.

One thing that was not talked about is, while the Social Security Administration has jurisdiction over the Ticket program and the things that Sue talked about, there is another important provision in the 1999 legislation, the Ticket law that you talked about, Senator Snowe, and that is the Medicaid buy-in program. The State of Maine has such a program.

There are about 75,000 people, mainly SSDI people, who are receiving Medicaid without the kind of spend-down that Jim has to deal with. Just a personal anecdote. About 10 days ago, I was called by a young man in Utah, whom I think has the same kind of disability that Jim has. He got on the Medicaid buy-in program. He has decided that, in spite of his severe disabilities, he can, in fact, go ahead and lose his SSDI and stay on Medicaid.

Now, that is not a high percentage of people on Medicaid buy-in, but there are some there who can do that. So the Medicaid buy-in—I do not know how many you have on the program in the State of Maine; Colorado does not have such a program, Senator. So, that would be complementary to, in effect, the gradual reduction approach and the Initial Earned Income Disregard. So that is it, in summary.

There are other details in there as far as our approach, but the idea of trying to make these programs more similar so that you do not have to have a cast of thousands out there explaining it.

You may still have to have a cast of thousands. You still have people who help people on income taxes and you have Turbo Tax and so forth, and you are still going to have some assistance as far as people understanding what their options are.

Senator SALAZAR. Well, thank you very much.

Mr. JENSEN. But it is clear, and I think that is important.

Senator SALAZAR. We thank you very much for your report and your recommendations. I will be asking Allen Jensen and Sue, and Jim questions on the work incentives when it is back to me in just a second.

Senator Snowe?

Senator SNOWE. Mr. Jensen, can you tell me about the lack of benefit counseling services? To what extent has that affected the program's ability to operate? Has that been a major barrier for many individuals? Ms. Suter, do you want to speak to that as well?

Mr. JENSEN. Benefits counseling is helpful. But I think we have to recognize that the number of people out there, the number supported by Social Security, is still rather limited.

There are things that are going on that build on what the Federal Government is doing, in a number of States they, in effect, are having a benefits information network so that all the provider agencies, like independent living centers and rehabilitation providers that are connected with State rehabilitation agencies, have people who are trained, who can help with the benefits counseling and work incentives counseling.

What you need to do is place in all the agencies that are dealing with people with disabilities who want to work, some level of knowledge so that the disabled can have an understanding of work incentives.

The support from the Social Security Administration is where the disabled have access to the highest-trained people. Those who know less about it, but at least have some basic understanding, can be complementary to the Federal support as well. This type of support is something that should be promoted, beginning with the SSI work incentives.

Senator SNOWE. It seems to me that the first step in this process is to encourage and help people participate in the program.

Mr. JENSEN. Yes. You have a good network in Maine. They are trying to coordinate with the vocational rehabilitation agencies, the independent living centers, and the medical center there in Maine.

Senator SNOWE. I am interested in what you said about the Medicaid buy-in and how that has worked for people, because in Maine it has been very effective.

Mr. JENSEN. Yes.

Senator SNOWE. The Medicaid buy-in program helps people who otherwise would not be able to purchase any health insurance, by allowing them to purchase insurance through the Medicaid program. I can see where it helps those who are disabled to go off of SSI, for example, and helps them obtain the full income and benefits of working.

Mr. Brown, did you participate in the Ticket to Work program?

Mr. BROWN. Actually, I got a Ticket to Work, and I did not have any clue what it was supposed to be. I didn't know if I just handed it to some employer. But I finally went and asked a vocational rehabilitation person and was informed that it really did not apply to me whatsoever, because they said that all it would do was ensure that I wouldn't be medically evaluated while I was searching for work. They said that I wouldn't be reviewed anyway, because it's pretty obvious to anybody that I do have a disability. So, the Ticket really did not apply in my situation.

Senator SNOWE. Well, Ms. Suter, are they sent out just to everyone? After hearing Mr. Brown's situation, are they just sent out? Are there no explanations with the tickets or are they tailored to those they are distributed to? What is the basis for doing that?

Ms. SUTER. By law, the Ticket is sent out to most beneficiaries who come on the rolls between ages 18 and 65. When we send the Ticket out to individuals, and this gets back to what I talked about before, we include information on our 800 number, our program manager, Maximus, and how you can find out more about the Ticket. We include information about resources there in the community that you can talk to through the 800 number. So, we provide that information.

As Mr. Brown said, though, what we found out and what we are doing now is, it is not good enough to just send out a letter and send out a Ticket. There needs to be that linkage on the community level. That is why, as Allen mentioned, we have the work incentives planning organizations. We have 104 throughout the country.

Those organizations work with Ticket holders to say, this is what the Ticket is about, these are the work incentives, how can we help you reach your goal? They are community organizations.

There are also a lot of individuals working for WIPAs who have disabilities, and some of whom have been beneficiaries and are now working. So, we know we have to do that high touch with beneficiaries to get them involved in the program.

Senator SNOWE. Do you support raising the income level? Have you indicated that earlier?

Ms. SUTER. We have had a lot of good suggestions from beneficiaries, from the Ticket panel. We are certainly happy to look at all of those suggestions.

Senator SNOWE. I mean, is that something that the Congress—for example, would the administration be opposing it?

Ms. SUTER. No. I think this administration would be open to looking at all the recommendations.

Senator SNOWE. Great. Thank you, Mr. Chairman.

Senator SALAZAR. Thank you, Senator Snowe.

This is a question to each of the panelists. With the reality that many of the incentives for SSDI and SSI programs are very complex, that reality creates serious complexity for the beneficiaries and others involved in the program.

Do you think that the work incentives for these programs should be simplified, and if so, how? Why do we not start with Dr. Stapleton and we will just go across. If you will take a minute each or so.

Dr. STAPLETON. Sure. I agree that complexity is a huge problem. I think what often happens, and this clearly happened with Ticket, is we add on new things to things that are already complex, and they make the new things more complicated than you would think they should be.

So, I would definitely encourage reforms in the line of making SSI more similar to SSDI in terms of its work incentive provisions. I think that is a very good idea.

Senator SALAZAR. All right.

Mr. Jensen?

Mr. JENSEN. Well, as I indicated, I think the idea of having a similar SSI and SSDI program so that you have a gradual reduction in both programs, as compared to a cash cliff in one and reductions after \$85 in the other, the idea that you can have a continued attachment back—sounds like a broken record here—to the cash benefit program if your work attempt fails, if those could be in both programs, I think it would be something that would say, if you are getting Social Security benefits, then you are going to be able to have this kind of protection if you try to work.

You are going to have differences as far as from State to State in Medicaid. That is a State-run program. Even the Medicaid buy-in programs are different from State to State.

Senator SALAZAR. Thank you, Mr. Jensen.

Mr. JENSEN. I think the idea of similarities would be a—

Senator SALAZAR. So those similarities would deal with the complexity, in large part, is what you are saying?

Mr. JENSEN. That is right.

Senator SALAZAR. All right.

Mr. Brown?

Mr. BROWN. Yes. I definitely think they need to be simplified.

Senator SALAZAR. How would you do it?

Mr. BROWN. What is that?

Senator SALAZAR. How should it be simplified?

Mr. BROWN. Well, for one, people who are working need to be able to learn the rules and be able to tell you what is going on. One thing we had discussed was like a one-stop program where you could go in and find out how the rules that are out there would affect each different program you are on. Like, I go to Social Security and they have told me that, well, this is how it will affect your—well, they will not even give you a definite answer.

They say this may affect your Social Security in this way, but then that may affect your Medicaid, and we do not know anything about that. So then I go to Medicaid, and they say, well, it might happen in this way, but we do not know if that will then affect your Social Security benefits. So if people knew all the regulations for each program and they would not be offsetting one another.

Senator SALAZAR. So there is a lot of confusion.

Mr. BROWN. There is a lot of confusion out there.

Senator SALAZAR. The complexity creates confusion.

Mr. BROWN. Exactly.

Senator SALAZAR. Ms. Suter?

Ms. SUTER. I agree, we need to simplify the program. I think as Dave mentioned, I think building on the work incentives has complicated it. We have an infrastructure in place with our area work incentives in the field, our work incentives programs. I think that anything we could do to bring the two programs together would be a big help in simplifying it.

Senator SALAZAR. All right.

Our colleague, Senator Bunning, has joined us on the committee, and so I will turn it over to him for his questions.

Senator BUNNING?

Senator BUNNING. First of all, I would like for my statement to be put into the record. Thank you.

Senator SALAZAR. Without objection.

Senator BUNNING. Thank you.

[The prepared statement of Senator Bunning appears in the appendix.]

Senator BUNNING. Ms. Suter, when I was chairman of the Social Security Subcommittee in the House of Representatives, I worked very hard on what finally became the Ticket to Work Act. I was not successful in passing it in the House. Or I was, but the Senate stopped it. Then when I got over here in 1998 in the Senate, Senator Kennedy and Senator Jeffords and a few others took my work and passed that bill. So, it has been in effect since 1998 or 1999.

What have you done to implement the Ticket to Work Act, and why in the world has it not worked? Because all of the things that you have talked about here today were covered by the Ticket to Work Act.

Ms. SUTER. Senator, as you know, we completed rolling out the program in 2004. We agree that the numbers are very low, the participation numbers from beneficiaries and Employment Networks. We are learning a number of things about the program, the complexity of reaching out to beneficiaries. We are instituting a number of new things to improve the program.

Given what you have heard here today, we have proposed new regulations that address the participation rate for Employment Networks that do a better job of partnerships between State vocational rehabilitation agencies that will make it more attractive for beneficiaries and offer more choices.

We have new initiatives in place to better do outreach and marketing. We have targeted mailers going out. We have community organizations that are working individually with Ticket holders. So, we have a number of things that we are doing.

We have de-bureaucratized the Employment Networks, the payments to Employment Networks so there is less red tape, and we are working on developing the partnerships.

Senator BUNNING. Did the Ticket to Work Act not protect those who tried and fell off the wagon, and tried again and fell off and were not able to maintain their employment for at least 36 months?

Ms. SUTER. Yes. That is part of the program.

Senator BUNNING. That is part of the program.

Ms. SUTER. Yes.

Senator BUNNING. And does the Social Security system realize that—this was in 1997—for every person that we got working, we saved \$3 billion over a period of time? For every 1 percent, excuse me, of the disabled who went to work, we saved about \$3 billion for the Social Security system so that they could take care of more people. Is the Social Security system aware of that?

Ms. SUTER. Yes.

Senator BUNNING. They are?

Ms. SUTER. Yes.

Senator BUNNING. It is beyond my comprehension that something that was passed in 1998, 1999, and it is now 2007, and you are still not making it work. You are rewriting regulations.

I was told by a very good friend of mine, who happened to be the vice chairman of the Social Security Committee when I was chairman, who came to the Social Security system and worked there for quite a long time—she is doing something else now—that there was no intent at the Social Security system to ever make the Ticket to Work program work. Is that true or false?

Ms. SUTER. That is false.

Senator BUNNING. Then why has it not worked?

Ms. SUTER. I think, for a number of reasons, Senator. I have been in the program 3 years. I have seen the former Commissioner was, and this Commissioner is, very committed to making the program work. Again, I think it gets back to, we have to alleviate the fears for the mixed messages we send to individuals, that you can work and there is the potential to work.

We have to put in place, and we have put in place, an infrastructure in the community to work with individuals on an individual basis to show them how the Ticket can assist them in the benefits of trying work. That is a slow process. We have learned a number of things from what we have seen in the program. We have learned a number of things from the Ticket panel.

Senator BUNNING. The Social Security system has never come back to the Congress of the United States and asked for any additional help. Never. Now, if you need help legislatively and you do not have enough tools to work with, why have you not come back to us?

Ms. SUTER. Senator, I have mentioned some things today that would assist us. I think we are going to continue. I think this committee has been very good about getting the resources for Social Security, for the whole gamut, whether it is the backlog or return to work. As you know, our resources are spread very thin. More resources are always helpful.

Senator BUNNING. The backlog has quadrupled since I was there. I mean, you want to talk about backlog, the backlog was in the hundreds of thousands at that time, 200,000, I believe. The backlog just continues to get bigger and bigger and bigger because we get less and less people approved.

There is more bureaucracy in running the SSDI and SSI programs than ever before. You kind of have to really want to make it happen if you want to take care of those disabled people who are on this program.

Go ahead.

Senator SALAZAR. Thank you, Senator Bunning. Thank you for your excellent questions and observations, that there has not been a lot of progress. In fact, there has been a decline in terms of dealing with some of these issues that have been on the table for a very long time.

A question, Jim, for you. Some people believe that many employers have a bias against hiring individuals with disabilities. They also believe that many employers fear the cost of accommodations for workers with disabilities, and fear that if the employee with disabilities joined the group health care insurance plan, costs to the business and premiums to its employees would rise significantly.

Have you had an employer refuse to hire you or ask inappropriate questions regarding your medical condition? Have you experienced discrimination or disparate treatment in the workplace?

Mr. BROWN. For the most part, the jobs that I have found, the two or three part-time jobs that I have worked at, were good. But there have been others, for example, when I was working with one of the after-school programs, they did refuse to give me a promotion to director of one of the programs, and it was totally a disability-related thing because I was not able to do CPR on a kid.

They said that just in case one of the other workers did not show up, if I was going to be the only one, they did not want me there alone with the kids because of that. At the same time, they always had more than one person working there. Just because of the liability of having one person alone with the kids, you want to have somebody there as a witness.

Then there was another occasion when I applied for a job and went to a first interview, and I had not mentioned anything about a disability. They right away were saying, well, we would have to make some accommodations because the restrooms are not accessible, and we do not know what we would do about that. I would have had to go around through a back garage door to get into the building to start with.

Anyway, I went to a second interview and it ended up, they never called back. I kept calling to see what the status was on it, and they would not ever give me an answer on whether they were hiring or not. I finally had seen the position re-advertised, so I gave up on it and assumed it was.

Senator SALAZAR. Do you think this happens, Jim, with respect to the general disabled population? Do you think your experiences are happening with other people?

Mr. BROWN. Yes, I do. I am sure that there are ones who are discriminated against because of that. I even put it in my letters that

I am in a wheelchair, like when I am applying for something, and people have told me not to.

But I told them, well, I think people are pretty quick and they are going to pick up on it right away that I am. [Laughter.] So if they want to discriminate against me, they might as well do it in the letter instead of wasting my time to go to the interview.

Senator SALAZAR. Well, thanks a lot for your testimony on that issue, Jim.

Let me try to get Ms. Suter and Dr. Stapleton in on this. It is with respect to the fear of reapplying for SSDI. Beneficiaries may fear that if they leave the SSDI or SSI programs because of work, they will have a difficult time obtaining reinstatement of SSDI or SSI benefits.

Given the number of work incentives that allow beneficiaries to return to benefit payment status, such as the incentives under current law or expedited reinstatement under both SSDI and SSI, are these well-founded fears, or are they based on beneficiaries' limited knowledge of these work incentives? What is SSA doing to provide better information to these beneficiaries? Ms. Suter, and then Dr. Stapleton.

Ms. SUTER. I do think that that fear is out there. As you mentioned, we do have the expedited reinstatement process. In one of our messages out to beneficiaries, our local work incentive seminars, we talk about expedited reinstatement.

So we let people know about that and get the word out. I think the idea that you do not have to reapply and that you can try going to work and not be penalized for that, I think is an extremely important message to get out there.

Senator SALAZAR. Dr. Stapleton?

Dr. STAPLETON. I do not have specific expertise on expedited reinstatement and that specific fear. I do know that there is a very high level of distrust among beneficiaries about anything that Social Security does that tries to support them in going back to work.

I think that has been a big issue for Ticket to Work. People get these Tickets in the mail and they think SSA is trying to get them off the rolls, and they do not want to have anything to do with it. I think uncertainty about what the government is going to do and how things are going to change is a really big problem.

Senator SALAZAR. Thank you.

Senator Bunning?

Senator BUNNING. Yes. This goes to the heart of the problem, because I sincerely believe that there is a mistrust with the disabled community that Social Security is trying to help them, other than give them paid benefits.

Could it be that the disabled beneficiaries do not use the Ticket to Work to go back to work because they are disabled? In other words, is it better for me to stay off that and just collect rather than try to go back to work and succeed? Because there are so many built-in safeguards in Ticket to Work that the beneficiaries should not be frightful, at least for 3 years, because there is protection out there for 3 years in this bill, or in the current law.

I would like to get, Dr. Stapleton, your opinion of that, too. According to what you just said, you think that they mistrust the So-

cial Security system so much so that they think that the Ticket is a bad deal.

Dr. STAPLETON. I think that may be too strong a way to put it. But think about Jim's case for a minute. He did not know a lot about the Ticket when he found out about it, and I do not think he got very good advice.

But it sounded to me from his testimony that his biggest issue was the Medicaid. He could not afford to lose his Medicaid. To use the Ticket most productively requires you to earn enough so that you do get off the rolls. Well, if he got off the rolls he would lose his Medicaid.

Senator BUNNING. But he would get it back if he fell off the ability to work. We find out that people do fall off the ability to continue working over a long period of time.

Dr. STAPLETON. Well, maybe you should ask Jim to speak to that. My guess is, his expenses for the assistance that he gets from Medicaid would just overwhelm his earnings and just make it not worthwhile.

Senator BUNNING. Jim, is that true?

Mr. BROWN. Yes, it is. My expenses are somewhere between \$20,000 to \$30,000, even closer to \$30,000 when I include things like transportation, those kinds of costs. It is just so much that I cannot do it on a full-time job.

Senator BUNNING. Well, then maybe one of the solutions, legislative solutions, is that you would not lose Medicaid, that you would continue to get Medicaid even if you were working and earning.

That is one of the things that we may have to look at, because we think it is important, not only for you personally in your personal self-worth, the fact that you want to contribute and that you can contribute, that maybe Medicaid should not be even in the equation. We could take a real look at that law the way it is written presently and make sure that Medicaid never falls out. Would that make a difference?

Mr. BROWN. It would. I had wondered about that even before I heard about the Medicaid buy-in, why we could not use that, even if we paid as much as a normal insurance policy and we are still covered by that for the personal care and some of the adaptive equipment that we have to have to be able to live our daily lives.

Then we could go to work and have that and be paying into that, and be paying taxes. We would also be healthier and all that, with the mental aspects of working and the pride that goes along with that. That would be wonderful.

Senator BUNNING. Mr. Jensen, this is the last question I will ask. You talked about Medicaid buy-in extensively in your testimony and said that about 75,000 individuals are currently participating in the program. Can you give us a sense of who these people are? How critical is the buy-in program in getting them back to work?

Mr. JENSEN. In the surveys that have been done by the States that had Medicaid buy-in programs, when I evaluate the program, it has certainly showed up as saying, I could not work unless I had the Medicaid buy-in program. So I think that this has been a very important element of the work incentive. As I indicated, there are 38 States that have it.

It turns out that I will be working with the State of Montana, one of the 13 jurisdictions that does not have a buy-in program, and I imagine I will see Jim again out in Montana as we work on that.

So I think there are a number of people in the buy-in who have certainly increased their earnings, they have more disposable income, but they are also afraid of going over that SGA limit as far as that is concerned. So, if you do not have to spend down—Jim talked about in his testimony that, in order to get Medicaid, he had to spend down to, now, \$550 under the medically needy program. If he did not have to do that, and even if he kept below the SGA, he would have a lot more disposable income.

So I think that it has been an important step to provide the continued Medicaid for people on SSDI who cannot now receive it, because there is not the kind of work incentive we have on the SSI side that Congress put in place.

So I would say that it is successful. There are still people who fear going over the SGA, but there are a number of people—I think before you came in I talked about the phone call from the gentleman in Utah who has decided to stay on buy-in and leave his SSDI. So that has been what he has needed. But that is not going to be for a high percentage, but it certainly is for some of them.

Most States in the Medicaid buy-in have a higher asset test. It is now \$2,000 for SSI. Almost all the States, in the discretion by the State legislatures, have said we need to have that higher and allow people to accumulate some resources. So, I think that is the other step.

It is proving also that that is not a budget buster, to have a higher resources test in those programs. Here again, it was \$1,500 in 1974; now, 33 years later, it is \$2,000. That \$500 increase was made over a 5-year period in the middle of the 1980s. It is time to make some changes on that as a work incentive, too.

Senator BUNNING. Thank you, Mr. Chairman.

Senator SALAZAR. Thank you very much, Senator Bunning.

As you can tell, this is a very important issue for this committee. It is an important issue for both Senator Baucus and Senator Grassley, Senator Bunning, Senator Snowe, all the members of this committee.

We have a vote that is coming up in a few minutes, so we are going to adjourn the hearing. There are a number of other questions that we have of you, so what we will do is, we will send you those questions. If you would respond to those questions, we would appreciate it so they could be made a part of the record.

[The questions appear in the appendix.]

Senator SALAZAR. As I said earlier, your written submissions here today will be made a part of the record. Ms. Suter, Mr. Brown, Mr. Jensen, Dr. Stapleton, we thank you very much for your testimony today. We thank you for helping us try to fix this problem that faces us with Social Security and people with disabilities.

The hearing is adjourned.

[Whereupon, at 11:36 a.m., the hearing was concluded.]

# A P P E N D I X

## ADDITIONAL MATERIAL SUBMITTED FOR THE RECORD

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Testimony  
United States Senate Committee on Finance  
"Barriers to Work for Individuals Receiving Social Security Disability Benefits"

Presented by  
Jim Brown  
June 21, 2006

Mr. Chairman and members of the Finance Committee, over 200 years ago Thomas Jefferson wrote of our inalienable rights, that of life, liberty, and the pursuit of happiness. At the time, the right to the pursuit of happiness did not include blacks, the Native Americans, or women. It did not and still does not include the disabled. I will discuss this pursuit of happiness, how the disabled are excluded, and changes necessary to include us in that right.

The pursuit of happiness may mean great wealth, nice cars and big houses. It may be power and prestige, being a mover and shaker in the business world. To many it may simply be enough to get by on in a house with a white picket fence, a swing set in the backyard for their kids and grandkids as they grow old together with the love of their life. Whatever the vision, the vast majority of the disabled are left out.

I found this out after I broke my neck on a trip to Hungary. With no insurance, and mounting medical bills, I had to turn to government assistance for help. I had to sell the cows I had invested in since a young boy to become eligible for Medicaid. The Medicare I'd paid taxes for wouldn't require such sacrifice but wouldn't help for two years either.

When I tried going back to work I found my right to the pursuit of happiness was gone. I wanted the prestige of working a full-time job and modern technology makes that a possibility but found if I make more than \$900/month, according to Social Security, I am no longer considered disabled. Regardless how much I make my hands and legs won't work and I'll have disability related expenses. Over the course of a lifetime personal care, adaptive equipment and wheelchair related expenses for a disabled person can total well over \$1 million more than an able-bodied person faces.

I wanted to work and make my own money, not wanting to be a beggar or a burden on others. I'd gladly have given up my \$600 Social Security check but I was told I had to stay eligible in order to get Medicaid assistance for the personal care and other expenses Medicare doesn't cover. I got a part-time job but was disheartened to learn I had to give all my earnings over \$540 a month to Medicaid as a spend-down to retain eligibility. I loved my job working with the kids though, so I kept at it.

I was even more disheartened later, when I learned I would have been better off if I had never worked and paid into Social Security since I would be eligible for SSI instead of SSDI. Under SSI I would be allowed to make more money, cuts to financial assistance would be gradual, and I wouldn't have a spend-down for Medicaid assistance.

I face these basic choices; either I don't work and just let the government take care of me through SSDI payments, Medicaid, housing assistance and food stamps, I work part-time and give my paycheck to the government, or I have to somehow find a job with a \$50,000 starting salary so I can pay my own way. The first two options are discouraging and the last unrealistic.

There needs to be a fourth option. It needs to be realized that a disability is a physical or mental condition, not an economic condition. I realize the programs are designed to discourage people from getting on them, but they do more to discourage those who truly need the help. We need programs that will bridge the gap between the part-time job and the \$50,000 a year job, covering the extra 20-30,000 dollar yearly disability related expenses until we are promoted enough that we are finally able to pay our own expenses. The entire system would be better if we were at least working to help pay for it.

Honorable Senators, in Jefferson's day the disabled rarely lived and if they did, were shut away in homes and forgotten. Now, 21st-century technology keeps us alive and healthy, we live independently and can get out into the community. We should not have to stay home and stifle our abilities just because something in our brains or bodies doesn't work right and we need an extra hand.

Policies must be upgraded so we can truly live, live with hope and dignity, enjoying the right to the pursuit of happiness. Honorable Senators, I urge you to leave a legacy. Help change the policies so we also get access to that last inalienable right.

Thank you for the opportunity to speak with you on behalf of disabled people everywhere. I'll be happy to entertain any questions.

### Addendum

Chairman Baucus and honorable members of the finance committee, I am honored at the responsibility of representing the disabled at this hearing. I am glad we have the opportunity of presenting our case to you and hope we can rectify the situation very soon so that we also can access the American dream. I will share my story.

#### **BARRIERS I FACED**

- I would not be covered by Medicare for two years after my disability
- The only option for assistance was Medicaid
  - I had to sell my cows and pay the money to the hospital because I couldn't have over \$2000 in assets
  - I lost the only way I could see of regaining financial independence
- Following are disincentives and frustrations I faced when going back to work
  - Low SGA (Substantial Gainful Activity) amount
    - If I make over \$900 a month I lose Social Security benefits and with that, I was told, my Medicaid eligibility
  - Medicaid spend-down
    - Any income over \$540 per month has to go to Medicaid
    - Income is based on gross income, not net income
  - Medicare didn't have such strict rules, but didn't pay personal care expenses
  - Private insurance through work would not pay personal care expenses
  - Subsidized housing costs
    - Also based on 1/3 of gross income
    - There is no upper limit equal to current market value
- I needed purpose and saw that kids were fascinated by me, while adults seemed awkward and afraid
  - To intervene, I started volunteering at Head Start
  - I worked part time in an after-school program
- I was offered a promotion to three-quarter time
  - I could get no definite answers from Social Security and Medicaid as to how my benefits would be affected
  - I took the job and reported it
  - My Medicaid caseworker advised me to pay spend-down of \$500 rather than actual expenses of over \$2000.
  - Subsidized rent increased
  - I made no extra money but I loved the extra purpose and responsibility
- Three years later I was charged with a Social Security overpayment and ordered to repay \$4750... within 30 days please
- I appealed but it was denied

I was informed about IRWE's (Impairment Related Work Expenses) and Trial Work Period at a Ticket to Work seminar

- o I had unknowingly used my trial work period when it was \$200 per month
  - o I was told my Medicaid spend down was an IRWE and to submit proof of payment
- Later, a different agent at Social Security ruled that the spend-down was not an IRWE because it paid for Medicaid, not "direct" medical expenses.
    - o I appealed until I was upheld

Since then, fearful of facing another Social Security overpayment, or otherwise jeopardizing my personal well-being, I have only worked part time and volunteered with Head Start, Eagle Mount, Reading Rocks and the 2006 political campaign to fill my extra time with meaningful activity

- I have learned I would have been better off if I had never worked and paid into the Social Security system
  - o I would be eligible for SSI rather than SSDI
    - I could make more money without being penalized
    - Social Security payments would be cut back gradually rather than the all or nothing of SSDI
    - I would have no spend-down for Medicaid coverage so would not be limited to \$540 per month

#### **OTHER BARRIERS**

Cost of adaptive equipment

- o Many disabled cannot work without adapted devices to reach, grasp or speak, and cannot afford the technology without assistance

Marriage Penalties

- o If we marry, we may lose eligibility for Medicaid assistance
  - Hope for marriage and supporting a family is a major reason for returning to the workplace.

#### **RECOMMENDATIONS**

- Raise SGA amount
  - o Amounts are so low we have to stifle our abilities and only work part time so we are eligible for assistance with medical costs
    - These costs can amount to over \$1 million in the course of a lifetime
  - o It forces us to remain on food stamps and in government subsidized housing to be able to make ends meet
  - o **BENEFIT:** If we could make more money we can also spend more and help the economy
- Allow us to work and maintain health benefits (make a bridge from part-time, to full-time employment, to self-sufficiency)
  - o **BENEFIT:** If we work we have purpose and are happier and healthier, thus decreasing medical expenses
  - o **BENEFIT:** We have to have the extra assistance so should at least be allowed to help pay for it
  - o **BENEFIT:** As we move to self-sufficiency we get private insurance and use less assistance from Medicaid



**Statement for Senator Bunning  
Finance Hearing  
June 21, 2007  
“Barriers to Work for Individuals Receiving  
Social Security Disability Benefits”**

Mr. Chairman, thank you for holding this important hearing today.

Helping and encouraging disabled Americans to re-enter the workforce has long been an area of interest of mine. In fact, I introduced legislation in the House of Representatives back in 1998 to create the Ticket to Work program. Although my bill passed the House that year, it didn't get through the Senate. The next year, I worked as a newly elected Senator to finally get the Ticket to Work bill passed and signed into law.

I thought at the time that we were finally going to be able to help people receiving disability benefits who wanted to go back to work to be able to do so. At the same time, we would also be helping the Social Security trust funds by reducing the number of people who were relying on them.

However, I think it is safe to say that the Ticket to Work program hasn't been a success. As for December 2006, there were approximately 49 million people on Social Security. Of these, about 812,000 resided in Kentucky. About 6.8 million Social Security beneficiaries are disabled workers, with about 167,000 living in my state of Kentucky.

According to Social Security, approximately 10.2 million people have been issued tickets under the Ticket to Work Program. However, only 171,000 tickets of them have actually been used by beneficiaries.

For a program that was supposed to encourage disabled workers to go back to work, this is a dismal take-up rate. I hope our witnesses can provide suggestions to us about ways we can improve the Ticket to Work program.

I firmly believe that many Americans currently receiving disability benefits would like to work, earn an income and provide for themselves and their families. However, as we will hear from our witnesses, this isn't an easy process, and many people feel they cannot risk losing their health or other benefits to make this change.

The witness from Montana explains the difficult decisions he has had to make to remain eligible for Medicaid. He does this by curtailing his work activity. To me, this system just doesn't make sense, and there has to be a better way.

I want to thank our witnesses for being here today, and I look forward to their testimony.

**TESTIMONY OF**

**ALLEN JENSEN, DIRECTOR, THE WORK INCENTIVES PROJECT,  
CENTER FOR HEALTH SERVICES RESEARCH AND POLICY,  
THE GEORGE WASHINGTON UNIVERSITY**

**ON BEHALF OF HIMSELF AND**

**ROBERT "BOBBY" SILVERSTEIN, DIRECTOR CENTER FOR THE STUDY  
AND ADVANCEMENT OF DISABILITY POLICY, AND PRINCIPAL IN THE  
LAW FIRM OF POWERS, PYLES, SUTTER, AND VERVILLE, P.C.**

**BEFORE THE UNITED STATES SENATE  
COMMITTEE ON FINANCE**

**JUNE 21, 2007**

**BALANCING PUBLIC POLICIES THAT FACILITATE WORK AND THOSE  
THAT ENSURE A FAIR AND DECENT LEVEL OF INCOME SUPPORT  
DURING PERIODS OF WORK INCAPACITY**

**BACKGROUND**

Good morning. My name is Allen Jensen, director of the Work Incentives Project, Center for Health Services Research and Policy, The George Washington University. Thank you for the opportunity to present testimony today regarding our Nation's disability, health and employment-related programs. These include the Supplemental Security Income (SSI), Social Security Disability Insurance (SSDI),<sup>1</sup> Medicaid (including the Medicaid Buy-In Program), Section 1619 of the Social Security Act, Medicare, Ticket to Work, vocational rehabilitation, workforce investment, and our civil rights laws, including the Americans with Disabilities Act.

Over the past 40 years at the state and national level in a variety of positions, I have been involved in program and policy development related to social security income assistance,

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<sup>1</sup> Title II of the Social Security Act establishes the SSDI program. SSDI is a program of federal disability insurance benefits for workers who have contributed to the Social Security Trust Funds and became disabled or blind before retirement age. Disabled widows and widowers of insured workers are eligible for disability benefits. In addition, dependent children of fully insured workers (often referred to as the primary beneficiary) also are eligible for disability benefits upon the retirement, disability, or death of the primary beneficiary. Section 202 (d) of the Social Security Act also establishes the Childhood Disability Benefits program, which authorizes disability insurance payments to surviving adult children of retired, deceased, or workers with disabilities who are eligible to receive Social Security benefits, if the child has a permanent disability originating before age 22. Hereinafter in this testimony, the term "SSDI" refers to all programs that provide benefit payments made to individuals on the basis of disability under Title II of the Social Security Act and the Childhood Disability Benefits program shall be referred to as Disabled Adult Children Program and the beneficiaries of such program shall be referred to as DACs.

social services, employment and health care policy. Currently I am involved in university-based research for federal agencies and private foundations and utilizing the findings of that research to provide technical assistance to state officials, and state disability advocacy coalitions.

For the past decade, I have conducted much of my research in partnership with Robert “Bobby” Silverstein, Director of the Center for the Study and Advancement of Disability Policy and principal in the law firm of Powers, Pyles, Sutter, & Verville, PC. Our work involves trying to determine how to provide the proper balance between policies that facilitate work and those that ensure a fair and decent level of income support during periods of work incapacity.<sup>2</sup>

To place our research in context, a brief summary of participation in the income support and health care programs may be helpful. In December 2004, 9.8 million adults ages 18 – 64 received benefits from the Social Security Administration (SSA) on the basis of disability. There were 2.9 million who received only SSI; 5.8 million who received only SSDI and 1.2 million who received both SSDI and SSI. Over 330,000 SSI beneficiaries have earnings in any month and over 75,000 of those are in a non-payment status (i.e., they did not receive cash payments under SSI) because of their earnings and the use of the SSI/Medicaid work incentives. Appendix A includes a table that illustrates this information and also the range of options states have in determining Medicaid eligibility for SSI and SSDI beneficiaries.

An option provided to states first in the Balanced Budget Act of 1997 and also in the Ticket to Work and Work Incentives Improvement Act of 1999 was the authority to develop and implement Medicaid Buy-In programs which are intended to reduce work disincentives by allowing persons with disabilities to work and remain eligible for Medicaid. The primary participants are persons receiving SSDI. Over the past ten years, 38 states have developed and implemented Medicaid Buy-In programs and over 75,000 individuals are currently participating.

Five years after the Federal Medicaid Buy-In program was first authorized, my colleague Bobby Silverstein and I, along with Donna Folkemer of the National Conference of State Legislatures (NCSL), conducted the first case studies of state Medicaid Buy-In programs. This research project, which was supported by the Department of Health and Human Services, developed a framework for state decision making and fiscal impact development. That study and ongoing analysis since then of the state Medicaid Buy-In programs serve as the bases for the provision of the technical assistance I continue to provide to many states in developing Medicaid Buy-In programs.

I am currently providing assistance to Montana, Florida, Arkansas and with the District of Columbia utilizing the experience and evaluations of the early implementation states, like Iowa, to help inform policy and administrative procedures in those and other states.

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<sup>2</sup> For a select list of articles, papers and policy briefs prepared by Allen Jensen and Robert Silverstein, see Appendix D.

Current information on the characteristics of state Medicaid Buy-In programs can be found at [www.medicaidbuyin.org](http://www.medicaidbuyin.org).

## **PREMISES FOR POLICY RESEARCH**

Our research regarding our nation's disability, health, and employment-related programs has been based on several premises.

### **1. Facilitate Achievement of the Goals of Disability Policy Stated in the ADA**

Policy initiatives focusing on meeting the needs of persons with disabilities should be assessed in terms of whether they facilitate achievement of the goals of disability policy articulated in the Americans with Disabilities Act—

- Equal opportunity (including individualization, reasonable services and supports, and integration into the community),
- Full participation (including self-determination and informed choice),
- Independent living, and
- Economic self-sufficiency.

### **2. Recognize Interrelationships among SSI, SSDI, Medicaid and Medicare and Other Programs Impacting Work and Barriers to Employment**

It is not helpful to focus on a particular policy initiative as a silo in isolation from other programs; rather we must recognize the interrelationships among programs. The SSI and SSDI programs do not operate in isolation from each other, Medicaid and Medicare, or from other federal and state programs. For example, a work disincentive under the SSDI program, such as the so-called “cash cliff,” where a beneficiary loses eligibility if he or she earns more than a specified amount, has a dramatic adverse impact on the success of other programs designed to increase work and earnings—such as the Medicaid Buy-In program, the Ticket to Work program and the vocational rehabilitation program.

Under the Medicaid Buy-In program, adults with disabilities may work and be eligible for Medicaid i.e., they can continue to be eligible for Medicaid even when their earnings exceed the Substantial Gainful Activity test for eligibility for SSDI. The program is an essential component of efforts to remove barriers to employment by persons with significant disabilities. However, the Medicaid Buy-In program does not protect SSDI beneficiaries from losing their cash benefits and surveys in many states indicate that fear of total loss of SSDI is a remaining employment barrier. The Medicaid Buy-In program is essential but without other needed policy changes and program initiatives is not sufficient to remove the major remaining barriers to employment.

### **3. Consider Fiscal Impact of Removing Employment Barriers**

In assessing policy options/alternatives, cost implications should be considered. In terms of disability, health care, and employment-related programs, policy-related research

should strive to include policy recommendations that enhance the potential for net long-term savings over the working life of persons with a significant disabilities by enabling them to increase their work effort and earnings.

#### **4. Reflect Insight from Persons with Disabilities and other Stakeholders**

As articulated earlier in our testimony, a key goal of disability policy is the policy of full participation—people with disabilities must be involved in decisions affecting their lives, including the policymaking process. Thus, lessons learned from researching existing programs must reflect insight derived from stakeholders, particularly persons with disabilities.

#### **OVERVIEW OF PRESENTATION**

Today, we would like to share with you the major lessons we have learned in the course of conducting our research.

- First, we will share key **realities** that provide a foundation for many of our conclusions and recommendations. These realities include the fact that:
  - SSI and SSDI are programs of last resort.
  - There is significant overlap of beneficiaries receiving cash benefits under the SSI and SSDI programs.
  - The ability to work over time varies considerably for individual beneficiaries.
  - Most beneficiaries are unable to sustain significant work although a significant minority can, if provided security and supports.
  - Tangible and intangible factors make it impossible to identify which individual beneficiaries will be able to sustain work.
- Second we will identify three overarching **themes** that provide a framework for guiding policy development in this area. These themes are:
  - **Security**—beneficiaries are more likely to risk working with the assurance that benefits will resume if work efforts fail or successes are intermittent because of one's disability.
  - **Simplicity**—beneficiaries are more likely to risk working if and when they have sufficient information to make informed choices about the impact of their decision on the availability of cash and health benefits.
  - **Sustainability**—SSA and state-level infrastructures have the capacity to provide assistance and guidance to beneficiaries regarding decisions to risk working through the provision of adequate and accurate information and services.
- Third, we will identify key **policies** that we believe will facilitate increased work and earnings for those beneficiaries capable of doing so. The key policies include:

**Security and Simplicity:**

- **Continued attachment** to programs in non-benefit status as long as the disability continues.
- **Gradual reduction in benefits** as earnings increase instead of cash cliff.
- Allow for increased **savings**.
- **Comparability** between the SSI and SSDI work incentives.

**Sustainability:**

- **Capacity of SSA** to administer work incentives and provide timely and accurate adjustment of benefits.
- **State and local systems change initiatives** that support infrastructure development, work incentive counseling, and services.

I would like to point out to the Committee that my colleague Bobby Silverstein and I have developed a comprehensive proposal to address the SSDI cash cliff and other policy barriers in SSI, Medicaid and Medicare. The proposal can be found in a paper entitled, "*Gradual Reduction Choice Option and Related Policy Proposals*" (December 2005). In addition, we prepared an accompanying memorandum entitled, "*A Framework for Preparing Cost Estimates for SSDI \$1 for \$2 Gradual Reduction Demonstration Proposals*." (December 2005). The documents can be found in the SSI and SSDI section of the web site [www.disabilitypolicycenter.org](http://www.disabilitypolicycenter.org). A summary explanation of the specific components of our proposal is found in Appendix B of this testimony.

**KEY REALITIES**

We have identified six realities/assumptions that provide a foundation for our policy conclusions and recommendations on how to provide the proper balance between policies that facilitate work and those that ensure a fair and decent level of income support during periods of work incapacity:

- SSDI and SSI programs are programs of last resort.
- There is an increased overlap between populations served by SSI and SSDI programs.
- There are significant variations in work and earnings for individual beneficiary's overtime.
- Most beneficiaries are unable to sustain significant work effort and earnings.
- A significant minority of beneficiaries will choose to increase work effort under certain circumstances.
- The presence of tangible and intangible factors makes it impossible for policymakers to identify ahead of time which beneficiaries will choose work.

### **1. SSI AND SSDI are programs of last resort.**

We reviewed the Report of the Disability Policy Panel of the National Academy of Social Insurance entitled *Balancing Security and Opportunity: The Challenges of Disability Income Policy*. (1996). We agree with a series of overarching conclusions reached by the Panel of Experts that:

- The SSDI and SSI beneficiary populations include those with the most significant disabilities impacting work;
- SSI and SSDI are programs of last resort;
- The strict and frugal design of the SSI and SSDI programs makes remaining at work preferable to benefits for those able to work;
- SSDI benefits are modest in relationship to workers prior earnings; and
- Benefits offer an essential form of economic security for persons with disabilities with limited capacity to earn.

Overall, less than 55 percent of those who apply for disability benefits under the Social Security Act were allowed in FY 2002. Further proof of the strictness of the definition of disability is the fact that among denied applicants, 58 percent were not working and over two-thirds of those not working said they had been out of work for three years and over three-fourths said they were unable to work because of poor health.<sup>3</sup>

### **2. There is an increased overlap between populations served by SSI AND SSDI programs.**

**The increasing role of the SSDI program in providing assistance to younger disabled workers and disabled adult children, in addition to assisting older near-retirement disabled workers has blurred the differences between the SSDI and SSI programs.**

Approximately 30 percent of SSI beneficiaries between the ages of 18-65 (1.2 million) are also eligible for SSDI benefits. Some of these beneficiaries are concurrently eligible because of SSI state supplementation. More specifically, even though their SSDI benefit is in excess of the federal SSI benefit standard plus the \$20 disregard, in states with SSI supplementation they still receive an SSI payment. In addition, nearly two-thirds of the Section 1619(b) SSI/Medicaid work incentive program participants are concurrent SSI/SSDI beneficiaries.<sup>4</sup>

### **3. There is a significant variation in work and earnings for individual beneficiaries over time.**

**The ability to work, work effort, and level of earnings varies significantly from month to month and year to year for many individual SSI and SSDI beneficiaries.**

<sup>3</sup> Committee on Ways and Means, U.S. House of Representatives, *OVERVIEW OF ENTITLEMENT PROGRAMS, THE 2004 GREEN BOOK* at 1-28.

<sup>4</sup> Social Security Administration. *Annual Statistical Supplement*, 2004, Table 7 D 1.

According to the General Accountability Office (GAO), of working SSDI beneficiaries with earnings above the Substantial Gainful Activity (SGA), which currently is at \$900 for disabled beneficiaries, in a given year, nearly one-half experience an eventual reduction in earnings in subsequent years. For example, of beneficiaries in 1985 who earned between 75 and 100 percent of the annualized SGA level, 47 percent had no earnings by 1989 while earnings of another 26 percent had fallen to between 1 and 74 percent of the annualized SGA level.<sup>5</sup>

According to SSA staff, nearly one-half of SSI beneficiaries receiving wages in one year stop working in the subsequent year. More specifically, 51 percent of blind or disabled adults had no wages in a year following a year of reported wages and 35 percent had maximum variation of more than 50 percent.<sup>6</sup> They also report that during a 15 year period only half of those employed in one year had earnings in each of the succeeding three years.<sup>7</sup>

This reality is important because it lays the foundation for the policy objective described at the end of our testimony to provide continued attachment to the SSDI and SSI programs when earnings reduce benefits to zero (as long as the impairment continues) in order to reduce risk and uncertainty which are major barriers to work.

#### **4. Most beneficiaries are unable to sustain significant work effort and earnings.**

**Most persons receiving SSI, SSDI or concurrent beneficiaries (i.e., beneficiaries receiving both SSI and SSDI benefits) are unable to sustain work above SGA for a significant period of time.**

According to SSA staff in a 2003/2004 report, utilizing SIPP data matched to SSA administrative records, only 22 percent of SSDI beneficiaries worked at some time during 1999.<sup>8</sup> According to a 2002 GAO report, from 1985-1997 on average, only about 7.4 percent of SSDI beneficiaries who worked (comprising about 1% of the total SSDI caseload) had annual earnings between 75 and 100 percent of the annualized SGA level. In 1995, about 58 percent of SSDI beneficiaries who worked earned no more than 50 percent of the annualized SGA level.<sup>9</sup>

Using data from SSA relating to work experience of SSI recipients, (*SSI Disabled Recipients Who Work*, 2004 (July 2005)), only 4.8 percent of SSI recipients (all ages)

<sup>5</sup> U.S. Government Accountability Office. *SSA Disability-SGA Levels Appear to Affect the Work Behavior of Relatively Few Beneficiaries, But More Data Needed*, GAO-02-224 (January 2002) at 2, 15, 16.

<sup>6</sup> Balkus, Richard, and Wilschke, Susan. *Annual Wage Trends for Supplemental Security Income Social Security Recipients in Social Security Bulletin*, Vol. 65, No. 2, 2003-2004 at 51-52.

<sup>7</sup> *Id.* at 51-53.

<sup>8</sup> Martin, Teran and Davies, Paul S. "Changes in the Demographic and Economic Characteristics of SSI and DI Beneficiaries Between 1984 and 1999" in *Annual Wage Trends for Supplemental Security Income Recipients, Social Security Bulletin*, Volume 65, No. 2, 2003/2004 at 9.

<sup>9</sup> U.S. Government Accountability Office. *SGA Levels Appear to Affect the Work Behavior of Relatively Few Beneficiaries, But More Data Needed*, GAO-02-224 (January 2002) at 9.

worked in 1983, 6.4 percent in 1999, and 5.6 percent in December 2004. In December 2004, the percent of SSI recipients that worked was 7.8 percent. Of the SSI recipients (all ages) that worked, 59.3 percent earned less than \$400 per month and 86 percent earned less than \$1,000 per month.

Survey data from several Medicaid Buy-In programs is consistent with the GAO and SSA findings. For example, in Iowa, the Buy-In participants not working or that didn't want to work more (61% of participants) were asked to evaluate a number of statements and choose those that fit as to "agree" or "strongly agree," 63.2 percent reported that their health has gotten worse for reasons unrelated to working and 30.6 percent reported that working has caused their health to get worse.<sup>10</sup> In Minnesota, 48 percent (physical health problems) and 30 percent (mental health problems) reported that health issues prevented them from working some time during the past year.<sup>11</sup>

We believe this reality provides insight into the possible impact of a policy change. Policymakers should be wary of making any change to current law that imposes a work mandate on all beneficiaries when in fact most beneficiaries are unable to sustain work above SGA for a significant period of time. The current purpose of SSDI as a partial wage replacement program is appropriate and the current structure (Trial Work Period (TWP), Extended Period of Eligibility (EPE), cash cliff, and expedited reinstatement) meets the needs of most beneficiaries.

It is also important that our public policy encourage beneficiaries to work, reflect high expectations regarding the potential for work, and provide necessary services and supports, and protections. As we have stated in our introductory remarks, we should strive for a balance between the policies that facilitate work and those that ensure a fair and decent level of income support during periods of work incapacity.

**5. A significant minority of beneficiaries will choose to increase work effort under certain circumstances.**

**A significant minority of SSI and SSDI beneficiaries will choose to work above SGA for a sustained period of time (over a beneficiary's lifetime) if public programs provide: appropriate information to make informed choices; sufficient incentives that are simple to understand; and provide for security when exacerbations of one's condition occur; necessary long-term services and supports; and protections.**

Using data from SSA, (*SSI Disabled Recipients Who Work*, 2004 (July 2005)), of the limited number and percentage of SSI recipients that work (5.6% of all SSI recipients and

<sup>10</sup> Iowa: *Medicaid for Employed People with Disabilities: A Client Profile and Program Evaluation*. Iowa Department of Human Services (March 11, 2005), Figure 6-10, at 47.

<sup>11</sup> Minnesota: *How MA-EPD Does the Job-Survey of Minnesotans Enrolled in the Medical Assistance for Employed Persons with Disabilities Program*. Minnesota Department of Human Services (August 2004), page 78 and questions A41 and A42. The full report is at [http://www.dhs.state.mn.us/main/group/disabilities/documents/pub/dhs\\_id\\_029455.pdf](http://www.dhs.state.mn.us/main/group/disabilities/documents/pub/dhs_id_029455.pdf). Utah: *Self Reported Experiences of Individuals with Disabilities Involved in the Utah Medicaid Work Incentives Program*.

7.8% of SSI recipients aged 18-64), there are significant numbers and percentages of persons on SSI with earnings and resulting reduced levels of benefits. For example, of all SSI recipients that worked, 40.7% earned more than \$400 per month and 14% earned more than \$1,000 per month.

Using the same data from SSA (*SSI Disabled Recipients Who Work*, 2004 (July 2005)), there has been a gradual but significant increase in the use of the Section 1619 work incentives by SSI beneficiaries since its inception in 1981 when it was a temporary program. (The program was permanently authorized as an entitlement, effective July 1, 1987.) In December 1988, 35,545 beneficiaries utilized the Section 1619 work incentives. By 1993, there had been an increase to 55,327 and by 2004 the number had increased to 90,796. In short, during the 15 year period between 1988 and 2004, the program experienced nearly a 150% increase in participation.

The experience under the Medicaid Buy-In programs may also shed some light on the increased interest by SSDI beneficiaries (the primary participants in the Buy-In programs) in working when certain barriers to work (e.g., concern about loss of health care) are addressed. There has been a gradual but significant increase in enrollment in Medicaid Buy-In programs since their inception. In a survey of Vermont Medicaid Buy-In participants, 80% indicated that the Medicaid Buy-in program was very important in enabling them to keep working.<sup>12</sup> In Kansas, 61% of survey respondents indicated that their level of independence has increased since enrolling and 59% said their financial status has improved since enrolling.<sup>13</sup> In Minnesota, 72% of participants said that they would not be able to work without the Medicaid Buy-In program. 92% of participants in the Medicaid Buy-In program reported that working improved their quality of life.<sup>14</sup>

In Iowa, a recent survey of Medicaid Buy-In participants found that 40 percent of the participants indicated that they would like to increase the amount they are working over the next 12 months.<sup>15</sup> In Wisconsin, one-third of the participants reported that they wanted to work more hours.<sup>16</sup>

<sup>12</sup> Vermont: Survey of Enrollees in the Medicaid for Working People with Disabilities Program, Prepared for the State of Vermont Department of Aging and Disabilities, October 2003 at 11. Full report available at [http://www.dad.state.vt.us/dvr/voc rehab/vwji/s5\\_reports.htm#mbirpts](http://www.dad.state.vt.us/dvr/voc rehab/vwji/s5_reports.htm#mbirpts)

<sup>13</sup> Kansas: *Satisfaction Survey of Medicaid Buy-In Participants*, Reported in Policy Brief # Six, November 2004, University of Kansas Medicaid Infrastructure Change Evaluation Project at 1. <http://www.workinghealthy.org/WHpolicybriefno6.pdf>.

<sup>14</sup> Minnesota: *How MA-EPD Does the Job-Survey of Minnesotans Enrolled in the Medical Assistance for Employed Persons with Disabilities Program*. Minnesota Department of Human Services (August 2004), at 82, Question A54 at 2. The full report is at [http://www.dhs.state.mn.us/main/group/disabilities/documents/pub/dhs\\_id\\_029455.pdf](http://www.dhs.state.mn.us/main/group/disabilities/documents/pub/dhs_id_029455.pdf).

<sup>15</sup> Iowa: *Medicaid for Employed People with Disabilities: A Client Profile and Program Evaluation*. Iowa Department of Human Services (March 11, 2005), Figure 6-10, at 45. The full report is available at [http://www.dhs.state.ia.us/dhs2005/dhs\\_homepage/docs/MEPD-04\\_report-master.pdf](http://www.dhs.state.ia.us/dhs2005/dhs_homepage/docs/MEPD-04_report-master.pdf).

<sup>16</sup> Wisconsin: *Medicaid Purchase Plan Evaluation Annual Report*, December 2003. Submitted to the Wisconsin Department of Health and Family Services by APS Healthcare, Inc. The full report is available at <http://dhfs.wisconsin.gov/WIpathways/pdf/MAPPAnnualReport2003.pdf>.

States' Medicaid Buy-In programs have enabled a significant number of SSDI beneficiaries to work and have Medicaid without having to spend down their income under Medically Needy eligibility criteria. The rate of participation in the Medicaid Buy-In programs by SSDI disabled workers, disabled adult children and disabled widows(ers) is estimated to be as high as ten percent in Minnesota, a state with few restrictions (e.g., no unearned income limits or high cost shares).<sup>17</sup>

It is not possible to know the precise percent of beneficiaries that would choose to sustain work above SGA for a significant period of time. However, we can use experiences under existing programs, including SSI and Section 1619, to obtain estimates.<sup>18</sup> And current experience indicates that the numbers are sufficient to warrant an effort to encourage work.

This reality is important because it lays the foundation for the option of continuing eligibility when earnings exceed SGA and the concept of continued attachment as a form of ongoing support for beneficiaries who work.

**6. Tangible and intangible factors make it impossible to identify in advance particular beneficiaries who will be able to sustain work.**

**Because of a variety of factors, including tangible and intangible variables impacting the heterogeneous population of beneficiaries, it is difficult, if not impossible, for policymakers and program administrators to determine/predict which particular beneficiaries (based on predetermined criteria) will be able to work above SGA for a sustained period.**

Set out below are a series of **tangible variables** impacting work activities of the heterogeneous population of SSDI beneficiaries:

1. The impact of type and severity of disability, age, time of onset of disability (i.e., birth, during teens, after years of employment).
2. The impact of level of skills, education, experience and work previously performed,
3. The state in which the individual resides.<sup>19</sup>

<sup>17</sup> See e.g., Jensen, Allen; Silverstein, Robert; Folkemer, Donna; Shaw, Tara. *Policy Frameworks for Designing Medicaid Buy-In Programs and Related State Work Incentive Initiatives*, Table 8. Prepared for the U.S. Department of Health and Human Services. The full report is located at <http://www.aspe.hhs.gov/daltcp/projects.htm#GWU5>.

<sup>18</sup> For a comprehensive analysis of how SSI and Section 1619 data and Medicaid Buy-In data should be used to project the numbers of SSDI beneficiaries that may increase their earnings if a SSDI \$1 for \$2 policy were to be adopted, see Jensen and Silverstein "A Framework for Preparing Cost Estimates for SSDI \$1 for \$2 Gradual Reduction Demonstration Proposals." (December 14, 2005). See [www.disabilitypolicycenter.org](http://www.disabilitypolicycenter.org).

<sup>19</sup> A review of SSA and SSI Work Incentives File and Revised Management Information Counts System (REMICS) data indicates significant variation among the states in the number of SSI beneficiaries who work and the level of earnings. See Table in Appendix 2. In addition, the recent report by Mathematica "Explaining Enrollment Trends and Participation Characteristics of the Medicaid Buy-In Program, 2002-

4. The strength of the state and local economy and job market.
5. The level of need for and availability of ongoing acute health care and long-term health-related and employment-related services and supports (including transportation and housing) to sustain their jobs.

Set out below are a series of **intangible variables** impacting work activities by the heterogeneous population of SSDI beneficiaries:

- **Information**—What level of confidence and trust does the individual have that he/she understands the consequences of options related to the impact of working?
- **Economics**—Does the individual believe he/she will be better off economically if he/she works, increases work effort, or changes the nature of his/her employment?
- **Independence**—What level of importance does the individual place on being financially independent through earnings and ability to accumulate resources from working?
- **Values**—What personal value does the individual place on working?
- **Personal Self-Confidence and Self-Perception**—What level of self-confidence does the individual have related to his/her ability to work in general as well as ability to work at the job available and to sustain a work effort?
- **Coping with Stress**—What ability does the individual have to cope with physical and mental stress?
- **Risk-taking**—What level of risk is the individual willing to incur related to his/her ability to sustain a work effort and potential loss or reduction of entitlement benefits if he/she works?
- **Expectations and Encouragement by Agencies, Providers and Employers**—What level of expectations and encouragement to work in competitive, integrated settings is provided to the individual by agencies, service providers, and employers?
- **Family support**—What is the level of encouragement and support provided to the individual by his/her family?
- **Informal Network of Support for Working**—What is the level of encouragement and support provided to the individual by friends, and acquaintances?

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2003” (January 14, 2005) indicates wide variation in participant earnings among the states with Medicaid Buy-In programs.

This reality is critical because it suggests that a “one size fits all” policy approach that attempts to determine in advance which beneficiaries (already determined to be unable to work) should be forced to work is inappropriate. To the contrary, these realities support a policy based on choice by individual beneficiaries.

### **OVERARCHING THEMES PROVIDING A FRAMEWORK FOR SPECIFIC POLICY RECOMMENDATIONS**

We have identified three overarching themes that we believe provide a framework for guiding the development of policy that strives for a balance between policies that facilitate work and those that ensure a fair and decent level of income support during periods of work incapacity. These themes are security, simplicity, and sustainability.

- **SECURITY.** In light of the realities described above, the decision by a beneficiary to risk working must be rational—work must pay. It is essential that the beneficiary has the security of knowing that benefits will resume if work efforts fail or successes are intermittent because of one’s disability.
- **SIMPLICITY.** Disability and health care programs are complex. In the face of complexity, taking the safe course of action (i.e., not risking work) is often the wisest. We must strive to simplify our programs through policy changes and/or through the provision of assistance to help navigate the system.
- **SUSTAINABILITY.** Our infrastructures at the federal and state levels must have the capacity to support work incentive initiatives.

### **POLICY RECOMMENDATIONS BY NATIONAL COUNCIL ON DISABILITY AND DISABILITY ADVOCACY ORGANIZATIONS**

Before we discuss our policies recommendations in more detail, we would like to recognize that the National Council on Disability and groups representing the disability community have made a number of important policy recommendations for improving the implementation of the disability benefit, health care, and employment-related programs. We support the policy objectives of many of these recommendations, including those described in summary form in Appendix C.

### **SPECIFIC POLICY RECOMMENDATIONS**

#### **SECURITY AND SIMPLICITY**

Consistent with the themes of security and simplicity, we would like to focus on four key policies:

- Continued attachment to programs in non-benefit status as long as the disability continues;
- Gradual reduction in benefits as earnings increase instead of cash cliff;

- Reward work while allowing some savings; and
- Provide greater comparability of the SSI and SSDI work incentives.

### **Continued Attachment to Supports**

In designing and implementing the SSI and SSDI programs, it is important to recognize the reality that they are programs of last resort. A program of last resort means that before applying for benefits, the person with a medical condition that gradually worsens over time kept trying to work but those numerous work attempts were not successful. For those with a sudden injury, many go back to school using rehabilitation funds and gain a new skill. However, the uncertainty related to the disabling condition and needed connection to ongoing support means that time limited work incentives do not fit the reality of what many beneficiaries need to attempt and sustain work.

The uncertainty of many mental or physical disabilities linked to reoccurring health conditions means that the continued availability, when needed, of income assistance and health and support services is an essential part of an employment support disability policy. That is what we call “continued attachment.” Current law provides for a degree of “continued attachment” to the SSI and Medicaid programs; but it is income limited and assets limited. Current SSDI and Medicare law provides for a degree of “continued attachment” to SSDI and Medicare after a person starts work; but it is time limited.

*We recommend that the SSI, SSDI and Medicaid programs include the policy of continued attachment as long as the individual’s disability continues. This continued attachment would be without time limits or income limits. During those periods when beneficiaries have higher incomes, they would receive gradually reduced benefits (see below) or no benefits at all (zero benefit status). [For recommendations regarding asset limits, see page 14 of the testimony.]*

### **Gradual Reduction**

Since the SSI program began in 1974, there has been a policy allowing for gradual reduction in benefits as earnings increase. The reduction in benefits begins after what is called the “initial earned income disregard” of \$85 month for a persons receiving only SSI. The earned income disregard has not been changed since 1974 when the SSI benefit was \$150 per month compared to the current \$623 per month SSI standard. In 1980, the SSI and Medicaid programs changed temporarily to provide for a continuation of SSI and Medicaid benefits when the beneficiaries earnings exceeded the Substantial Gainful Activity (SGA) test for disability. Medicaid continues up to an earnings level equivalent to the amount of income and the value of the Medicaid they would receive if they were not working. SSI recipients can return to cash benefits if they can no longer work. These are known as the Section 1619 work incentives. The Section 1619 program was made permanent, effective in 1987.

In contrast, the SSDI program is an all or nothing program. A significant work disincentive for SSDI beneficiaries is the so-called “cash cliff” where a beneficiary who

earns more than Substantial Gainful Activity (SGA) (currently \$900 per month for disabled beneficiaries) becomes ineligible for benefits, after a trial work period, and an extended period of eligibility if he or she earns more than SGA. The cash cliff is the most significant work disincentive in the program.

**The cash cliff not only impacts eligibility for the SSDI program, but it also impacts the outcomes/results of other federal programs designed to increase work and earnings, such as the Ticket to Work program, the Vocational Rehabilitation Program, and the Medicaid Buy-In programs.** Some beneficiaries (with complex impairments that adversely impact their ability to work over time) make rational decisions to keep their earnings below SGA to retain eligibility.

*Elimination of the cash cliff is a key policy objective. On the merits, most policymakers agree that something must be done. Previous efforts have failed because of cost estimates by the actuaries. Those efforts proposed to start the gradual reduction at the SGA level. This policy would be consistent with the principal of “do no harm” i.e., current beneficiaries would not be harmed because under current policy they would be ineligible for benefits if they earned more than SGA. If policymakers, however conclude that the alternative of starting the gradual reduction at SGA is too costly, then we recommend that Congress consider the Gradual Reduction Choice Option which is fully described and explained in Appendix B of our testimony and can be found on the internet at [www.disabilitypolicycenter.org](http://www.disabilitypolicycenter.org).*

*In a nutshell, consistent with the “do no harm” principle, under the gradual reduction choice proposal, a beneficiary would be provided the choice whether to continue to be subject to current policy or choose a second option under which the gradual reduction would begin at one-half of SGA and in exchange for starting the reduction in benefits at this level, the individual would be entitled to continued attachment to the program as long as his or her disability continued. Our gradual reduction choice option proposal also includes incremental changes to the work incentive provisions under the SSI, Medicaid and Medicare programs.*

#### **Reward Work While Allowing Some Savings**

Significant increases in earnings by SSI beneficiaries can be further encouraged by allowing for a greater accumulation of resources. The \$2,000 limit for an individual and \$3,000 limit for a couple that is currently allowed under SSI and Medicaid has not been increased since 1988. At state option, most state Medicaid Buy-in programs allow for an accumulation of resources that is higher than the SSI standard. The policy in Medicaid Buy-in programs allowing for increased savings is intended to enable and reward persons with significant disabilities to increase their levels of independence and economic self-sufficiency. We believe that similar rewards should be authorized for working SSI beneficiaries (See Appendices B & C).

*We recommend that the resource limit be increased and indexed. The limit has not been updated since 1988. If this recommendation is deemed not feasible because of*

*costs considerations, at a minimum, states should be provided the option to provide for a higher resources test for SSI beneficiaries with earnings.*

### **Comparability**

As explained earlier in our testimony, there is a significant overlap in the population of beneficiaries receiving benefits under both the SSI and SSDI programs. In fact, these concurrent beneficiaries now constitute nearly one-third of the adult disabled beneficiaries under SSI. Consistent with this reality, the Committee should consider alternative strategies that make the work incentive provisions in these two programs more compatible. **In our Gradual Reduction Choice proposal, we recommend that the earned income disregard be set at one-half of SGA for both programs (recall that under the SSI program the current disregard is \$85).** It is important to note that consistent with the principle of “do no harm” only those SSDI beneficiaries who choose the gradual reduction choice option would be subject to this disregard; all other SSDI beneficiaries would still be able to work up to the SGA level, without being subjected to this disregard and a gradual reduction in benefits.

### **SUSTAINABILITY**

Under sustainability, we would like to focus our testimony on the following two policies:

- Capacity of SSA to administer work incentives and provide timely and accurate adjustment of benefits; and
- Support state and local systems change initiatives that enhance infrastructure development, work incentive counseling, and services.

### **SSA Capacity**

Implementation of enhanced work incentive policies will require a significant commitment of resources by Congress to SSA. SSA must have the administrative capacity and procedures to process earnings information from beneficiaries accurately and on a timely basis to prevent overpayments and other confusion that can negate work incentive policies.

### **Systems Change and Infrastructure Development**

As explained above, we have concluded that changes in policy such as removing the cash cliff and providing for continued attachment are necessary to enhance employment outcomes for SSI and SSDI beneficiaries. However, we also have concluded that these changes are in no way sufficient to generate better employment outcomes. A key component in any work incentive initiative must include comprehensive work incentives planning and assistance (also known as benefits counseling). Beneficiaries have told us that they often distrust SSA and need someone who they can trust to help them navigate the system and respond when they face personal barriers and institutional roadblocks. They need ongoing assistance to utilize work incentives. We have also learned from the

experience of implementing the current SSI and Medicaid Buy-In program work incentives that there must be a concerted effort to train eligibility workers and service staff in order to increase the likelihood that beneficiaries will be willing to risk work and utilize the work incentives available to them.

In addition, it is critical that states receive ongoing support to continue to improve their infrastructures and break down artificial barriers among state agencies. We recommend that SSA, CMS and other federal agencies **jointly** support comprehensive state work incentive initiatives. Authorized use should include:

- Improved implementation of the Section 1619 and SSI programs to expand the numbers and percentages of SSI beneficiaries who work and to increase earnings levels;
- Benefits counseling (work facilitation);
- Expanded funding and support for personal assistance services, including services provided in the workplace;
- Improved implementation of Medicaid buy-in programs; and
- Expansion and improvement of state work incentive initiatives, including efforts to develop comprehensive seamless systems of services and supports.

#### **SUMMARY REMARKS**

Based on decades of research, we would like to reiterate to the Committee one piece of advice—please be cognizant of the maxim “do no harm.” It is critical that you and your staff understand the consequences and unintended consequences of alternative proposals in your attempt to provide the proper balance between policies that facilitate work and those that ensure a fair and decent level of income support during periods of work incapacity.

**APPENDIX A**  
**Supplemental Security Income (SSI) &**  
**Social Security Disability Insurance (SSDI) Beneficiaries &**  
**Medicare and Medicaid**

	<i>18 – 64 years old December 2004</i>	<i>Medicare &amp; Medicaid Eligibility &amp; Options</i>
SSI only	2,850,815	Medicaid State Options - Automatic - SSI Criteria state administered - State criteria (209 (b)) Medicaid waivers
Concurrent SSI & SSDI	1,116,293	Medicare (2 yr wait) Medicaid (See state options)
SSDI only Disabled worker, Disabled adult children & Disabled widows & widowers	5,756,093	Medicare (2 yr wait) Medicaid State Options - Poverty Level option - Standard of need option - Medically Needy option - Medicaid Buy-In Medicaid waivers
Subtotal Ages 18 – 64	9,773,201	
SSI only – payment status	(17,394)	Medicaid: Section 1619 (a)
SSI only – nonpayment status (not included in SSI –only or concurrent)	(89,350) (December 2006)	Medicaid: Section 1619(b)
	<i>Other Ages December 2004</i>	
SSI Disabled Children	993,127	Medicaid (See state options for SSI)
SSI on basis of disability over age 65	749,000	Medicare (if also OASDI) Medicaid (See state options for SSI)
<b>Total All Ages</b>	<b>11,515,328</b>	
<b>Adults with Disabilities:</b> SSI suspension status, SSDI or neither	<b>67,980</b> December 2006	<b>Medicaid Buy-In</b>

**APPENDIX B****COMPONENTS OF THE GRADUAL REDUCTION CHOICE  
APPROACH. AND RELATED POLICY PROPOSALS****EXCERPTED FROM****GRADUAL REDUCTION CHOICE OPTION AND RELATED POLICY  
PROPOSALS (DECEMBER 2005)**  
**[www.disabilitypolicycenter.org](http://www.disabilitypolicycenter.org)****1. Retain Current Initial Eligibility Standards.**

The criteria for the initial determination of eligibility (including i.e., the definition of disability) under the SSDI and SSI programs will not be changed.

**2. Maximize Comparability Between SSI and SSDI.**

There is the need to maximize comparability between the SSI and SSDI work incentive provisions as a means to encourage and enable beneficiaries to work or increase their work effort and update the SSI work incentives but at the same time maintain SSI as a federal minimum income assistance program and maintain SSDI as a wage replacement program for the insured worker and his/her family. Both programs should embody policies that facilitate, not impede achieving the overarching national goals of disability policy. Increasing comparability has the potential of increasing utilization of work incentives and level of earnings by reducing confusion because of current differences between SSDI and SSI work incentives.

**3. Provide SSDI Beneficiaries with an Informed Choice (which entails tradeoffs) Between Current SSDI Policy (cash cliff) and an Alternative (providing gradual reduction in benefits).**

**Choice and Tradeoffs for SSDI Beneficiaries.** Provide choice for the individual SSDI beneficiary to determine whether he or she wants to utilize current policy (TWP, EPE, the “cash cliff,” and expedited reinstatement) or utilize the gradual reduction choice option (which includes, among other things, a gradual reduction in benefits after an initial earned income disregard of one-half of SGA and no time limit on continued attachment to the SSDI program when benefits are reduced to zero). In other words, the choice will entail a tradeoff. On the one hand, in utilizing current policy the beneficiary can choose limited risk and limited reward i.e., limited earnings below SGA and no reduction in benefits up to the SGA level followed by a cash cliff. On the other hand, the beneficiary can choose the gradual reduction choice option which entails short-term risk (i.e., a gradual reduction in benefits at earnings less than SGA) to obtain increased disposable income (i.e., continued eligibility for cash benefits above SGA) and long-term security (i.e., no time limit on continued attachment to the SSDI program as benefits are reduced to zero).

**Choice Times.** A beneficiary's earnings would be subject to treatment under the current policy (i.e., "the default") until he/she affirmatively chooses the gradual reduction choice option. This initial decision can be made at any time after the individual obtains sufficient information and work experience to make an informed choice. This initial decision to utilize the gradual reduction choice option would continue until an "open season" during which the beneficiary would have the option to return to current policy. The open season would be available on an annual basis for a duration comparable to that currently available to Medicare beneficiaries related to enrollment in Part B. Thus, the individual would be permitted to exercise the option to move back and forth between options but only during an annual open season.

**Informed choice.** As explained above, when an individual initially becomes eligible for SSDI cash benefits, the "default" is current policy. The individual must affirmatively choose the gradual reduction choice option. An individual will explicitly make a choice between the SSDI cash cliff option or the gradual reduction in benefits option i.e., the individual will sign-off on the option chosen. The choice must be informed, i.e., the administrative infrastructures must ensure that the beneficiary has a sufficient level of confidence and trusts the information provided and the beneficiary must understand the consequences of his or her decision, including the nature and extent of the risk.

#### **4. Earned Income Disregards and Gradual Reduction in Benefits**

**Uniform Initial Earned Income Disregard for SSI and SSDI.** There would be one initial earned income disregard before there is a reduction in SSDI benefits and SSI benefits that would apply to SSI-only beneficiaries, SSDI-only beneficiaries and concurrent SSI/SSDI beneficiaries. The initial earned income disregard would be one-half of SGA as it applies to disabled beneficiaries and one-half of the special SGA as applied to blind beneficiaries. The reduction in benefits would occur as soon as the individual has earnings in excess of the initial earned income disregard and impairment-related and blind work expenses. The higher SSI initial earned income disregard would apply to all SSI beneficiaries with earnings, not just concurrent SSI/SSDI beneficiaries.

**\$1 for \$2 Reduction in Benefits.** The gradual reduction in SSDI and SSI benefits after the initial earned income disregards would be \$1 reduction in benefits for \$2 of earnings.

**Order of Reduction for Concurrent Beneficiaries.** For concurrent SSI/SSDI beneficiaries, Federal SSI cash benefits would be reduced first, SSI state supplement benefits second, the individual's SSDI benefits next, and OASDI auxiliary benefits would be the last to be reduced. The current \$20 disregard of any income (earned or unearned) would still apply in determining SSI benefits.

**Individual's SSDI Benefit Level is Beginning Point for Reduction Based on Earnings.** The individual's SSDI benefit amount would be used as the unearned income level at which SSDI benefits are reduced based on earnings as a means to recognize SSDI as an individualized wage replacement program and the insured worker's previous contributions to the Trust Fund. In other words, the reduction based on earnings would apply against the SSDI benefits the individual is eligible to receive.

**Impairment-Related Work Expenses (IRWE) Disregard.** Provide that an SSDI beneficiary who chooses the SSDI gradual reduction option can apply for an individualized determination of impairment-related work expenses in determining earnings not to be counted in reducing SSDI benefits as is now provided for SSI beneficiaries with earnings. There would be one IRWE disregard allowed for concurrent SSI/SSDI beneficiaries.

**Blind Work Expenses (BWE).** Provide that an SSDI beneficiary who is eligible on the basis of blindness and chooses the gradual reduction option can apply for an individualized determination of BWEs in determining earnings not to be counted in reducing SSDI benefits as is now provided for SSI beneficiaries who are blind with earnings. There would be one BWE disregard allowed for concurrent SSI/SSDI beneficiaries.

**Student Earned Income Exclusion.** Provide that an SSDI beneficiary who chooses the SSDI gradual reduction choice option and who is under age 22 and regularly attending school will have earnings excluded from income at a higher rate than the initial earned income disregard as is now provided for SSI student beneficiaries with earnings. There would be only one exclusion for those who are concurrent beneficiaries.

**Asset Accumulation.** Expand the purpose of a Plan for Achieving Self Support (PASS) to include not only employment goals but also asset accumulation (savings) for SSI beneficiaries related to housing and independent living.

**5. Provide for Continued Attachment to the SSDI, SSI, and Medicaid Programs as Work Incentives. Medicare for Working SSDI Beneficiaries with Reduced Benefits.**

**Continued Attachment to SSDI under the Gradual Reduction Choice Option.** Those SSDI beneficiaries who chose the SSDI gradual reduction choice option would continue to be considered SSDI beneficiaries in a non-payment status when their earnings make them no longer eligible for cash benefits. They will be able to return to SSDI cash payments if they have a reduction in their earnings as is now the case in the SSI program.

**Continued Attachment to SSI and Medicaid.** SSI beneficiaries who exceed the Section 1619(b) threshold for Medicaid eligibility would be able to continue their

attachment to SSI (non-payment status) and Medicaid (non-benefit status) without the current 12 month time limit.

**Medicare for Working SSDI Beneficiaries with Reduced Benefits.** Consistent with current policy regarding continued eligibility for Medicare, a beneficiary would continue to be eligible for Medicare as long as he or she is in SSDI payment status. To the extent the beneficiary is in nonpayment status, the current time limits and eligibility for regular Medicare and the Medicare Buy-In would apply.

**6. Increase Work Incentives under Medicaid for SSI and SSDI Beneficiaries.**

**State's Option to Increase Section 1619(b) Earnings Limit.** Each state would have the option to establish an earnings limit (for continued Medicaid eligibility for SSI beneficiaries in nonpayment status) at a level higher than the minimum Section 1619(b) threshold established each year for each state by SSA under administrative regulations. Current policy, which enables an individual to have an individualized Section 1619(b) earnings limit based on higher medical costs, would continue.

**State's Option to Increase Resources Limit for Working SSI Beneficiaries.** In addition, states would be authorized to establish a higher resources limit and additional resource exclusions (as work incentives) than under current law for SSI beneficiaries with earnings. Such funds from earnings would be in separate accounts as is now the case under the administration of PASS plans. Under this authority, State's may also provide for exclusions of retirement accounts and "independence" accounts. Such accounts would be disregarded for purposes of SSI eligibility.

**Disabled Adult Children and Section 1619(b) Eligibility.** Under current law, persons who become newly eligible or have increases in their DAC benefits under Title II are protected against loss of Medicaid eligibility if their new eligibility for benefits or increased amount of benefits makes them ineligible for SSI. However, for SSI beneficiaries who were utilizing Section 1619 their loss of SSI status makes them ineligible for the work incentives under the provisions of Section 1619(b). We are proposing that for purposes of continued eligibility for Medicaid under Section 1619(b) they would be "deemed" to be SSI beneficiaries.

## APPENDIX C

**SELECTED POLICY RECOMMENDATIONS BY  
THE NATIONAL COUNCIL ON DISABILITY  
AND  
OTHER DISABILITY ADVOCACY ORGANIZATIONS**

The following recommendations have been proposed over the years by others. We support the policy objectives of these recommendations.

**SSI and SSDI programs.** Increase the SGA level for disabled beneficiaries (currently \$900) to be consistent with the level of blind beneficiaries (currently \$1,500). This change would increase the percentage of beneficiaries willing to risk work and increase their disposable income.

**SSI program**—Increase and index the resource limit (currently \$2,000 for an individual and \$3,000 for a family). This limit has not been updated since 1988. Increase and index the income disregard to at least recognize the cost of living since 1974 to approximately \$250.

**SSDI and Medicare**—Eliminate the 24 month waiting period for eligibility for Medicare for SSDI beneficiaries. Allow permanent access to Medicare for beneficiaries who work—provide lifetime certification of health coverage for beneficiaries with lifelong conditions.

**Disabled Adult Children**—Ensure that past work above SGA does not remain a barrier to SSDI benefits for people who otherwise are eligible for DAC benefits.

**Benefits counseling.** Dramatically increase funding for the Work Incentives Planning and Assistance Grants (formerly benefit counseling). This recommendation is essential to assist beneficiaries understand work incentive policies and to navigate the system of services and supports. Without sufficient numbers of qualified counselors no work incentive policy will have broad-based, nationwide success.

**Ticket to Work program.** Consistent with the policy set out in the proposed regulation promulgated by SSA, modify the payment systems to provide enhanced payment for upfront costs (increase milestones and allow for payment by state vocational rehabilitation agencies for certain costs and then allow employment networks to still receive payments) Note: The Ticket to Work program will always be of limited efficacy so long as the SSDI cash cliff exists and a policy is not adopted that allows outcome payments when benefits are reduced rather go to zero.

**Medicaid.** Congress should block CMS from implementing revisions to Medicaid policy regarding the scope of the rehabilitation services option. CMS, through administrative action is already narrowing the scope of the rehabilitation option. The effect of these actions is to discourage states from using best practices designed to enhance employment of beneficiaries.

**APPENDIX D****Selected Publications, Papers, and Manuals****By Allen Jensen and Robert Silverstein**

(Selected papers, articles and policy briefs can be downloaded from [www.disabilitypolicycenter.org](http://www.disabilitypolicycenter.org) and [www.medicaidbuyin.org](http://www.medicaidbuyin.org))

Silverstein, Robert; Jensen, Allen. Systems Change Information Bulletin #2: Opportunities for State VR Agency Participation in Statewide Systems Change (January 2007).

Jensen, Allen; Silverstein, Robert. Systems Change Information Bulletin #3: Medicaid Infrastructure Grant Resource Guide: Potential Uses by a State VR Agency (January 2007)

Jensen, Allen; Silverstein, Robert. Systems Change Information Bulletin #4: Medicaid Infrastructure Grants and State VR Agencies (January 2007).

Jensen, Allen; Silverstein, Robert. Systems Change Information Bulletin #5: Work Incentives & Benefits Planning and Assistance & State VR Agencies (January 2007).

Jensen, Allen; Silverstein, Robert. Systems Change Information Bulletin #6: The Role of State VR Agencies in Proposing Reforms to Existing Work Disincentives in the SSI and SSDI Programs (January 2007).

Jensen, Allen; Silverstein, Robert. Gradual Reduction Choice Option and Related Policy Proposals (December 2005).

Jensen, Allen; Silverstein, Robert. A Framework for Preparing Cost Estimates for SSDI \$1 for \$2 Gradual Reduction Demonstration Proposals (December 2005).

Silverstein, Robert, George Julnes and Renee Nolan. What Policymakers Need and Must Demand from Research Regarding the Employment Rate of Persons with Disabilities, Behavioral Sciences and the Law (Wiley InterScience, 2005).

Jensen, Allen; Silverstein, Robert; Folkemer, Donna; Straw, Tara. Policy Frameworks for Designing Medicaid Buy-In Programs and Related State Work Incentive Initiatives (May 2002).

Folkemer, Donna; Jensen, Allen; Silverstein, Robert; Straw, Tara. Medicaid Buy-In Programs: Case Studies of Early Implementer States (May 2002).

Folkemer, Donna; Jensen, Allen; Silverstein, Robert; Straw, Tara. The Medicaid Buy-In Program: Lessons Learned from Nine Early Implementer States (May 2002).

Jensen, Allen; Silverstein, Robert; Folkemer, Donna. A Summary of the Federal Income Maintenance and Health Care Programs for Disabled Persons Who Are Working or Want to Work (May 2002).

Silverstein, Robert. Policy Brief: Final Regulations Implementing the Ticket to Work and Self-Sufficiency Program (The Ticket to Work Program) (March 2002).

Silverstein, Robert. Policy Brief: Proposed Regulations Implementing the Ticket to Work and Self-Sufficiency Program (The Ticket to Work Program) (January 2001).

Silverstein, Robert. Emerging Disability Policy Framework: A Guidepost for Analyzing Public Policy. Iowa Law Review, August 2000, Volume 85, Number 5.

Silverstein, Robert. Appendix 1: An Overview of the Emerging Disability Policy Framework: A Guidepost for Analyzing Public Policy. Iowa Law Review, August 2000, Volume 85, Number 5.

Silverstein, Robert. Appendix 2: Major Disability-Related Legislation 1956-2000. Iowa Law Review, August 2000, Volume 85, Number 5.

Silverstein, Robert. Policy Brief: The Ticket to Work and Self-Sufficiency Program and Established Under the Ticket to Work and Work Incentives Improvement Act of 1999 (February 2000).

Silverstein, Robert, Allen Jensen. Policy Brief: Improvements to the SSDI and SSI Work Incentives and Expanded Availability of Health Care Services to Workers with Disabilities Under the Ticket to Work and Work Incentives Improvement Act of 1999 (February 2000).

**Responses to Questions Submitted for the Record From Allen Jensen  
By Chairman Baucus**

*Responses prepared by Allen Jensen and Bobby Silverstein*

**1. What are your most important recommendations for reducing barriers to employment for individuals receiving Social Security Disability Benefits?**

Our most important recommendations for reducing barriers to employment are:

1. Provide for continued attachment to the SSDI benefit program for beneficiaries as long as their medical condition continues
2. Provide for a gradual reduction in benefits as earnings increase and immediate return to benefits as their earnings decrease
3. Ensure adequate infrastructure and resources at SSA and at the state and local level to administer work incentives and to inform and support decision making by beneficiaries.

1. Continued Attachment

Fear of loss of basic income support and uncertainty about their ability to sustain employment if they tried to work is a major barrier to employment for SSDI beneficiaries. As we stated in our written testimony:

In designing and implementing the SSI and SSDI programs, it is important to recognize the reality that they are programs of last resort. A program of last resort means that before applying for benefits, the person with a medical condition that gradually worsens over time kept trying to work but those numerous work attempts were not successful. For those with a sudden injury, many go back to school using rehabilitation funds and gain a new skill. However, the uncertainty related to the disabling condition and needed connection to ongoing support means that time limited work incentives do not fit the reality of what many beneficiaries need to attempt and sustain work. The uncertainty of many mental or physical disabilities linked to reoccurring health conditions means that the continued availability, when needed, of income assistance and health and support services is an essential part of a employment support disability policy.

Current SSDI law provides for a time-limited attachment under the Extended Period of Eligibility (EPE) provision. However, most medical conditions of those receiving SSDI are permanent in nature.

2. Gradual Reduction in Benefits

The sudden loss of all SSDI benefits (the cash cliff) after a Trial Work Period and the three months grace period is a very significant barrier to SSDI beneficiaries attempting to begin or return to work. Returning to employment for persons with a medical condition is usually a transition for those with just a temporary medical condition. Those found eligible for SSDI must meet criteria for a disabling condition this is expected to last at least twelve months.

The establishment of interrelated policies of continued attachment, gradual reduction and immediate resumption of benefits when earnings cease or reduce would create a true "safety net" for persons with

severe physical or mental disabilities who have gone through the experience of applying for programs of “last resort” and in spite of their significant disability want to attempt a return to some level of employment.

Reducing Fears by Parents of Disabled Adult Children A significant number of those receiving disability benefits under Title II of the Social Security Act, are Disabled Adult Children (DACs) who are receiving benefits on the basis of their parent’s earning record who qualified as an insured worker. The responsibility felt by parents and other family members for the well-being of disabled family member extends to protecting them from harm which they feel may occur if they attempt work.

Parents of adult children with a disability have a special set of hopes and fears – especially as the parents grow older and are concerned about the needs of their adult child as the parent’s ability to provide support declines and eventually will not be personally available. This fear by the parent, if their child works too much under current SSDI law, of loss of basic income support for their adult child with a disability that began before the age of twenty-two is another aspect of the employment barriers by SSDI beneficiaries.

Continued attachment, gradual reduction and immediate restoration of benefits not only by an adult beneficiary with a significant work history, but also for adults whose disability began at birth or in childhood could provide significant relief from the fears felt by parents and other family members of disabled adult children.

3. Ensure adequate infrastructure and resources at SSA and at the state and local level to administer work incentives and to inform and support decision making by beneficiaries.

SSA Capacity – Implementation of enhanced work incentive policies will require a significant commitment of resources by Congress to SSA. SSA must have the administrative capacity and procedures to process earnings information from beneficiaries accurately and on a timely basis to prevent overpayments and other confusion that can negate work incentive policies.

Systems Change and Infrastructure Development Changes in policy such as removing the cash cliff and providing for continued attachment are necessary to enhance employment outcomes for SSI and SSDI beneficiaries. In addition, a key component in any work incentive initiative must include comprehensive work incentives planning and assistance (also known as benefits counseling).

Beneficiaries have told us that they often distrust SSA and need someone who they can trust to help them navigate the system and respond when they face personal barriers and institutional roadblocks. They need ongoing assistance to utilize work incentives. We have also learned from the experience of implementing the current SSI and Medicaid Buy-In program work incentives that there must be a concerted effort to train eligibility workers and service staff in order to increase the likelihood that beneficiaries will be willing to risk work and utilize the work incentives available to them.

In addition, it is critical that states receive ongoing support to continue to improve their infrastructures and break down artificial barriers among state agencies which is a key role played by state Medicaid Infrastructure Grant projects.

We would also refer you to the recommendations of a number of disability advocacy organizations that included in Appendix C of our written testimony.

**2. Please describe how your benefit offset proposal eliminates the “cash cliff” in the SSDI program?**

In summary and consistent with the “do no harm” principle, under our benefit offset proposal, which we call the “Gradual Reduction Choice Proposal”, a beneficiary would be provided a choice. That choice would be whether to continue to be subject to current policy of a “cash cliff” beginning at SGA, or choose a second option under which a gradual reduction or benefit offset would begin at one-half of SGA and in exchange for starting the reduction in benefits at this level, the individual would be entitled to continued attachment to the program as long as his or her disability continued. In an effort to make the SSDI and SSI work incentives similar and thus simplify work incentives our proposal also includes incremental changes to the work incentive provisions under the SSI, Medicaid and Medicare programs.

Our proposal changes the current policy of an SSDI beneficiary having no choice but to face a “cash cliff” if they earn too much for too long. Under our proposal the cash cliff would be avoided by an individual choosing to utilize an option under which their benefits continue when their earnings exceed SGA, which in 2007 is \$900. They would have a \$1 reduction in benefits for every \$2 of earnings beginning at one-half of SGA.

Our proposal involves tradeoffs for an SSDI beneficiary. On the one hand, the beneficiary may choose current policy with limited risk and limited reward, i.e., limit their earnings to below SGA and no reduction in benefits up to the SGA level followed by a cash cliff. On the other hand, the beneficiary may choose the gradual reduction choice option that entails short-term risk (i.e., a gradual reduction in benefits after initial earned disregard of one-half of SGA) to obtain increased disposable income (i.e., continued eligibility for cash benefits above SGA) and long-term security (i.e., no time limit on continued attachment to the SSDI program when benefits are reduced to zero).

The gradual reduction choice option is not meant for all beneficiaries. The proposed strategy is designed to provide a new option for those SSDI beneficiaries who personally decide that they have sufficient confidence in their ability to sustain employment over a period of time at an earnings level somewhat greater than SGA and/or for beneficiaries whose primary concern is security—knowing they will preserve their attachment to the program even when their earnings increase substantially for a given period of time. Beneficiaries need a form of social insurance that protects them against the uncertainty often times intrinsic to the medical conditions and impairments which initially qualified them for SSDI disability benefits.

For other individuals the gradual reduction at one-half of SGA and continued attachment to SSDI without a time limit or earnings limit could provide a greater opportunity to improve their disposable income, their quality of life and independence. For example, a person with a significant physical disability from an injury who is an SSDI beneficiary may receive assistance from the state vocational rehabilitation agency with adaptive equipment and assistance and help with retraining intended to enable the individual to work in spite of their disability. However, the individual may not know how many hours they will be able to work and what level of earnings they will have. With the choice available, the SSDI beneficiary can still use the Trial Work Period provision in current law to take the time to determine whether they will have the ability and the necessary supports to sustain earnings so that they can decide what is best for them during a “choice time” as described below.

If they decide that the gradual reduction with continued attachment is best for them, then, as their earnings increase, their benefits would be gradually reduced beginning when their earnings exceed

one-half of SGA. They would have continued eligibility when earnings exceed SGA and they would have the protection of continued attachment when their earnings increase even to the point where they no longer receive SSDI benefits. Also, they would have a gradual increase in benefits if their earnings decrease or return to full benefits if they no longer have earnings.

The choice between the current policy with the cash cliff at SGA and the gradual reduction choice is not a one time choice but one that the SSDI beneficiary can make on a periodic basis. In designing the Gradual Reduction Choice proposal, selecting the appropriate frequency of the choice involves creating a balance between the degree of risk for the individual and the administrative burden on the Social Security Administration. The longer the period of time in which the gradual reduction choice remains in effect (benefits reduced beginning with earnings below SGA), the greater the potential for an individual (whose earnings decreased) being disadvantaged with less net income compared to the SGA cash cliff option under which there is no reduction in benefits below SGA. However, the greater the frequency of choice increases the administrative time required by SSA to make individualized modifications to a beneficiary's records.

Under the proposal, a beneficiary's earnings would be subject to treatment under the current policy until he/she affirmatively chooses the gradual reduction choice option (the default). This initial decision can be made at any time after the individual obtains sufficient information and work experience to make an informed choice. If the beneficiary moves from the choice option to the cash cliff option, existing policies apply i.e., Trial Work Period months not used remain available (taking into account months no longer counted under the rolling 60 months provision).

This initial decision to have earnings considered for purposes of the \$1 for \$2 gradual reduction would continue until an "open season" during which the beneficiary would have the option to return to current policy. The open season would be available on an annual basis for a specified duration. The open season approach is intended to address concerns over administrative burden on SSA by concentrating a specific administrative task for a limited time period. The open season concept is one that is used in private health insurance plans and related to enrollment in Medicare Part B.

The gradual reduction choice option may be chosen primarily because of the security it provides, even though, in the short run, or periodically for a few months the SSDI beneficiary may have had more total income in a particular month if he or she had worked just below SGA. As we discussed in our written testimony, providing security for SSDI beneficiaries is a core provision to reduce work disincentives and increase the percentage of SSDI beneficiaries with earnings and their level of earnings.

**3. There are currently many separate work incentives in the SSDI and SSI programs. This creates serious complexity for beneficiaries and others involved with the program. What recommendations do you have to simplify the work incentives under both the SSDI and SSI programs?**

Our recommendations for simplifying work incentives fall under three categories:

1. Provide that both the SSI and the SSDI programs have provisions that allow beneficiaries to work and not lose all of their cash benefits or lose their attachment to those programs.

2. Provide for an initial earned income disregard for beneficiaries who work and make it the same for SSI and SSDI. The initial earned income disregard would apply to SSDI beneficiaries who chose the gradual reduction option and to all SSI beneficiaries.

3. Simplification for SSI and SSDI beneficiaries includes having the necessary infrastructure and level of service staff at the Social Security Administration and at the state and local level so that the beneficiaries who work have confidence and trust that if they have earnings their benefits will be accurately and in a timely manner adjusted to reflect the amount of their earnings. If the policy is simplified but the administration of the policy is inadequate and confuses the beneficiary and causes uncertainty, then simplification of the program policies can be negated.

Approving and implementing new work incentive policies should include having the Social Security Administration develop an operational plan for implementing new SSDI policies and related improvement in SSI work incentives. This should include a clear plan as to the necessary resources that will be needed by SSA to adequately implement new work incentives. The experience of SSA's Four-State Benefit Offset Pilot Program (Utah, Wisconsin, Connecticut and Vermont) in which a gradual reduction of SSDI benefits is being tested, should be utilized. Those states have experience in working with SSA in trying to ensure accurate and timely benefit adjustments based on earnings.

**4. The Medicaid Buy-In program helps disability beneficiaries return to work and retain health care coverage. Why have 18 states been so slow in adopting the Medicaid Buy-In program?**

There are currently a total of thirty-seven states that have implemented a Medicaid Buy-In program. In three other states state legislation has been enacted to establish a Medicaid Buy-In program but it has not yet been implemented. In six other states there are active efforts underway to study, develop cost estimates and consider policy options for a Medicaid Buy-In program.

The primary reason that states have been slow in adopting a Medicaid Buy-In program is that they create additional Medicaid costs to states. A significant number of Medicaid Buy-In participants are SSDI beneficiaries who move from being eligible for Medicaid under a state's Medically Needy program under which a beneficiary must incur considerable medical care costs before the Medicaid program pays for health care services. Under the Medicaid Buy-In program in most states the premiums or cost share paid by the participants is considerably less than the spend down under the state's Medically Needy program.

Those states with the least restrictive Medicaid Buy-In programs and with the largest enrollments established their programs before the turn down in the economy in 2001-2002. Since that time a number of states have developed Medicaid Buy-In programs but they have included significant restrictions in eligibility for the program. These restriction have been primarily unearned income restrictions which provide, for example, that if a applicant who has SSDI benefits or other unearned income above the Federal Poverty Level such income would make the individual ineligible for the state's Medicaid Buy-In program.

**5. If income disregards and asset limits were to be indexed for inflation, would you expect to see more beneficiaries leaving the SSI program? Is it time to look into indexing these figures?**

Indexing the \$65 initial earned income disregard on the basis of cost-of-living increases since the program began on January 1, 1974 would enable those 330,000 SSI beneficiaries with earnings in any

one month to benefit a great deal more from their attempt to work, improve their standard of living and improve the potential to live more independently.

Increasing the income disregards would not necessarily result in more beneficiaries leaving the SSI program. The reason is that the earnings level at which they would no longer be receiving SSI benefits would increase when the initial earned income disregard is increased. However, it could be expected to increase the number of SSI beneficiaries with earnings since the reward from working would be substantially improved.

A primary emphasis in Medicaid for adults with disabilities is to enable them to live in the community and not in institutions. An increase in the initial earned income disregard for SSI for those 330,000 SSI beneficiaries with earnings would provide a significant source of self support for housing for those individuals.

It would also be complementary to the efforts in Home and Community Based Waivers and the Money Follows the Person initiative in the Deficit Reduction Act of 2005 to establish initiatives to reduce the numbers of persons with disabilities living in institutional settings by enabling working SSI beneficiaries to have more disposable income to support independent living. .

Increasing the earned income disregard under the SSI program would be of particular benefit and provide relatively high impact on total income to those with relatively lower levels of earnings. That includes those younger SSI beneficiaries with disabilities who are transitioning from school to work to at least part time work. It would also be of particular significance to those with developmental disabilities whose earnings capacity may be less but, nevertheless are making efforts to increase their level of self sufficiency.

As part of our comprehensive proposal to improve work incentives for SSDI beneficiaries, the Gradual Reduction Choice Proposal and Related Proposals, we recommended increasing the earned income disregard more than an index from the level in 1974 but instead to one-half of the SGA level.

This proposed increase in the SSI initial earned income disregard to one-half of SGA is intended to fit with the proposal to provide the option for SSDI beneficiaries to choose to not have a "cash cliff" at the SGA level but instead would have a gradual reduction in SSDI beginning at one-half of SGA. This is also part of the effort to simplify the work incentives by making the SSI and SSDI work incentives similar. This is particular important for those 1.1 million individuals who are concurrently eligible for SSI and SSDI.

Increasing the asset level for SSI beneficiaries would be complementary to efforts both in SSI and SSDI under the current work incentives (Section 1619 and Medicaid Buy-In) to increase both the number of beneficiaries with earnings and the level of their earnings.

Low income SSI beneficiaries generally do not have access to credit or other means to make down payments for cars or housing or direct purchases of items related to independent living arrangements. Under current SSI law the primary means for SSI beneficiaries to save for purchases of any significant value is by having an SSA- approved Plan for Achieving Self Support which is provided for in SSI law. Under approved PASS plans SSI beneficiaries are allowed to disregard additional earnings and have additional assets if it is part of such a PASS plan which is intended to improve their ability to be self supporting. A general increase in the SSI asset limit would make it possible for more SSI beneficiaries to accumulate resources without the administrative burden on the beneficiary and the

staff-intensive effort that is required by SSA to approve and to monitor a PASS plan. The need for PASS plans will continue and we are recommending that the purpose of a PASS plan be broadened to include not only employment goals but also asset accumulation (savings) for SSI beneficiaries related to housing and independent living.

**6. What can be done to improve the opportunities for health care coverage for former SSDI and SSI beneficiaries?**

The availability of a Medicaid Buy-In program in many states has provided the opportunity for continued health care coverage for some small percentage of SSDI beneficiaries who decide that Medicaid Buy-In is a key part of the ongoing support they need to support their work and they can earn enough to no longer need SSDI.

For former SSDI and SSI beneficiaries, the continued availability of Medicaid services when they become employed- either as their sole health services coverage or as a wrap around to employer-based health insurance - is an important source of support. In addition, former SSDI and SSI beneficiaries can become newly eligible for a state's Medicaid Buy-In coverage even if they are working at the time of application and they meet the medical criteria for SSI or SSDI without consideration of the fact they are employed

However, there are still a significant number of states who either do not yet have a Medicaid Buy-In program or the state's Medicaid Buy-In is very restrictive and in those states there are few participants. There are federal law and regulation which place restrictions on states in the design of their Medicaid Buy-In programs that have limited their ability to target the program. Those restrictions should be examined to determine if more flexibility should be provided to states while at the same time ensuring that access to the program is not unreasonably denied.

Providing on going support and security for SSDI and SSI beneficiaries as they increase their work effort through our proposed "continued attachment" to the program while they are in a non-payment status can enable those beneficiaries to gradually increase their work effort toward full time employment. Full time employment and sufficient time with an employer are often the criteria that need to be met for a new employee – with a disability or not – to gain access to employment-based health insurance.

It has also been recommended by disability advocacy organizations to allow permanent access to Medicare for beneficiaries who work—provide lifetime certification of health coverage for beneficiaries with lifelong conditions.

**Senator Olympia J. Snowe**  
**Senate Committee on Finance**  
**Hearing on “Barriers to Work for Individuals Receiving**  
**Social Security Disability Benefits”**  
**June 21, 2007**

Thank you, Mr. Chairman, for your tireless leadership on Social Security, an issue that is vital to so many of my constituents. As you know, roughly 20 percent of Maine’s population relies on Social Security or Social Security disability benefits. I appreciate your concern for the disabled and your willingness to hold this hearing so that we may better understand the reasons that smart, willing individuals find it difficult to return to work once they start receiving disability benefits.

Social Security disability benefits provide a lifeline to those who are blind or otherwise become disabled. The Social Security Disability Insurance program is exactly that—insurance. Each paycheck, workers pay into SSDI in order to protect themselves against a possible calamity. If the unthinkable happens, and an individual can no longer work, because of a car accident, a reoccurring medical condition, or prolonged mental illness, that worker can apply for disability benefits. These benefits will provide a minimum monthly payment, an average of about \$978 per month, to take care of the worker’s basic needs.

Unfortunately, many disabled workers must wait years before they finally receive disability benefits. As of December 2006, the SSA's had pending over 568,000 initial disability claims. Currently in Maine it takes an average of 469 days to process a Social Security disability claim. These casework backlogs and excessive wait times harm the disabled and are unacceptable. Often the disabled community feels that the SSA denies almost all disability applications and that even a preponderance of medical evidence may not be sufficient to prove a disability to the SBA. Consequently, once workers go through the long process of getting approved for disability benefits, they do not want to repeat this arduous process again.

Living with a disability is difficult. Many disabled workers were passionate about their previous jobs and find it painful to accept that they can no longer be able to contribute to the working world. Out of their strong desire to be independent, and self-sufficient, many disabled workers want to determine what types of jobs they *can* do with their disability.

Unfortunately, finding a job that fits their capabilities is not easy, and it may take several tries for disabled workers to successfully return to the workforce. While transitioning back to work, many disabled workers must try out new jobs until they find one that fits their abilities and health. However, under the SSA’s current program, once disabled workers earn above \$900 a month, they will lose their SSDI benefits. If later, the job is not a good match for the workers’ abilities, or their medical condition deteriorates, they can quickly become unemployed again, and be forced to reapply for disability status.

I believe the SSA must find ways to better help disable workers return to work and utilize their capabilities. At the same time, I know that the SSA is facing serious staffing and funding shortages. Because of these shortages, local offices often can not help the disabled plan how to return to work or answer complicated questions about work incentives programs. In order to better help the SSA fulfill its mission, of serving the elderly and disabled, this June 15, Senator Kerry and I sent a bi-partisan letter to the Senate Appropriators requesting that an additional \$430 million be dedicated to the SSA's administrative expenses. If appropriated, the SSA will be able to use this money to hire additional staff, reduce disability casework backlogs, and better service the public.

American is the land of opportunity and adaptability. We need to work with the Social Security Administration to find solutions so that the disabled who desire to work, have the support they need to adapt and achieve their aspirations. We need to better structure our disability programs and remove existing barriers that discourage work. I look forward to hearing your testimony and thoughts on how to best help the disabled realize their full potential in the workplace.

Thank you, Mr. Chairman, once again for holding this hearing.



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## **TRANSFORMING DISABILITY POLICY**

*Presented to:*

**United States Senate**  
**Committee on Finance**

*Hearing on:*

**Barriers to Work for Individuals Receiving Social  
Security Disability Benefits**

*Presented by:*

**David C. Stapleton, Ph.D.**  
**Cornell University Institute for Policy Research**

June 21, 2007

This briefing paper is largely based on the knowledge I gained through work that was performed under grants and contracts from the Social Security Administration, the National Institute for Disability and Rehabilitation Research, the Centers for Medicare and Medicaid Services, the Assistant Secretary for Planning and Evaluation in the Department of Health and Human Services, and various other agencies and organizations. I gratefully acknowledge the contributions of individuals in those agencies and organizations to the information contained herein, as well as to those of many collaborators and a variety of other experts who have influenced my thinking. The views expressed in this briefing paper are, however, my own. This testimony does not include information about agency-funded projects that are still in progress.

**TRANSFORMING DISABILITY POLICY****Full Testimony**

Thank you for inviting me to testify today. My testimony reflects the research I have conducted under many grants and contracts over the last 14 years, as well as the research and expertise of many others, but the views I present are my own. You might know that I am currently involved in work on four Social Security Administration projects, most notably the Ticket to Work evaluation and the Benefit Offset National Demonstration. Although my work on these projects has influenced my thinking about disability policy, I have not been asked to testify specifically on these projects, and am not cleared by SSA to do so.

I begin by touching on a topic that might seem off point, but which I will argue is not. SSA Commissioner Michael Astrue has provided exceptionally frank testimony to Congress about the poor performance of SSA's disability determination process.<sup>1</sup> He has told you about the very significant hardships that this process imposes on applicants, many of whom are experiencing considerable medical and economic hardship. Partly from personal experience involving his father, he recognizes that the current determination process treats many applicants in an unconscionable manner.

Commissioner Astrue is not the first SSA Commissioner to make process improvement a top priority. Notably, the two previous Commissioners have also done so, yet little progress has been made. I've been professionally involved in some of these efforts myself, and I testified to the Subcommittee on Social Security of the House Ways and Means Committee on this topic almost exactly five years ago.<sup>2</sup> I have become increasingly convinced that the problems with the

determination process are more a reflection of larger problems with federal disability policy than they are with poor process design, poor management, or inadequate resources. I hasten to add that increased funding and procedural improvements could improve the process, but I also believe that the process will continue to be very problematic in the absence of successful, transformative change to federal disability policy. My greatest concern is that efforts to transform disability policy will take a back seat to efforts that focus on improving the determination process and that, by themselves, will at best achieve limited success.

Because of time limits, my remarks on the transformation of disability policy will focus on the Social Security Disability Insurance program; parallel points apply to other programs.

Over 6.5 million workers currently receive SSDI benefits.<sup>3</sup> I think it is critical to preserve this program for those workers whose physical or mental impairments prevent them from permanently earning a substantial sum under any reasonable circumstance. The SSDI program has become unduly burdened, however, because it is trying to meet the needs of significant numbers of workers with disabilities who would be better served by a program that helps them continue to be self-sufficient through work. Current programs serving that purpose are inadequate and, as a result, many turn to SSDI for lack of a better alternative. SSA is stuck with determining which of these applicants meet SSDI eligibility criteria.<sup>4</sup>

Last summer the Social Security Advisory Board outlined the structure for a 21<sup>st</sup> century disability program, reflecting input from many experts, including leading advocates.<sup>5</sup> This structure includes SSDI as part of an income support program for those who are unable to attain a reasonable standard of living through work for very long periods, if not permanently. The structure also includes two other critical components. The second component is a “transitional”

program that provides an array of support services and work incentives to those people with disabilities who can, with such support, achieve substantial self-sufficiency and a reasonable standard of living through work. The third component is a common entry system to the transitional and long-term support systems, which the Board calls “triage” assessment. Workers with disabilities would be encouraged to enter triage assessment early, even while they are still employed. The process would be designed to quickly identify: a) those with very short-term challenges, or with challenges that can readily and reasonably be addressed by their employer; b) those who are clearly unable to contribute substantially to their own support under any reasonable circumstance for a year or longer; and c) those in the gray area in between the other two groups. The first group would not receive additional services, the second would enter SSDI, and the last would enter the transitional program.

Many disability leaders and organizations have been advocating for improvements in services and supports to help people with disabilities lead more self-sufficient and fulfilling lives. At the same time, however, they are very protective of existing programs. These two positions are not at all contradictory, given federal and state fiscal pressures, poor coordination across agencies and levels of government, the nature of bureaucracy, the constant shifting of political winds, and the many unanswered questions about how and how well new services and supports would work.

Yet I see substantial commonality between the framework recommended by the Advisory Board and the objectives of many advocates. Notably, a draft report entitled “Being American: The Way Out of Poverty,” written by Bryon MacDonald and Megan O’Neil of the World Institute on Disability, recommends a new program that would parallel SSDI, called

Employment Support Insurance, and that would serve many workers who might otherwise end exit the labor force and enter SSDI.<sup>6</sup>

There are many differences in the details of the Advisory Board's recommendations and those of the World Institute report, but I think the large area of common ground in these two reports is much more important: each calls for a new program or system that helps people with disabilities achieve or sustain economic independence before they are truly unable to do so, and reduces their reliance on long-term income supports.

In theory, at least, such a program could both improve the lives of people with disabilities and reduce the burden of disability programs on taxpayers, for at least two reasons. First, current policies waste the considerable productive capabilities of people with disabilities. Presumably, a well-designed program would: help participants use their capabilities to achieve a higher standard of living; be less costly to the government; and increase government revenues from payroll, income and other taxes. Second, our current support system is a patchwork of highly fragmented programs, reflecting the responsibilities and interests of multiple agencies, multiple Congressional committees, and multiple levels of government. Each one on its own might make sense, given the existence of the others, but inefficiency is high because: fragmentation makes it very difficult for people with disabilities to obtain the support they need when they need it, services are often duplicated; and program provisions interact in counterproductive ways.<sup>7</sup>

Can we achieve such lofty goals in practice? I do not know, but I think there is some reason for optimism. The latest reason is intriguing new evidence from a pilot program in the United Kingdom. The Pathways to Independence program offers a package of work incentives and supports to workers who enter the UK Incapacity Benefits program.<sup>8</sup> The IB program is

intended to provide both short- and long-term disability benefits. Evidence from a methodologically strong evaluation indicates that the new program increases the employment of IB entrants by 22 percent after about 10 months, and reduces the number continuing to receive income support by 14 percent. Implementing a similar program in the United States is problematic because we do not have a national short-term disability program, and because responsibility for the supports that would be required are spread across several agencies. Nonetheless, the findings from the UK pilot at least suggest that a well designed program in this country could reduce the flow of workers with disabilities out of the labor force and into SSDI by a very substantial magnitude.

The need for transformative change is already pressing, and becoming more urgent with each passing year. Long-term trends show that more and more working-age people are not working because of self-reported work limitations, and a larger and larger share are relying on SSDI for support. This statement applies to both sexes and all age groups. In fact, based on the Current Population Survey, the percentage of Americans aged 21 to 64 not active in the labor market because of a reported work limitation was higher in 2004 than in any year since 1981, the first year for which this statistic is available.<sup>9</sup> This statement applies to both men and women. There is controversy about these estimates because of problems with the CPS definition of disability, but the trends are confirmed using other surveys and other broad-based measures of disability. Some will also point out that the employment rate for people with disabilities who say they can work is increasing. That's certainly true, but this simple statement masks the reality that a larger and larger percentage of working-age people with disabilities say they cannot work.

Perhaps more germane, and certainly less disputable, is the fact that the percentage of working-age people who receive SSDI benefits is historically very high, for every age/sex group.

One recent analysis by David Autor and Mark Duggan found that the percentage of men age 60 to 64 receiving SSDI increased from 11.9 percent in 1984 to 13.3 percent in 2004.<sup>10</sup> Growth for younger men was much higher, and growth for women in all age groups was higher than for men because of growth in female labor force participation.

Additional statistics show that people with disabilities, as a group, have received little benefit from this country's impressive economic growth; instead, they are falling further and further behind their counterparts without disabilities.

The relative decline of the economic fortunes of working-age people with disabilities has occurred despite high and rapidly growing government expenditures for their support. In 2002, the most recent data for which comprehensive estimates are available, federal expenditures to support working-age people with disabilities totaled \$226 billion, accounting for over 11 percent of all federal outlays, and 2.2 percent of gross domestic product.<sup>11</sup> The bulk of these expenditures were for income support and health care. States spent an additional \$50 billion, mostly to pay for health care. From 1984 to 2002 federal expenditures for this population increased by 80 percent more than all federal outlays, and by almost 60 percent more than gross domestic product.

It is especially troubling that these trends have occurred despite tremendous advances in medicine and technology, and despite the establishment of the rights of people with disabilities at the federal level, under the Americans with Disabilities Act and other legislation. Some might blame both of these apparent advances for the declining fortunes of people with disabilities, but I find their arguments and evidence unconvincing. Instead, it seems much more plausible that the declining fortunes of people with disabilities have occurred because federal disability policy has

failed to keep pace with medical advances, technological innovations, changes in the nature of work, and society's views about both the rights and responsibilities of people with disabilities.

The stress on SSDI and the broader support system for people with disabilities will almost certainly become much worse in the next two decades as the Baby Boomers enter and pass through their 50s and 60s.<sup>12</sup> In the absence of significant progress toward helping working-age people with disabilities attain a greater degree of self-sufficiency, SSA's disability determination process will face an increasingly daunting workload, government expenditures to support working-age people with disabilities will continue to grow rapidly relative to the growth of all federal outlays and the economy, and Congress and the Administration will find it increasingly difficult to protect SSDI from eligibility tightening and benefit cuts. We need to find better alternatives.

I urge this Committee, all government leaders, and advocates for people with disabilities to support the design, testing, and eventual implementation of transformative disability policy changes – changes that will help people with disabilities achieve both greater economic self-sufficiency and more fulfilling lives. Within that framework, the highest priority should go to efforts that will reduce the premature exit of workers with disabilities from the labor force and into SSDI.

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<sup>1</sup> See, especially, <http://waysandmeans.house.gov/hearings.asp?formmode=detail&hearing=527&comm=4>.

<sup>2</sup> See <http://waysandmeans.house.gov/legacy.asp?file=legacy/socsec/107cong/6-11-02/6-11stap.htm>

<sup>3</sup> See Table 5.D4 in SSA, *Annual Statistical Supplement to the Social Security Bulletin, 2006*, <http://www.ssa.gov/policy/docs/statcomps/supplement/2006/5d.html>

<sup>4</sup> Extensive additional information about the need for transformative change and a discussion change principles appears in Stapleton, D.C., O'Day, B., Livermore, G.A., & Imparato, A.J. Dismantling the Poverty Trap: Disability Policy for the 21<sup>st</sup> Century. *Milbank Quarterly*. Volume 84, #4, 701 – 732, 2006.

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- <sup>5</sup> Social Security Advisory Board, *A Disability System for the 21<sup>st</sup> Century*, 2006. <http://www.ssab.gov/sumrDisabilitySystem.shtml>.
- <sup>6</sup> A draft summary of the report can be found at <http://www.wid.org/programs/california-work-incentives-initiative/public-policy-activities/being-american-the-way-out-of-poverty/>.
- <sup>7</sup> These points are illustrated for health care and related services provided to people with disabilities in N. Goodman, D.C. Stapleton, G.A. Livermore and B.O'Day, *The Health Care Financing Maze for Working-Age People with Disabilities*, 2007 <http://digitalcommons.ilr.cornell.edu/edicollect/1234/>.
- <sup>8</sup> See S. Adam, C. Emmerson, C. Payne and A. Goodman (2007) *Early Quantitative Evidence on the Impact of the Pathways to Work Pilots*. UK Department of Work and Pensions, 2007. [www.dwp.gov.uk/asd/asd5/rports2005-2006/rrep354.pdf](http://www.dwp.gov.uk/asd/asd5/rports2005-2006/rrep354.pdf).
- <sup>9</sup> Statistics derived by the author from annual statistics on the prevalence of work limitations and the employment rate of those with work limitations available at [www.disabilitystatistics.org](http://www.disabilitystatistics.org).
- <sup>10</sup> See Autor, D.H. & M. G. Duggan (2006). *The Growth in the Social Security Disability Rolls: A fiscal Crisis Unfolding*. *Journal of Economic Perspectives*, 20(3) 71-96.
- <sup>11</sup> See Goodman, N. & Stapleton, D.C. (Forthcoming). *Federal Expenditures for Working-age People with Disabilities*. *Journal of Disability Policy Studies*. 18(1). A summary appears at <http://digitalcommons.ilr.cornell.edu/edicollect/189/>.
- <sup>12</sup> The urgency of the need for change is discussed more extensively in D.C. Stapleton, R.V. Burkhauser, P. She, G.A. Livermore and R.R. Weathers, II. 2007. *Income Security for Workers with Disabilities: A Stressed Support System in Need of Innovation*, available by request to [dcs28@cornell.edu](mailto:dcs28@cornell.edu).



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The Honorable Max Baucus, Chairman  
Committee on Finance  
United States Senate  
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Dear Senator Baucus:

The following are my responses to the questions you sent to me on August 10, 2007, as follow-up to my testimony before the Finance Committee on June 21, 2007. I am pleased for the opportunity to provide further input into the Committee's deliberations.

**1. Mr. Stapleton, you have articulated a strong view that we need to provide governmental support for those people whom your new programs designate as "expected to work."**

This statement does not appear to be intended as a question, but I will make a comment on the language. Like many other experts, I am urging rapid consideration of programs that would, in effect, create a new gateway to the programs that are designed to provide long-term income support for those who cannot work, Social Security Disability Insurance (DI) and Supplemental Security Income (SSI). Our society expects all working-age people to provide for their own support unless they have exceptional circumstances. In fact, current applicants to DI and SSI are expected to work; the application process allows them to prove that they cannot work, under outdated rules that do not consider advances in assistive technologies, accommodations and the nature of today's work. The new system would not designate those who are "expected to work." Instead applicants would be expected to work, just as they are now, and the program would provide a process through which the government, and the individuals themselves, can realistically determine if they can work – but given a reasonable, publicly-provided "package" of assistance that might include various services, assistive devices, accommodations, and temporary or partial income support -- assistance they would need to attain a standard of living that is acceptable to society, and one that is better than they can attain under today's policies. The new system would also provide that support.

**2. What do you think it would cost to provide these supports?**

I assume this question pertains to the overall cost to the federal government. I believe that we could design and implement programs that both improve government assistance to working-age people with disabilities and *slow the growth in federal expenditures* to support them, for two reasons. First, our current policies waste the considerable capacities of people with disabilities by creating barriers and disincentives to work. As a result, the federal government provides more income support to people with disabilities than it would have to under more well designed policies and, as significantly, people with disabilities contribute less to payroll and income tax revenues than they would under a well designed program. Second, our current programs are so complex and fragmented that they are incredibly inefficient. I think considerable savings could be achieved by offering more integrated supports to working people with disabilities.

Given fiscal realities, it is unrealistic to consider the development and implementation of any major new program that does not slow the growth of net government expenditures to support working-age people with disabilities. That goal can only be achieved by addressing the inefficiencies described above.

To illustrate the magnitude of savings that might offset the direct costs of a new program, consider the savings that would be achieved by reducing the number of DI beneficiaries by 10 percent, in the long run. I do not believe that we can move 10 percent of current beneficiaries off the rolls, but I do believe that a long-run reduction of this magnitude is achievable through a program that offers services to workers at the front-end, before they enter SSDI. As described in my testimony, the findings from the Pathways to Independence initiative in the United Kingdom provide support for this view. It is also consistent with past research in the United States, which finds that a substantial share of workers who enter DI do so after they are laid off for reasons that have to do with the economy, not their impairment. It is also worth pointing out that, according the Social Security Advisory Board's most recent Disability Chartbook, 4.2 percent of disability insured workers who were on the rolls in 2004, which is 20 percent higher than the comparable statistic from the previous peak, which was decades earlier in 1975 (3.5 percent). That's partly because of aging, but statistics in the Advisory Board's first Chartbook show that the most important reason is rapid growth since at least 1990 is growth in the statistics within age groups. Against this backdrop, a long-term 10 percent reduction under a policy that is designed, in part, to reduce DI entry, seems achievable.

In 2006, DI benefits totaled \$94 billion, according to SSA's actuaries. So a 10 percent reduction would be equivalent to savings of \$9.4 billion. There would be comparable savings from Medicare. It is harder to predict the effect on tax revenues, but they it likely be large. Back of the envelope calculations suggest another \$3 to \$5 billion.<sup>1</sup> Overall I think it is realistic to expect long-term annual savings for current programs, based on 2006, of anywhere from \$15 to \$25 billion per year. If expenditures for the new program were below that level, net savings would accrue to the federal government. By comparison, in FY2005 federal expenditures to support the state vocational rehabilitation service agencies – the primary federal source of employment assistance for people with disabilities – was just \$3.5 billion.

I've provide the above numbers just for illustrative purposes. A more concerted effort to develop realistic numbers based on current evidence might yield substantially different results, but likely would also have a large range because of the inadequacies of current information.

If, contrary to my assumption, you are asking me about the specific cost of the program itself, I do not have an answer. I think there are many different ways to design and manage such a program. The above back of the envelope numbers suggest that we should be looking at programs that would cost no more than \$15 to \$25 billion. All I am asking the Committee to do at this point is to encourage and support efforts to design, debate and implement such programs.

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<sup>1</sup> Suppose those who worked under the new program, rather than enter DI, achieved average monthly earnings of \$2,000 (\$24,000) more than they would have had they entered DI – a modest amount relative to today's wage levels and the current substantial gainful activity level of \$900. At the current payroll tax rate of 15.3 percent (including the employer share), the average worker under the new program would generate \$3,672 more in payroll taxes per year. In December 2005 there were 6.5 million DI worker beneficiaries. If 10 percent (650 thousand) were, instead, participation in the new program, under the assumptions above they would be generating \$2.4 billion more in payroll taxes. If the average tax rate on the \$2,000 in additional earnings was 10 percent, the additional contribution to federal income taxes would be \$1.6 billion.

**3. Would eliminating the current waiting period for SSDI beneficiaries to receive Medicare benefits help beneficiaries? What do you recommend we do about those applicants without health care waiting for a decision regarding SSA disability benefits?**

Elimination of the Medicare waiting period would certainly help some SSDI beneficiaries, and there is good evidence on that score, such as that reported in the recent *Health Affairs* article by Gerald Riley. It will not, however, help applicants, including those applicants who retroactively are determined to be in their waiting period. My understanding is that the typical new beneficiary has 15 or fewer months left on the Medicare waiting period at the time of DI award; 9 months occur before the award is made. One other significant shortcoming of eliminating the waiting period is that it will likely induce entry into DI. Reputable researchers have produced estimates of the size of this effect. Although I suspect these estimates could be well off the mark, I don't doubt that some induced entry would occur. Elimination of the Medicare waiting period would also not help workers with disabilities who are not able to obtain the health care they need to remain employed, or who cannot pursue better job opportunities because of the consequences for their health insurance. Nor would it help employers who are finding it difficult to compete internationally because of the burden of high health care costs – a circumstance that creates strong incentives for employers to avoid hiring or retaining workers with high health care needs.

I would like the Committee and others to consider a much more radical health insurance proposal, designed to help workers stay in the labor force, provide health care cost relief to their employers, and delay their entry into DI. I am submitting, as an attachment, a short description of such a program. The idea needs further development and analysis, but I think it is worth consideration. In brief, it would allow workers with high long-term health care costs, and their employers, to buy in to a new Medicare program. Program enrollees would, however, have to accept a longer DI waiting period. The current DI waiting period is five months after substantial gainful activity ends. The new program might increase that to, say, 24 months, essentially reversing the current policy of a 24-month Medicare waiting period. There would be exceptions for workers whose disability becomes more severe, of course, but the idea is to help pay for this program by reducing DI expenditure growth.

This change to Medicare is essentially an example of the type of front-end program I described in my testimony and above. It's a program that helps the worker continue to work and not enter DI. Many people cannot work without good health care, and this program would help them obtain the care they need rather than force them to demonstrate that they cannot work, perhaps after their condition has become more severe because of inadequate treatment, or perhaps after they have exhausted their own financial resources to pay for care. It's also a program that might pay for itself, through enrollee and employer premiums, DI savings, and higher tax revenues. Such a program might have sufficient merit and political appeal to be enacted on its own. I think it would have greater merit and political appeal if it were embedded in a holistic program that addresses assistance needs beyond health care services.

4. **Mr. Stapleton, you have written that a significant share of the population of individuals who receive Social Security disability benefits should be expected to work, and that the government's role is to help them support themselves through work. You have remarked that such a change would be a challenge to administer. To implement your plan, a new step in the disability application process is needed to determine whether an individual is expected to work. This new step would add time and complexity to the current application process. In view of the fact that it already can take applicants for Social Security's disability programs 3 or 4 years to be approved for benefits, wouldn't it be imprudent to add another complex step in the application process?**

As I said told the Committee in June, the current delays in the determination process are unconscionable. The government can reduce those delays through increased funding for SSA and through improvements to the process, but the fundamental reason for the delays is the very large number of applicants who are turning to this program because they do not have the support they need to continue to work. It is not just the volume of these applicants that clogs the system, but also the complexity of their cases. More and more applicants are obtaining awards based on residual functional assessments, rather than the Listing of Impairments, and more and more are obtaining awards only after an initial denial. I believe that the growing complexity of cases reflects the likelihood that more and more applicants could work if they had reasonable support.

It is a mistake to view a new front-end program as just an additional step in the application process, because the aim of such a program is not to determine if an applicant to the program is unable to work, but rather to provide the applicant with the reasonable supports so that the applicant can work. It will be expensive, but as discussed in the answer to Question 2 my belief is that a well-designed program would pay for itself through lower DI benefits and higher tax revenues. It would also delay entry into DI for some, but only because that is one objective of the program.

A well-designed program would have would be able to help applicants more quickly than the current program, but some would be helped in ways that are different than the way they are helped now. Such a program would have an intake process designed to quickly provide support for those who need it most. That process would result in immediate award of DI benefits under rules would be more stringent, but easier to administer, than SSA's current rules. Some share of the remainder would be immediately eligible for temporary assistance. Because the assistance is temporary, determination of eligibility would not need safeguards against abuse that are as cumbersome as those in the current determination process. As return-to-work assistance is provided to those who do not immediately enter DI, much more will be learned about their capabilities, and that information can be very valuable in support of a later DI determination. Private disability insurers currently use a model that has these features, because it is efficient to do so.

The new Medicare benefit described in the previous question illustrates how a front-end program can reduce the burden on the current determination process. That program would necessarily have eligibility criteria and its own determination process. It is, however, much easier to determine if an individual has high health care needs than it is to determine if the individual cannot work. This would provide relief to the DI determination process in three ways. First, fewer workers would apply. Second, those that do apply would likely have less complex cases, because access to health care was not sufficient to help them stay in the labor force. Third, once the worker is enrolled in the new Medicare benefit, the government would automatically start collecting medical evidence that can be used to support the DI determination process if the worker eventually applies. The collection and inadequacy of existing medical evidence is one of the primary factors slowing the initial determination process now.

Thank you, again, for this additional opportunity to provide input to the Committee's deliberations.

Sincerely yours,

A handwritten signature in black ink, appearing to read "D. Stapleton". The signature is fluid and cursive, with the first letter of the first name being a large, stylized "D".

David C. Stapleton

Attachment: Healthcare Financing for Workers with High Healthcare Costs

### **Health Care Financing for Workers with High Health Care Costs**

Ideally, a health insurance financing solution for workers at risk for high health care costs over extended periods would:

- Assure that the workers can obtain the health care they need to continue work and maintain their quality of life in a timely manner;
- Allow them to change employers or have short periods of unemployment without loss of access to care;
- Maintain the financial incentive to be economically self sufficient;
- Limit the burden of health care costs on the employer as well as the worker;
- Produce public savings to offset public expenditures for the program (i.e., higher tax revenues and lower expenditures for other programs); and
- Be structured and administered in a manner that is efficient and that discourages wasteful use of health care services.
- Enable individuals to choose from a variety of providers and plans.

One approach would be to create a special health insurance program for “workers with high health care costs” that is subsidized by the government. Employers would make contributions that are approximately “cost neutral” – comparable to premiums paid on behalf of employees who are not eligible for the high-risk system. Workers would also pay modest premiums and be responsible for co-pays and deductibles, but the benefit would be structured in a way that limits the worker’s financial exposure to a reasonable maximum.

#### **The Medicaid Buy-in program**

The Medicaid Buy-in program is, in fact, an example of such a system, but it has been implemented in a manner that falls far short of meeting the above objectives. Not all states have MBI programs, and enrollment is not high in states that do. Although working, most participants are also on SSDI, and many have very low earnings. It appears that a significant number are working a minimal amount just so they will qualify for MBI. Employers only contribute to the programs’ funding indirectly, at best -- if the individual is enrolled in the employer’s health plan and coordination of benefits works as intended (i.e., the employer’s plan is the first payer, operationally). Under that circumstance the employer’s liability can be very high, which creates a large disincentive to employ the worker at a competitive wage. MBI premium structures, co-pays and deductibles vary widely across states, as do many other important aspects of Medicaid coverage...

Changes to authorizing legislation and regulations could potentially move state MBI programs in a direction that would increase the extent to which they meet the objectives listed above, but there are four fundamental problems with MBI as a health plan for this population:

- MBI is an extension of a program that is essentially a “welfare” program, Medicaid – a program designed to meet the needs of individuals and families with

low incomes, not a program designed to meet the extraordinary health care needs of people who, were it not for the high cost of their health care, could support themselves through work, often quite well. MBI enrollees are subject to the same cost-control restrictions that apply to other Medicaid enrollees. Typically they must use doctors and facilities that will accept low Medicaid rates, endure long waits, comply with stringent utilization controls, etc. – in effect limiting access to care. These restrictions, along with the stigma of welfare, probably make MBI unattractive to many workers who might qualify.

- As a federal-state program, MBI is subject to the conflict between the fiscal objectives of state and federal governments – a conflict that frequently results in wasteful efforts to shift costs from state to federal budgets and vice versa. Given any federal legislative or regulatory requirements, states will seek ways to take financial advantage, as they have already done under MBI.
- States have a much weaker budgetary incentive than the federal government to support MBI programs, because the budgetary “savings” that can potentially be generated by increasing the incentive to work, rather than rely on public income support, accrue primarily to a federal program, SSDI.
- Many states administer their Medicaid programs in ways that lead to highly inefficient use of services.

It should also be noted that four states are testing health financing interventions for workers under the CMS Demonstration to Maintain Independence and Employment. The nature of DMIE intervention varies across the four states, including the definition of the target population. All are experimental extensions of the state’s Medicaid program. It remains to be seen whether they will achieve substantial success for their target populations.

#### **A new Medicare plan for workers not receiving SSDI**

An alternative way to implement a health insurance program for workers with high health care costs would be to create a new eligibility pool for Medicare: workers who are determined to have high need for health care over a sufficiently long period. Like SSDI and Medicare for SSDI beneficiaries, this program would be a component of social insurance. Individuals would earn entitlement to this insurance through work. Those eligible would be in a program that is available in all states and that, relative to Medicaid, provides better access to physicians and other providers.

Other program features might include:

- Only those who would meet medical and non-medical eligibility criteria for SSDI apart from earnings limits would be eligible; by definition, those receiving SSDI would not be eligible unless they gave up their income benefits.
- Special coverage for services and equipment critical to support work.
- Eligible workers would be allowed to choose between the new benefit and their employer’s coverage, but would not be able to enroll in both. The employer of an enrollee who chooses the Medicare coverage would be required to pay a Medicare

premium commensurate with the employers' contributions to the health benefits of other workers.

- An option that allows workers to obtain equivalent coverage from the employer's group, with Medicare paying part of the premium. This would create a mechanism under which the worker would have more choices and would not be fully segregated from other workers with respect to health care coverage. Further, the employer's insurer could compete with the new Medicare plan. As part of the insurer's plan offerings, the insurer could offer a coverage "extension" for employees eligible for the new Medicare coverage. Certain requirements would need to be satisfied to insure that the coverage is at least as desirable for eligible workers as the new Medicare coverage. Under this option, an employed worker who becomes eligible for the new Medicare program would be able to continue their employer coverage, but with the extension. The premium structure would need to make selection of this option attractive to workers, employers, Medicare and the private insurer. This option is only likely to be viable if private insurers, in collaboration with employers, can achieve significant efficiencies that cannot be achieved by Medicare.
- Indefinite continuation of coverage during periods of low earnings as long as the individual meets other eligibility criteria and is actively attempting to return-to-work or increase earnings. Administration of this provision would likely be problematic. It would be simpler to offer time-limited continuation, but that would be problematic, too.
- A longer SSDI waiting period for workers who enroll in the new Medicare benefit, with exceptions for those experiencing significant worsening of their medical conditions or impairments. The normal SSDI waiting period is five consecutive months with earnings below SGA. Enrollees in the new Medicare coverage could be required to wait a much longer (e.g., 24 consecutive months). The length of the waiting period could potentially be reduced as the enrollee continues in the program, and could be shorter for older enrollees than for younger ones.
- At SSDI application, the worker would no longer be eligible for the special coverage to support work, but would continue to be enrolled in Medicare. Hence, the Medicare waiting period would be eliminated for this group. The longer SSDI waiting period would prevent workers from enrolling in the new program just to obtain Medicare during the Medicare waiting period.
- Existing SSDI beneficiaries could exit SSDI and obtain the modified benefit

#### **Public subsidies for extensions of employer coverage**

A third approach would be to only implement a program that is described above as an optional feature of the new Medicare program. Employers would offer an enhanced health insurance plan to eligible workers, and the government would make a premium payment on their behalf.

Eligibility criteria for this program could be the same as for the Medicare program described above. The main difference is that two important groups of workers would not be covered: a) those with employers that do not offer coverage to any employees, and b)

those temporarily not employed, but looking for work. Further, even those workers able to enroll in an extended coverage program through their employer would have fewer options available.

**Health care financing under a broader program to support workers with disabilities**

The financing options described above assume no change in the availability of other types of supports to workers with significant disabilities. There is, however, significant interest in the development of “early intervention” programs for workers who experience disability onset. Such a program would have a strong emphasis on keeping such workers in the labor force and off the SSDI rolls. The health insurance options described above might be most attractive if they were implemented as a component of such a program, in part because such a program could offer supports and incentives for work that would not fit well as part of a program that is confined to address health care financing alone.

**Barriers to Work for Individuals  
Receiving Social Security  
Disability Benefits**



**Statement of  
Sue Suter  
Associate Commissioner  
for  
Employment Support Programs**

**Before the  
Senate Finance Committee**

**June 21, 2007**

**Sue Suter  
Associate Commissioner  
for  
Employment Support Programs  
Social Security Administration**

**Testimony before the  
Senate Finance Committee  
June 21, 2007**

**Mr. Chairman and Members of the Committee:**

Thank you for the opportunity to discuss the Social Security Administration's (SSA) efforts to assist beneficiaries with disabilities in addressing the barriers that make it difficult for them to return to work. Providing opportunities for beneficiaries with disabilities to return to work has been part of the disability program since its inception more than 50 years ago. In 1999, Congress expressed its bipartisan support for building on these efforts by passing the *Ticket to Work and Work Incentives Improvement Act of 1999*. This legislation has become an important tool in our ongoing return to work efforts. SSA's programs to reduce employment-related financial disincentives also support The President's New Freedom Initiative, which integrated all federal agencies in a process of including more Americans with disabilities into the workforce, through training, education, and reduction of programmatic barriers. The President and the Administration have put into place an array of supports, of which this program is one

SSA serves a diverse population of individuals with disabilities through the Social Security Disability Insurance (SSDI) and the Supplemental Security Income (SSI) programs. SSDI and SSI beneficiaries represent various age groups and have different impairments, levels of education, work experience, and capacities for working. Assisting beneficiaries with disabilities to return to work has been among one of the most challenging issues facing SSA, and helping individuals with disabilities take advantage of employment opportunities remains one of SSA's highest priorities.

To this end, SSA is working to ensure that all beneficiaries have the opportunity to engage in productive work. Our efforts can generally be placed in two categories— the Ticket to Work Program for those who need help in preparing for employment and Work Incentives for those who are ready for employment and need help transitioning off the disability rolls.

### **The Ticket to Work Program**

First, I would like to briefly outline the Ticket to Work program (Ticket program). The Ticket program is an important part of SSA's comprehensive set of policies designed to assist people with disabilities overcome obstacles to entering the workforce and to return to work. Prior to the Ticket program, State vocational rehabilitation (VR) agencies were generally the only avenues for beneficiaries to receive services.

The Ticket program, established in December 1999, represented an historic milestone in that it was the first time that Congress explicitly recognized that while many people receiving disability benefits from Social Security want to work, and could become able to work, they face a number of significant barriers that prevent them from reaching their employment goals. Congress established the Ticket program to expand the universe of service providers and to provide Social Security beneficiaries with disabilities choice in obtaining the services and supports they need to find, enter, and maintain employment.

Thanks in large part to the leadership of this Committee, Congress acknowledged with the Ticket legislation that individuals with disabilities face a variety of barriers to returning to work and included provisions specifically designed to address these barriers.

The legislation authorized the Commissioner of Social Security to issue a ticket to SSDI beneficiaries and disabled and blind SSI beneficiaries. In this voluntary program, each beneficiary who receives a Ticket to Work has the option of using his or her ticket to obtain services from a provider known as an employment network (EN) or from a State VR agency.

ENs may choose to whom they provide services. When the beneficiary and a provider agree to work together under the program, the provider will supply, without charge to the beneficiary, various employment support services to assist the beneficiary in obtaining or regaining and ultimately maintaining self-supporting employment. When the beneficiary achieves certain work outcomes, we pay the provider.

Final regulations implementing the Ticket program were published on December 28, 2001. The Ticket program was implemented in phases beginning in February 2002 and, as of September 30, 2004, the Ticket rollout was completed in all 50 States and in the U.S. territories. As of June 1, 2007, approximately 10.2 million beneficiaries have Tickets that are available to be assigned to ENs and State VR agencies.

Although fully available since September 2004, the Ticket program is still evolving. We are seeing success as indicated by modest growth in both the amount and number of financial payments to ENs.

While the Ticket program trends have been modest so far, we are committed to continuing improvement through ongoing program analysis and evaluation so that all beneficiaries who are willing and able to participate in the program can do so. We have learned a number of lessons about the Ticket program over the past few years. For instance, we have heard reports from beneficiaries who have experienced difficulty finding an EN who will help them find a job, and others report that they want to work their way off of SSA benefits incrementally, starting with part-time employment and stepping up to full-time when they have increased their confidence.

We have a number of initiatives underway designed to recruit more ENs and to provide beneficiaries with the information they need to either assign their Ticket or pursue other employment options. Through our marketing contractor, Cherry Engineering Support Services, Inc. (CESSI), we are contacting all ENs that have never had a Ticket assignment or who currently are not actively accepting Tickets to explain the benefits of providing employment-related services to beneficiaries and determine their interest in continuing with the Ticket program. We are also responsible for recruiting new ENs and establishing partnerships, while developing successful business models for ENs and community partners. We have implemented an outreach program for ENs and have developed Ticket program marketing and outreach messages geared to beneficiaries and prospective ENs.

We are also providing information to beneficiaries via Work Incentive Seminar (WISE) events, bringing together beneficiaries, ENs and other partners in their local communities. Ten pilot WISE events will be conducted in FY 2007. The first four have already occurred. After the fifth event tomorrow, we will evaluate the results, make any necessary adjustments, and schedule the second five events. We currently plan to roll out WISE events nationally in the fall. Furthermore, building on earlier mail marketing experience, next month we will mail Ticket marketing materials to 500,000 beneficiaries who are most likely to be interested in assigning their Ticket.

#### **Proposed Changes to the Ticket Program**

We recognize that outreach is not enough. Based on our early experience and recommendations received from the Ticket to Work and Work Incentives Advisory Panel and other outside organizations, it became apparent that changes are needed to increase participation by both beneficiaries and ENs and to improve outcomes. Accordingly, on September 30, 2005, SSA published a

notice of proposed rulemaking (NPRM) in the Federal Register. We believe that the kind of proposed changes in the NPRM would significantly enhance beneficiary access to services and choice and improve the likelihood that beneficiaries will return to work.

The changes proposed in the NPRM are intended to improve the program in three areas—EN payment, beneficiary choice, and expanded eligibility. Most notably, the NPRM proposed to increase payment rates to ENs to increase their participation. Next, the NPRM sought to better coordinate services provided by State VR agencies and ENs, allowing State VR agencies to provide initial, intensive rehabilitation services and ENs to follow-up with ongoing support that many individuals need to maintain their work effort. Third, the NPRM proposed to expand eligibility rules to allow more beneficiaries to be eligible for a ticket without first requiring a continuing disability review (CDR) to be conducted. These changes are intended to increase beneficiary access to the employment services and supports they need to return to work and maintain their attachment to the workforce long enough to exit the disability rolls.

#### **Other Work Incentive Improvements Included in the Ticket Legislation**

Congress, led by this Committee, included additional work incentive provisions in the 1999 Ticket legislation. Along with our other work incentives, SSA is actively promoting use of these newer work incentives to assist beneficiaries with disabilities return to work:

- Extending Medicare Hospital (Part A) and Supplementary Medical Insurance (Part B) coverage for an additional 4 ½ years for working SSDI beneficiaries (i.e., from 39 months to 93 months);
- Expediting reinstatement so that qualified beneficiaries may request reinstatement of their benefits within 60 months of benefits having stopped, without having to file a new application; and
- Exempting work activity as the basis for a medical CDR for beneficiaries who have received SSDI benefits for at least 24 months.

#### **New Partnerships Established by Ticket Legislation**

The Ticket legislation also established an infrastructure that encourages participation and collaboration of various types of public and private organizations in assisting beneficiaries return to work despite barriers.

- ENs are under contract with SSA to deliver rehabilitation and employment support services to beneficiaries. These organizations assist beneficiaries formalize their work goals, develop a plan to achieve them, and over time execute the plan to reach a measure of financial self-sufficiency.

- Work Incentive Planning and Assistance (WIPA) grantees are community-based organizations that assist beneficiaries understand the work incentives and how they can affect their benefits. WIPAs are available as a resource to ENs and other agencies that assist beneficiaries with disabilities to return to work such as One-Stop Career Centers, School-to-Work programs, and State VR Agencies.
- Protection and advocacy (P&A) grantees provide information, advice, advocacy, and other services to beneficiaries.
- Area Work Incentive Coordinators and Work Incentive Liaisons throughout the SSA field office structure provide return to work information to beneficiaries with disabilities.

### **Other Work Incentives**

In addition to the Ticket program, there are a number of other incentives in place to encourage disability beneficiaries to return to work. The focus for these incentives is to help people who are able to venture into the workforce. Generally, these incentives provide for continued benefits and medical coverage while working or pursuing an employment goal. For example, in the SSDI program, they include the trial work period and the extended period of eligibility (EPE). In the SSI program, examples of work incentives are special rules for earnings after disability is established and the Plan to Achieve Self-Support (PASS). In addition, special rules about impairment-related work expenses (IRWE), expedited reinstatement (EXR), and medical insurance apply to both SSDI disability beneficiaries and SSI disability beneficiaries.

#### ***Trial Work Period***

In the SSDI program, the trial work period allows beneficiaries to test their work for at least 9 months. During the trial work period, beneficiaries receive their full benefits regardless of how high their earnings might be so long as their work activity has been reported and they continue to have a disabling impairment. The trial work period continues until the beneficiary accumulates 9 months (not necessarily consecutive) in which he or she performed what we call "services" within a rolling 60-consecutive-month period. We currently consider work to be "services" if the beneficiary earns more than \$640 a month, or works more than 80 self-employed hours in a month. The dollar amount is adjusted each year to account for inflation.

#### ***Extended Period of Eligibility (EPE)***

At the end of the trial work period, a 36-consecutive-month EPE begins for SSDI beneficiaries, unless we review the individual's disability and find that the impairment has medically improved and is no longer disabling. (We do not perform these reviews when individuals are using their Ticket to Work.) During

the EPE, full benefits are paid for each month in which the beneficiary's earnings do not exceed the substantial gainful activity (SGA) level, and no benefits are paid for months in which earnings exceed the SGA level. Currently, SGA levels are \$900 a month if a beneficiary is not blind and \$1,500 if a beneficiary is blind. After the EPE ends, benefits terminate if a beneficiary's earnings exceed the SGA level in any month.

### ***SSI Earned Income Exclusions***

The trial work period and EPE provisions do not apply to the SSI program. In the SSI program, a disabled SSI beneficiary's payment is based upon his or her countable earnings. Under SSI rules, SSA excludes the first \$65 of earned income (or \$85 if there is no unearned income). Then we exclude ½ of the remaining earnings, i.e., we exclude \$1 for every \$2 earned after the first \$65. There are a number of other earned income exclusions such as impairment related work expenses, blind work expenses and the student earned income exclusion which can assist a disabled SSI beneficiary.

### ***PASS***

In addition, the SSI program allows a disabled beneficiary to establish a Plan to Achieve Self-Support (PASS). Disability beneficiaries can, with the help of SSA, develop a plan which has the goal of reducing or eliminating their dependence on the SSI program. Under the PASS provisions, an individual can set aside monies for specific goals (such as education, establishing a business, etc.) that will not be counted as income and resources for the SSI means test while the PASS is in effect. The PASS contains an occupational goal that is expected to increase the individual's prospect for self-support and specifies beginning and ending dates. It must also specify target dates for reaching milestones that reflect progress towards achievement of the occupational goal.

### ***Impairment Related Work Expenses (IRWEs)***

Both SSDI and SSI disability beneficiaries can deduct the cost of impairment-related items and services that they need to work from gross earnings when we determine whether an individual is engaging in SGA. We also exclude IRWEs from earned income when we calculate an individual's monthly SSI payment amount. Examples of deductible IRWEs include, the cost of modifying a vehicle needed to travel to work, assistive devices, and regularly prescribed medical treatment or therapy necessary to control a disabling condition.

### ***Expedited Reinstatement (EXR)***

Special rules make it easier for disability beneficiaries who return to work and whose benefits cease due to work activity to receive benefits again if they stop

working. In this situation, the EXR provisions of the law allow beneficiaries to have their benefits started again without having to complete a new application. To be eligible for EXR:

- The individual's SSDI or SSI benefits must have stopped due to earnings from work;
- The individual must not be performing SGA in the month he or she requests reinstatement;
- The individual is unable to work or perform SGA because of his or her medical condition;
- The individual has an impairment that is the same as, or related to, an impairment that allowed him or her to get benefits earlier; and
- The request for reinstatement is made within five years from the month his or her previous entitlement or eligibility was terminated.

### **Medical Benefits**

We have been told repeatedly by experts in the field that continued access to quality healthcare is essential to foster sustained return to work.

In the SSDI program, disability beneficiaries generally become entitled to Medicare in their 25<sup>th</sup> month of entitlement. Provisions in the law provide immediate coverage to disability beneficiaries entitled to benefits based on end stage renal disease and amyotrophic lateral sclerosis. Although cash benefits may cease due to work after the trial work period, most individuals with disabilities who work will continue to receive at least 93 consecutive months of hospital and supplementary medical insurance (Part A and Part B) under Medicare. In addition, after Medicare coverage ends due to work, some individuals who have returned to work may buy continued Medicare coverage, as long as they remain medically disabled. Individuals with low incomes and limited resources may be eligible for State assistance with this cost.

In the SSI program, disabled beneficiaries' Medicaid coverage can continue even if their earnings are too high to allow a SSI payment. Medicaid coverage will continue until an individual's earnings reach an annual "threshold" level. A threshold level is established for each State every year based on several factors including the average per capita Medicaid expenditures in the State, the SSI federal benefit amount, and the State supplementation rate, if applicable. For 2007, the amount ranges from \$22,174 to \$52,407. In addition if an individual's earnings exceed the State threshold, an individualized threshold can be used based on the individual's actual expenses, thus allowing consideration of case-specific Medicaid costs, living arrangements, and attendant care expenses.

### **Work Incentive Information and Coordination**

The Ticket, SSDI, and SSI work incentive provisions can be complex, and the interaction of the provisions and the ways in which they can affect an individual's benefits can be confusing. Field office personnel are trained in providing information to individuals about work incentives, and SSA publishes information on our website and in pamphlets to help individuals understand the provisions. One such piece of information is *A Summary Guide To Employment Support For Individuals With Disabilities Under The Social Security Disability Insurance (SSDI) And Supplemental Security Income (SSI) Programs*, often called the Red Book. We also have developed other methods for getting the information to individuals who need it in a way that meets their needs.

Networks of specialists exist within and outside of SSA to help individuals understand and take advantage of the various incentives and provisions. These specialists provide individuals with vital information to navigate the various work incentive provisions.

Within SSA, Work Incentive Liaisons (WILs) work in SSA's field offices and have received special training on SSA's work incentives. The WILs are the first stop within SSA for a personal discussion of how various incentives can work for a specific individual. In turn, the WILs are supported by a network of Area Work Incentive Coordinators (AWICs). AWICs serve as ombudsman and are the focal point of contact for local area advocates. They assist WILs as needed, coordinate employment support outreach activities, monitor related data, and help develop any needed training to maintain the work incentive expertise for all direct contact employees.

Outside of SSA, the WIPA program provides support to individuals through 104 cooperative agreements awarded across the country. WIPA awardees are community-based organizations such as Centers for Independent Living, Goodwill, State agencies, United Cerebral Palsy, and a host of non-profit organizations. Under the WIPA program, awardees are required to work with SSA's beneficiaries with disabilities directly to help them understand how Federal, State, and local work incentives can assist them in their return to work goals, and how work may affect their benefits.

Since 2002, SSA has worked with the Department of Labor's Employment and Training Administration on a Disability Program Navigator (DPN) position within the One Stop Career Center system. One of the primary purposes of the DPN initiative is to better inform SSA disability beneficiaries and other people with disabilities about the work support programs and provide effective linkages to the business community to increase employment outcomes. DPNs guide One Stop Career Center staff in helping individuals with disabilities navigate the services and benefits systems which impact their ability to gain and retain employment. The DPN's work closely with the AWICS, WILS, and WIPAs.

**Conclusion**

As I mentioned at the beginning of my testimony, SSA is committed to assisting beneficiaries with disabilities who want to return to work. Using all of the foregoing enhancements that Congress has provided, we will continue our efforts to grow the Ticket Program and remove barriers within our programs so that every beneficiary with a disability can realize his or her fullest potential. Thank you again for your support and interest in this matter, and I'd be happy to answer any questions you may have.

**United States Senate Committee on Finance Public Hearing**  
**“Barriers to Work for Individuals Receiving Social Security Disability Benefits”**  
**June 21, 2007**  
**Questions Submitted for the Record From Sue Suter**

*Chairman Baucus:*

**1. What are your most important recommendations for reducing barriers to employment for individuals receiving Social Security disability benefits?**

We are looking at a number of ways for reducing some of the critical barriers to employment for beneficiaries with disabilities to:

- Bring the Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI) disability programs closer together in terms of the availability of work incentives, employment supports, and health care.
- Make the SSA demonstration authority for Title II a permanent part of the program. Without this demonstration authority, we cannot test new ways to improve the programs and reduce the barriers our beneficiaries face.
- Extend Ticket waiver authority to Title XVI demonstration activity.
- Extend the Work Incentives Planning and Assistance (WIPA) and the Protection and Advocacy (P&A) programs and their funding to coincide with the Ticket Program authority.
- Eliminate the cash cliff in the SSDI program.
- Provide for ongoing medical benefits for beneficiaries who seek and/or become employed.

We are always looking for new ways to return disability beneficiaries to work and would be happy to work with Congress to find new solutions.

**2. Do you think that the work incentives for the SSDI and SSI programs should be simplified? What recommendations do you have for changes, and has SSA determined their cost?**

Work incentives should be simplified. The SSDI and SSI work incentive provisions are complex, and the interaction of the provisions and the ways in which they can affect an individual’s benefits can be confusing.

The SSDI and SSI work incentives should be brought closer together wherever possible. A significant step in this direction could be taken if a one for two earned income reduction is applied to SSDI to replace the current substantial gainful activity cash cliff impact. SSA will evaluate this change both in terms of budgetary and policy effects under the Benefit Offset National Demonstration Project.

We would very much like to work with Congress to determine what we can do to simplify the work incentives.

- 3. Beneficiaries seem to be very unfamiliar with SSDI and SSI work incentives and how they can help beneficiaries enter or return to the workforce. What is SSA doing to improve outreach to these beneficiaries? Does SSA have sufficient resources and/or staffing levels to provide the customer service necessary to explain these complex features of the disability programs? What is SSA doing to improve the clarity of information already available?**

SSA publishes information on its website and in public information materials to help individuals understand the work incentive provisions. One such document is “A Summary Guide to Employment Support for Individuals with Disabilities under the Social Security Disability Insurance and Supplemental Security Income Programs,” which is often referred to as the “Red Book.” As part of our outreach for the Ticket Program, we are also providing information about the SSDI and SSI work incentives to SSA’s beneficiaries with disabilities.

The Agency has trained networks of specialists that help people with disabilities understand and take advantage of the work incentives and employment supports. These specialists provide individuals with vital information to navigate the various work incentive provisions. Work Incentive Liaisons (WIL) work in each of our field offices and have received special training on SSA’s work incentives. The WILs are the first stop within SSA for a personal discussion of how various incentives can work for a specific individual. In turn, the WILs are supported by a network of Area Work Incentive Coordinators (AWIC). We have 54 full-time AWICs located primarily in each of our Area Directors’ Offices. AWICs serve as ombudsman and are the focal point of contact for local area advocates. They assist WILs as needed, coordinate employment support outreach activities, monitor related data, and help develop any needed training to maintain the work incentive expertise for all direct contact employees. In addition, Work Incentives Planning and Assistance (WIPA) Projects, which are funded via SSA grants, have Community Work Incentive Coordinators.

WIPA projects provide support to individuals through 104 cooperative agreements awarded to community-based organizations throughout the country and the territories. WIPA awardees are required to work with SSA’s beneficiaries with disabilities directly to help them understand how work incentives can assist them in their return to work goals and how work may affect their benefits. In addition, they assess beneficiaries’ ongoing employment support needs and make referrals on a case-by-case basis to Vocational Rehabilitation (VR) agencies, Protection and Advocacy agencies, Employment Networks (ENs), Department of Labor (DOL) One-Stop Career Centers, and other community-based organizations that provide employment-related services.

We contracted with Cherry Engineering Support Services, Inc. (CESSI) to serve as the Ticket to Work Program Manager for Recruitment and Outreach (PMRO). As the PMRO, CESSI designs, implements, and supports nationwide campaigns to market the Agency's work incentives programs, including the Ticket Program, to beneficiaries and service providers. CESSI also recruits new ENs and energizes existing non-active ENs to provide VR, employment, and other support services to Social Security beneficiaries with disabilities who want to work. In addition, CESSI promotes the creation of partnerships at all levels to support and sustain Agency work incentives programs, as well as assists local beneficiary support and provider organizations in marketing their services.

The WIPA projects, supported by SSA and CESSI, have begun conducting community-based informational events called Work Incentives Seminar (WISE) events that provide beneficiaries with disabilities the information and support they need to make informed choices about working. These events offer beneficiaries the opportunity to meet directly with WIPAs, ENs, employers, SSA field staff and other partners in their local communities. By the end of fiscal year 2007, we will have conducted 10 WISE events. After the pilots are completed, we will evaluate the outcomes. We plan to conduct these seminars nationwide.

We continually review our public information materials for both accuracy and clarity. Our publications on work incentives are normally reviewed annually for this purpose. We are continually looking to develop new material to help clarify existing work incentives.

Adequate funding is paramount if SSA is to fulfill its obligations to the American people, including the critical work that we do to ensure vigilant stewardship of the programs we administer. Our first priority is to eliminate the disability claims and hearings backlogs. Additionally, we are committed to improving SSA's service to the public and our stewardship of the Social Security trust funds and general fund appropriations. In addition to the disability workloads, the Agency's responsibilities include processing retirement and survivor claims, providing program information, maintaining the benefit rolls, and performing program integrity work such as continuing disability reviews (CDR). To accomplish these goals, we need to ensure that sufficient staff is available at SSA and the DDSs; and that the Agency's infrastructure, including efforts to automate more services used by the public, continues to be modern and efficient. We are trying to ensure that we have sufficient resources to provide the necessary services to help our customers to understand our work incentives and how these incentives can help them enter or return to the workforce.

- 4. What is SSA doing about these low participation rates of beneficiaries and ENs in the Ticket program? It has been 18 months since the public comment period closed on the proposed regulation. Why is it taking so long to get the final regulation published? What impact has the regulatory delay had on service provider and beneficiary participation rates?**

**What is SSA doing about these low participation rates of beneficiaries and ENs in the Ticket program?**

Beneficiary participation and participation of ENs are critical to the success of the Program. We are attempting to address the problems of low participation in a variety of ways.

- In the Notice of Proposed Rulemaking (NPRM) published September 30, 2005 (70 Fed. Reg. 57222), the Agency proposed some important changes to the Ticket to Work program regulations that are intended to increase both EN and beneficiary participation. The proposed rules would make changes to the EN payment systems to provide greater financial incentive for EN participation and attract more service providers to the program. These and other proposed enhancements to the program are also expected to expand beneficiary access to services and lead to greater beneficiary participation.
- On August 13, 2007, the Agency published a second set of proposed rules (72 Fed. Reg. 45191) to make other improvements to the Ticket to Work program that are intended to attract more service providers and beneficiaries to the program. This second NPRM would amend the rules which provide a participating beneficiary protection from initiation of a medical CDR if he or she is making timely progress toward self-supporting employment. The proposed rules would revise the work requirements used to measure timely progress; add alternative requirements for educational or technical training to allow beneficiaries who require additional training to return to work to qualify for CDR protection; and simplify and streamline the progress reviews to reduce the reporting burden for ENs and State VR agencies. The proposed rules also would expand the pool of available service providers by making it easier for one-stop delivery systems established under the U.S. DOL's Workforce Investment Act program to participate as ENs.
- We hired a marketing and outreach contractor, CESSI, who is charged with concentrating their efforts on recruitment of additional ENs.
- We have begun forging relationships with employers that may potentially become Ticket Program ENs, an example of which is Walgreens. Their Distribution Center in Anderson, South Carolina is under contract as an EN, and we plan to use their successes to interest other potential employer ENs.
- We have made systems, organizational, and process changes to improve the efficiency of the EN payment process.
- We have implemented an EN Help Desk, which provides a direct email or FAX link enabling ENs to follow up on overdue payment requests or to obtain answers to payment questions.
- We have simplified the EN Request for Proposal (RFP) document allowing for an easier proposal submission process. The new RFP may be accessed directly from SSA's website.
- We are developing successful business models for ENs and community partners.

- We are working with the U.S. DOL and representatives of their One Stop Workforce Centers that participate as ENs to discuss their experiences and challenges. We are using this information to refine our policy/processes to make participation as an EN more attractive to One Stop Centers.
- We are reaching out to beneficiaries with targeted recruitment mailings and community events like the WISE events being piloted in communities around the country. These events will bring beneficiaries together with the employment resource organizations available to them in their communities under the Ticket to Work Program.

**It has been 18 months since the public comment period closed on the proposed regulation. Why is it taking so long to get the final regulation published?**

After the September 2005 NPRM was published and the period for public comment ended, we prepared final regulations. However, we determined that we first needed to publish another NPRM for public comment that covers changes to the “timely progress” rules. The “timely progress” rules would change the definition of using a ticket for purposes of retaining exemption from a medical CDR while participating in the Ticket to Work Program.

We received over 100 responses to the NPRM published in September 2005 and carefully considered them. The NPRM also requested public comment on some issues concerning the Ticket to Work program, such as whether and how we might simplify the timely progress requirements for CDR protection. Because these issues were not within the scope of the NPRM, we had to address them in a separate NPRM.

On August 13, 2007, we published a second NPRM proposing changes to the timely progress rules. Because changes in the areas covered by the second NPRM are integral to the overall improvements proposed for the Ticket program, we decided to finalize all changes at one time. After the 60-day comment period ends on October 12, 2007, we will review the comments and then prepare one comprehensive final regulation covering the matters addressed in both NPRM. We expect to publish a final rule next year and implement it shortly thereafter.

**What impact has the regulatory delay had on service provider and beneficiary participation rates?**

Under our current rules, we continue to see very modest increases in the number of ENs accepting tickets, the number of beneficiaries going to work under the Ticket program, and the number of ENs receiving outcome or milestone payments. However, when the new rules are implemented, we expect much higher rates of provider and beneficiary participation.

We carefully weighed the option of finalizing and publishing changes for those provisions subjected to public comment in the September 2005 NPRM in advance of requesting and considering public comments on the timely progress provisions.

However, the earlier changes cannot easily be separated from changes to the “timely progress” rules. This interdependency of all of the changes, which taken together, are intended to strengthen the Ticket Program as a whole. This, along with our desire to minimize confusion for program participants and administrative burden especially for ENs, led to the decision to issue one comprehensive final Ticket rule covering and implementing all changes at the same time.

- 5. Do you agree that SSDI and SSI beneficiary fears of overpayments are valid, considering SSA’s current staffing shortages? What recommendations do you have to address these fears? What do you recommend to address the difficulty of avoiding overpayments, if the SSDI or SSI beneficiary works? Are there plans to improve a beneficiary’s ability to report earnings and have those reports entered into the system in a timely fashion? Has an automated system been considered?**

Overpayments are obviously a concern for beneficiaries with disabilities. Congress helped alleviate some of these concerns in the Social Security Protection Act of 2004, which requires that SSA provide a work report receipt.

SSA takes the issue of overpayments very seriously, and we have vigorously pursued eliminating this work disincentive. We have dedicated a significant portion of our systems resources to create a platform to improve the income reporting process.

To assist in preventing or reducing overpayments, we have developed eWork, a system that assists our staff in issuing receipts, and then controlling and adjudicating the resulting disability work reviews. eWork automates the generation of a work receipt when a report of work activity is received. Its database provides a centralized location for storing work reports and processing work-related CDRs.

We have developed an SSI Monthly Wage Verification (SSIMWV) program to handle wage reporting for SSI beneficiaries. A prototype of this application was made available in 10 percent of field offices nationwide in April 2005. In November 2006, an enhanced, web-based version was implemented in all field offices nationwide.

The SSIMWV software creates an electronic database of pay stub reports. The program issues a receipt showing what was reported and the date of the report. The receipts are archived on SSA’s On-line Retrieval System, providing an audit trail.

Another project to address concerns about overpayments in the SSI program is the monthly wage reporting system. In 2003, SSA began the first of two pilots to test a telephone-based automated monthly wage reporting system for SSI beneficiaries. The first pilot used a PIN/password system; the second involves knowledge-based authentication. An evaluation of the pilots revealed an accuracy rate of over 92 percent for monthly reporters. This correlated with \$200 per reporter in annual overpayment prevention. Based on the overall success of the two pilots, SSA is

seeking permanent authorization for this reporting system from the Office of Management and Budget.

**6. Would eliminating the current waiting period for SSDI beneficiaries to receive Medicare benefits help beneficiaries? What do you recommend we do about those applicants without health care waiting for a decision regarding SSA disability benefits?**

Medicare entitlement begins after an individual has been entitled to disability benefits for 24 months. One exception is that the 24 month waiting period is waived for beneficiaries with a diagnosis of Amyotrophic Lateral Sclerosis.

We will be looking at the Medicare waiting period issue via our Accelerated Benefits Demonstration Project. Beneficiaries selected for the demonstration project will be provided health benefits and employment supports. The target population will be newly entitled SSDI beneficiaries who have no health insurance. Providing this treatment should result in improving their medical condition and thereby increasing the likelihood that they will be able to return to work and improve their self-sufficiency.

**7. What can be done to improve the opportunities for health care coverage for former SSDI and SSI beneficiaries?**

Most SSDI beneficiaries who work will continue to receive at least 93 consecutive months of hospital and supplementary medical insurance under Medicare, after the 9 month trial work period. Regardless of cash benefit status, they do not pay a premium for hospital insurance. Although cash benefits may cease due to work, they have the assurance of continued health insurance as long as they remain medically disabled.

After the above premium-free Medicare coverage ends, individuals who have returned to work may be able to buy continued Medicare coverage, as long as they remain medically disabled. Individuals with low incomes and limited resources may be eligible for State assistance in paying the premiums. Premium Hospital Insurance (Part A) and Premium Supplemental Medical Insurance (Part B) are available at the same monthly cost that uninsured eligible retired beneficiaries pay.

SSI beneficiaries can continue to receive Medicaid coverage, even if their earnings alone or in combination with other income become too high for SSI cash benefits. To continue receiving Medicaid coverage, beneficiaries must still be disabled and must need Medicaid in order to work. Their gross earned income must not be sufficient to replace their SSI cash benefit and Medicaid coverage. This threshold amount varies by State, taking into consideration the amount of earnings that would cause beneficiaries to have their SSI cash payments to stop in the State and the annual per capita Medicaid expenditure in the State. The threshold amount for an individual can

also consider various factors, such as impairment related work expenses or publicly funded attendant care.

- 8. The success of the new Work Incentive Planning Assistance (WIPA) program seems critical to the success of all of SSA's return to work activities. What has SSA learned from the Benefits Planning Assistance and Outreach (BPAO) program regarding its budget and potential staff turnover? Has SSA evaluated the volume of services these contractors will need to provide, and is the budget for these services adequate?**

The WIPA program (formerly the Benefits Planning Assistance and Outreach program) provides substantial outreach and public information about the Ticket program, as well as facilitating beneficiary linkages to ENs and other community organizations that can help them succeed in their return to work efforts. In addition to these services, through September 2006 the BPAO program had provided benefits planning services to over a quarter million beneficiaries with disabilities and in-depth benefits analysis and employment plans to over 100,000 of those beneficiaries who intended to seek employment.

In 2002, SSA conducted a customer satisfaction survey to elicit opinions of the information and services provided by BPAO grantees. Overall, the survey found that participants had a very positive view of the program, with almost 90 percent of beneficiaries providing a rating of excellent, very good, or good. The survey also addressed participant work activity before and after counseling, and the percentage of beneficiaries who reported that they were working subsequent to their contact with the BPAO increased by 19 percent.

The WIPA program is funded from SSA's administrative budget and has been capped by legislation at \$23 million per year since the beginning of the program. Increased funding for WIPA services would allow us to expand as the demand for those services increases without negatively impacting the other services that we are able to provide our beneficiaries. We anticipate this demand to become even greater with the expansion of the Ticket program that is expected upon publication of the new Ticket regulations. Already, we have heard from some WIPA projects that it is difficult for them to recruit staff and that they experience high staff turnover because of funding uncertainty and limitations.

- 9. What other outreach is SSA planning in regards to the work incentives and the Ticket to Work program? How does this level of outreach compare to outreach activities conducted 5-10 years ago?**

The primary focus of work incentives and Ticket Program outreach will be community-based outreach events called WISE events. These are informational seminars that provide beneficiaries with the knowledge necessary to either assign their Ticket or pursue other employment options within their community. The goal of the WISE is to increase the beneficiary's understanding of work incentives and how

they impact the Ticket to Work Program, and to provide beneficiaries access to ENs for needed support.

The WIPA projects, with support from SSA and CESSI, the PMRO, will educate beneficiaries about work incentives and the Ticket to Work Program. They will also introduce the beneficiaries to their "Employment Team," consisting of the WIPAs, ENs, State VR agencies, AWICs, and other public and private community-based organizations.

Other current outreach activities include:

- Development of EN and beneficiary messaging that has been incorporated into draft handouts, brochures, and banners on the Ticket Program and the work incentives.
- Sponsor a 2-day summit in spring 2008, which will bring many of our partners together to collaborate on Ticket Program and return to work issues. This event will bring together the various partners involved in the Ticket Program, such as the WIPAs, the P&A agencies, ENs, AWICs, and others crucial to the success of the Ticket Program.
- Redesign of the SSA Work Site Internet website to make it more user-friendly for its various audiences. The redesigned website will improve our marketing strategy for the Ticket to Work program and enable us to share information with beneficiaries with disabilities, service providers, ENs, SSA staff, advocates, and others.

The first ticket was issued under the Ticket to Work Program in February 2002, just over 5 years ago. At that time, our primary focus for outreach under the Ticket Program was on providing basic information to all eligible beneficiaries on the SSDI and SSI rolls. To accomplish this initial outreach, we sent a packet that included the Ticket document, a message from the Commissioner, and a booklet about the Ticket program to more than 9 million beneficiaries over a 2 1/2 year rollout period. Interested beneficiaries were instructed to contact MAXIMUS, the Program Manager, if they had additional questions about the program or needed help in locating an EN to serve them. Some ENs also did outreach in their communities to beneficiaries potentially interested in their services. Our outreach efforts at that time were not targeted to specific groups, because we did not yet have experience with the program on which to develop targeted outreach efforts.

- 10. Over 10 million beneficiaries have received a ticket, but only 163,000 have deposited that ticket with a service provider. In your testimony, you indicate that the plan to market the Ticket program to beneficiaries is to target 500,000 beneficiaries. Why do 10 million beneficiaries have tickets if you believe only 500,000 are likely to use them?**

In July 2005, SSA conducted a targeted mailing project to develop a profile of beneficiaries with disabilities who would be good candidates for the Ticket Program.

SSA also reviewed the Mathematica Policy Research study results that looked for beneficiary characteristics which correlate with Ticket assignment and return to work.

Based on the analysis, we now have a basic profile for future targeted marketing efforts. Since SSA wants to gather additional information to complete the profile, we plan to implement the next phase of the project in the coming months.

This new mailer will target 500,000 Ticket eligible SSDI and SSI disability beneficiaries. Based on the results of the first mailing, SSA is targeting those beneficiaries who meet the following criteria:

- Receive cash benefits,
- Are entitled/eligible for benefits 15 years or less,
- Have earnings at or above the trial work level within the last 24 months, and
- Have not assigned their Ticket.

We have selected 10 targeted mailing sites, which will include one metropolitan area in each SSA region.

The reason why 10 million beneficiaries have tickets is explained below in the response to number 11.

**11. Did the original distribution of tickets target beneficiaries appropriately? What types of beneficiaries are included in that 10 million, who might not be likely to attempt work?**

SSA mails Tickets to all beneficiaries who meet the eligibility requirements. We cannot predict with certainty who will respond to the opportunity to use their Ticket. We give everyone who is eligible the opportunity to participate. However, we recognize that many individuals will not be interested in learning more about the Ticket Program. Many people believe they are medically incapable of participating in the Program.

Since the completion of the Ticket rollout in September 2004, Tickets are issued to disability beneficiaries who are newly awarded or to medical-improvement expected beneficiaries whose benefits have been continued after a medical disability review. The results to date indicate that only a percentage of the overall number of Ticket holders will choose to participate in the Ticket to Work Program. Nevertheless, we believe Congress intended to empower beneficiaries to determine whether or not they are willing and able to take advantage of the new opportunities the Program provides. In providing Tickets to so many beneficiaries, we are giving them the opportunity to obtain VR, employment or other support services from an approved provider of their choice to help them go to work and achieve their employment goals. Rather than concentrate on who might not be likely to attempt to return to work, we are focusing on better targeting of beneficiaries with disabilities who are good candidates for the Ticket Program.

COMMUNICATIONS

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July 3, 2007

The Honorable Max Baucus  
Chairman, Finance Committee  
United States Senate  
219 Dirksen Senate Office Building  
Washington, DC 20510-6200

**RE: Testimony on Barriers to Work for  
Individuals Receiving Social Security Disability Benefits**

Dear Chairman Baucus, Senator Grassley, and Members of the Committee:

As a person with a disability, currently receiving Social Security Disability Insurance (SSDI) benefits, and a tax payer who has worked for nearly three decades in the field of disability employment, I am writing to express my extreme concern about the millions of dollars we continue to spend on the yet-to-be-fully-implemented **Ticket to Work and Work Incentives Improvement Act of 1999 (TWWIIA) (P.L.106-170)**. While there are many parts of the program that are working, including the Medicaid Buy-in Program, the Medicaid Infrastructure Grant (MIG) program, and the Work Incentives Planning Assistance (WIPA) projects, the most important part of the Act -- the Ticket to Work program -- has failed. I urge you to immediately suspend ALL contracts dealing with marketing, outreach, training, and evaluation until the new regulations are in place and SSA adequately funds the program.

According to the spring 2007 Maximus Newsletter, only 2,819 beneficiaries found employment through the program from the start of Fiscal Year 2002 to the end of Fiscal Year 2003. I was glad to see Sen. Jim Bunning a long-time champion of TWWIIA, sought answers to these and other questions about the Ticket's failure.

I was not satisfied with the responses given by SSA and encourage the Committee to investigate how the millions of dollars are being spent by SSA and its contractors if not to transition people off of benefits and into the work force. SSA has spent more money flying staff, contractors, and subcontractors around the country to "market" and "evaluate" a program that does not exist.

Granted, I share everyone's desire to enable the nearly 10 million SSDI beneficiaries and prospective employers to learn about the Program, and I completely support program evaluation. However, the program has not been fully implemented. Neither employers nor beneficiaries who want to enter or reenter the work force have anything to gain from an unimplemented, half-baked program

Since the signing of this legislation in December, 1999, millions of tax payer dollars have been spent for such a small return – subcontractors like Maximus and CESSI are making a killing and do only enough "work" to win contracts for yet another year. The Ticket to Work Program has not produced what people with disabilities, advocates, and Congress intended and hoped for in part because key parts of the program have been inadequately funded. Employment Networks (EN) receive no up front funding for start-up costs. Thus, mostly larger Service Providers have become ENs, because they have enough funds to cover the costs until SSA pays them. More often than not, these service providers are the same ones that state vocational rehabilitation (VR) agencies funded for the last twenty-five years. These VR providers have done an extremely poor job in assisting individuals with disabilities in securing position that meet our education and experience level. Why on Earth would SSA fund VR to implement a new and innovative program? Because VR continues to receive cost-of-living-adjustments and other funding increases despite its record of low expectations and for people with disabilities and little-to-no proven experience transitioning people off the rolls into the work force.

We are doing a grave disservice to prospective ENs by getting them all excited and geared up to begin working with beneficiaries who want to go back to work. They soon learn that under the current regulations

1. ENs can only receive payment from SSA if the beneficiary is making above the SGA level,
2. Beneficiaries have to work full-time, and,
3. Payment to an EN is extremely slow and does not in most instances cover the cost of placement.

I am also concerned about the definition of "meaningful jobs." For a person with a disability who has a college and/or advanced degree, becoming a greeter at Wal-Mart or stocking shelves at CVS is not a career track position and does not hold the same appeal as a white collar position. The very same VR providers who are now serving as ENs commonly made these types of placements which continue

to be occurring under the Ticket to-Work legislation by many of the VR providers who now serve as ENs.

I totally agree with the written comments submitted by the National Council on Independent Living (NCIL) on the day of your hearing. I totally agree with NCIL's comments which

SSA currently has contracts that are still in progress to market the "new regulations," but because they are not finalized we have seen any new marketing materials since the beginning TTWWIIA. I ask this committee to ask for copies of these marketing materials to see what exactly is being marketed.

Thank you for the opportunity to comment on a program once gave me and millions of other SSDI beneficiaries with disabilities hope to find "meaningful work." It is a shame that unimplemented and inappropriately funded, the Ticket Program is a failure and a tragic waste of millions of dollars.

Please do not hesitate to contact me if I can provide you with additional information. I can be reached at (703) 845-0778 or [margiegame@aol.com](mailto:margiegame@aol.com).

Sincerely,



Marcie B. Goldstein, MA

CC: The Honorable Henry Waxman

Statement of Barbara Morgan RN, MSN  
Outreach Coordinator  
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111 School St.  
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Bristol, New Hampshire 03222

Submitted to the Senate Committee on Finance

Hearing on

“Barriers to Work for Individuals Receiving Social Security  
Disability Benefits”

June 21, 2007

As Outreach Coordinator for Holy Trinity Parish, I respectfully submit the following statement on behalf of the Parish. We appreciate the opportunity.

As a nurse Educator I have worked educating registered nurses, some 3000 over 25 years. Largely the population is mildly to severely disabled. Since my area is Mental Health Nursing I have stressed communication – including the need for listening, tolerating silence and validating data. Having said this, I feel the need for increased sensitivity to all clients, especially the disabled among us, as they seem to be invisible.

On viewing the testimony according to the Senate Finance Committee Website, I was impressed by the morass of red tape facing would be recipients.

For example Jim Brown said, “Policies must be upgraded so we can truly live with hope and dignity, enjoying the right to pursuit happiness.... Help change the policies so we also get access to that last inalienable right.” The benefits mentioned in his addendum are valuable.

I found testimony of Senator Chuck Grassley informative and educational, however what the disability program’s purport to do and in what the disabled clients receive, there seems to be a divide. The worthwhile networks exist, but due to poor communication and collaboration with one another, the benefits and intended results fail to reach the needs of the disabled persons – most especially those longing to work.

Continuing, I noted with interest that Senator Baucus, and his staff succinctly identified the therapeutic need for work and also that the government makes it hard for people to work. If in 2004 only 6 of 1000 SSDI beneficiaries left the program to work, what are the hurdles?? Fear, health and lack of rehabilitation services loom large. So recognizing the value of work and making it easier for all disabled persons to do so – is an identified need and must be met.

On my work as outreach coordinator for the Holy Trinity Parish and in concert with the Newfound Area Churches, I see enormous needs among our target population in Central New Hampshire (You might add distance and travel as major barriers to securing benefits.)

Needs of our families with disabled persons are everywhere if one has eyes to see. Once a need is identified, we work as members of the community to meet it. The Newfound Area Primary Care Team Community group seeks resources and this for the last eight years. (A similar time frame for the Ticket to Work Act) we in rural New Hampshire, realized funds were short on the federal, state, and local levels. Therefore, we have met knowing no one agency could meet the complex needs of our disabled clients. This involved:

- Developing a sense of trust among agencies
- Communicating with one another
- Collaborating with one another
- Relinquishing turf – formally held
- And supplying pizza! (this makes for a friendly eating meeting.)

Currently I am working with a disabled woman (bi-polar) and formerly dependant on drugs and alcohol. She lost a six year old child and had a ten year old child put in placement. She was physically injured, no mobility, no transportation and no income. The welfare officer is supplying rent for two months. She needs a pro-bono lawyer and finds it difficult to get food stamps. It will probably be 12 months before she is approved for SSI and then another 24 months before she will qualify for Medicare benefits. Her short term memory's impaired and has issues focusing her thoughts. These are big – enormous challenges for one who is grieving as well. There are no easy answers but red tape unduly delays relief.

Thank-you for considering the needs of one small rural community, I might suggest that our continuing efforts to meet the many needs that surface, might be a model in securing timely aid on a larger scale as well. Neighbors do help neighbors and people do help people. I would like to believe we are our “brother's keeper”.

We have been watching with great interest the development of the new beneficiary organization “Voices for Work” that came out of the Atlanta, Georgia - Ticket to Work and Work Incentives Advisory Panel Summit last February. The energy, enthusiasm and dedication this group has, can literally change the world for people with disabilities. The recommendations that the delegates submitted for the Summit Report will help make the Ticket to Work function and give the opportunity for these underestimated individuals to contribute to their communities and live fulfilling lives. There suffering has gone on long enough. Holy Trinity Parish is looking forward to collaborating with our state “Voices for Work” delegate, Monica Nagle Newton to widen the scope of our assistance to all our disabled persons and families.

**Testimony Presented to the Senate Committee on Finance Hearing,  
“Barriers to Work for Individuals Receiving Social Security Disability Benefits”**

John R. Vaughn  
Chairperson, National Council on Disability  
June 21, 2007

The National Council on Disability (NCD) is an independent federal agency making recommendations to the President and Congress to enhance the quality of life for all Americans with disabilities and their families. NCD is composed of 15 members appointed by the President and confirmed by the U.S. Senate. In light of the Senate Committee on Finance’s June 21, 2007, hearing, “Barriers to Work for Individuals Receiving Social Security Disability Benefits,” I would like to bring the following information and recommendations from NCD’s report, *The Social Security Administration’s Efforts to Promote Employment for People with Disabilities* (<http://www.ncd.gov/newsroom/publications/2005/ssa-promoteemployment.htm>), to the Committee’s attention.

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

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

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

For additional information and recommendations, please see the Executive Summary from NCD's *Social Security* report, included below. Again, the full report is available at: <http://www.ncd.gov/newsroom/publications/2005/ssa-promoteemployment.htm>. NCD is available to provide you with advice and assistance pertaining to issues of importance to people with disabilities and welcomes any inquiries. Please contact NCD's Congressional Liaison, Mark Seifarth, at [mseifarth@ncd.gov](mailto:mseifarth@ncd.gov), or reach NCD by telephone at (202) 272-2004 (v), (202) 272-2074 (tty). Thank you to the Committee for taking time to examine this important issue.

### **Executive Summary**

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

### **Introduction to the Problem**

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

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

The fear of losing benefits and medical insurance through an unsuccessful employment attempt starts well before adulthood with SSI beneficiaries. Many SSI recipients first apply for benefits as children while enrolled in public schools. These individuals often remain on the rolls well into adulthood, with very few transitioning from high school into

substantial employment after graduation (GAO, 1996b; GAO, 1998b). Failure to focus on Social Security and other public benefits during transition is not only a missed opportunity, but harm may be caused when students and family members are not educated or prepared for the effect of earnings on cash benefits and medical insurance (Miller and O'Mara, 2003).

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

#### Response of Congress and the Social Security Administration to the Problem

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

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

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

programs; and new work incentives, including expedited reinstatement (EXR) of benefits and postponement of continuing disability reviews.

### **The National Council on Disability's Study of the Problem**

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

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

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

### **Major Findings of the Study**

#### **Purpose and Mission of SSA's Disability Benefit Programs**

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

condition. The length of the application process in our current programs actually contributes to the ineffectiveness of our return-to-work efforts and our inability to intervene early in the disability process.

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

### **Beneficiary Perspective and Self-Direction**

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

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

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

### **Income Issues and Incentives**

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

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

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

#### **Coordination and Collaboration Among Systems**

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

The complex obstacles to employment faced by SSA beneficiaries require a comprehensive set of solutions. New approaches must be identified that emphasize beneficiary control of career planning and the ability to access self-selected services and supports. Public and private health care providers must develop new collaborations and new approaches to combining coverage from multiple sources to improve program efficiencies. SSA must continue to work with the Rehabilitation Services Administration (RSA) and the Department of Labor (DOL) to improve implementation of the TTW program and identify new approaches that will overcome the traditional inability of SSA beneficiaries to benefit from services provided by the nation's employment and training

programs. Secondary and postsecondary educational institutions must emphasize benefits counseling and financial management training as the foundation for beneficiary self-direction and economic self-sufficiency. Federal agencies and the business community must realize that collaborative approaches to incorporating beneficiaries into the workforce are needed as a way to reduce dependence on federal benefits while simultaneously enhancing the productivity and competitiveness of large and small business.

### **Recommendations**

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

#### **Beneficiary Perspective and Self-Direction**

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

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

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

**Reduce SSA Overpayments to Beneficiaries** - Congress and SSA should implement a series of procedural reforms to reduce overpayment to beneficiaries by increasing the use

of electronic quarterly earnings data and automated improvements to expedite the processing of work activity and earnings; piloting the creation of centralized work CDR processing in cadres similar to PASS and Special Disability Workload Cadres; and enhancing efforts to educate beneficiaries on reporting requirements, the impact of wages on benefits, and available work incentives.

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

#### **Income Issues and Incentives**

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

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

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

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

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

mechanisms, and ensure that an EN is able to accept Ticket assignment from a beneficiary, refer that individual to the VR agency for needed services, and not be required to reimburse the VR agency for those services.

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

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

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



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**John Lancaster**  
 Executive Director

June 21, 2007

The Honorable Max Baucus  
 The Honorable Chuck Grassley  
 Committee on Finance  
 U.S. Senate  
 219 Dirksen Senate Office Building  
 Washington, DC 20510-6200

Re: **Barriers to Work for Individuals Receiving Social Security Disability Benefits**  
 Committee on Finance Hearing, June 21, 2007

Dear Senators Baucus, Grassley and Committee Members:

We present written testimony on behalf of the National Council on Independent Living. We thank you for holding this important Hearing. We outline our grave concerns about the delayed and uneven implementation of the Ticket to Work and Work Incentives Improvement Act of 1999 (the Ticket Act) and present new frameworks for solutions. The correlation between poverty and disability in the U.S. is unacceptable from both a moral and economic standpoint. The time has come to reassess employment and disability and poverty in the U.S. and better serve the needs of Americans with disabilities.

Ten years ago, after considerable input from key stakeholder groups, including NCIL, the National Council on Disability provided Congress with its seminal Report on Social Security and employment, entitled: "Removing Barriers to Work: Action Proposal for the 105<sup>th</sup> Congress and Beyond." These recommendations, along with those from the National Academy on Social Insurance, NCIL, the Return to Work Group, and others, motivated hundreds of people nationwide to spend the next two years focused on health care, benefits and employment reform. They worked with the bipartisan Congress members who crafted the Ticket Act, the hopeful follow-up to the Americans with Disabilities Act promise with respect to health care, benefits and their connections to employment outcomes.

The National Council on Disability Report found that:

*"Social Security programs can be transformed from a lifelong entitlement into an investment in employment potential for thousands of individuals."*

Senator Grassley and Senator Bunning, you in particular with other bipartisan leaders put forth great effort over two years to move the Ticket Act through the Congress. NCIL urges Committee members to reevaluate employment, disability, and poverty by supporting oversight hearings that question Ticket Act implementation procedures to date.

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NCIL believes that Social Security, the Centers for Medicare and Medicaid Services, the Congress, and the Bush Administration have lost their focus and their drive to implement the Ticket Act, policy work that many consider the first phase of transformational reform.

NCIL is the oldest cross-disability, national grassroots organization run by and for people with disabilities. Our membership includes centers for independent living, state independent living councils, people with disabilities and other disability rights organizations. As a membership organization, NCIL advances independent living and the rights of people with disabilities through consumer-driven advocacy. NCIL envisions a world in which people with disabilities are valued equally and participate fully.

NCIL is proud to have been one of the leading organizations helping to shape the Ticket Act of 1999. We remain committed to ensuring the full and proactive implementation of this landmark legislation in a manner that empowers individuals with disabilities to get the information they need and leverage available incentives so that they can realize their full potential and find desirable jobs consistent with their goals. This commitment is reflected in recent discussions at NCIL's Board meeting in Boston 2006 that drilled down and focused on the current lack of predictability in incentives and employment supports for persons with disabilities, and new policy proposals and frameworks to remedy these untenable situations. NCIL's commitment is reflected by the more than 55 centers for independent living (CIL) that initially served as Social Security Benefits Planning, Advocacy and Outreach (BPAO) grantees, in the historic first round of these federal grants to explain federal rules so people can use them without penalty. Currently 37 CILs serve as Work Incentives Planning and Assistance (WIPA) Project grantees, the successor program to BPAO. The recent lack of predictability in incentives and employment supports for job seekers with disabilities and the uneven implementation of the newer WIPA grants has dissuaded CILs and other interested parties from participating.

**Baseline Principle and Goal**

Earnings Replacement and Employment Support Insurance Enhance Employment Outcomes  
*NCIL believes strongly that receipt of cash benefits and health coverage when work is not an option are not competing priorities with the employment supports needed for beneficiaries and people with disabilities when we are ready to work, at any point in our lives. These are equally important supports that must not be pitted against each other, as we hear often from some Social Security senior management, and some advocates, largely due to stated, chronic funding constraints from Congress.*

NCIL calls for Employment Support Insurance along with Earnings Replacement Insurance. These are new frameworks to improve the performance of the current Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI) programs and their connections to employment supports and outcomes. A Summary of NCIL's employment framework is available at [www.ncil.org](http://www.ncil.org) under the Employment and Social Security section. The NCIL framework runs parallel to and in some ways complements:

- Similar national proposals being discussed under the commonly used term "two-plan model," including a report last fall on employment from the Social Security Advisory Board ([www.ssab.gov](http://www.ssab.gov));<sup>i</sup>
- Informal reports from the Social Security Beneficiary Summit in February of this year that describe a recommendation from Social Security beneficiaries for a similar Work Supports Program. We look forward to reading the Beneficiary Summit Report to be public this coming July; and,
- Social Security's Ticket to Work and Work Incentives Advisory Panel current goal to develop a national employment investment strategy to transform approaches to assets, income, health care, and supports for people with disabilities.

It is right, proper, legal and necessary that the Ticket to Work program not rob Social Security Trust Funds of resources mandated by Congress to pay benefits when people cannot work. Congress frontloaded the funding for Welfare to Work reform legislation in 1996. It is long past due that Congress fund employment services, health coverage and personal assistance services *in ways that serve as the employment supports they are* for so many thousands of American beneficiaries with a disability.

Your hearing is timely, given the increasing number of SSI recipients, and the lower rate of SSI recipients with earnings. In 2000 there were 5.4 million SSI recipients; 360,427 of them had earnings from paid work. In 2006, there were over 600,000 added new SSI recipients; 349,420 of them had earnings from work.<sup>ii</sup> More SSI recipients and less of them with earnings eight years after enactment of the Ticket Act. We do not have a lot of time left to get this right. Current demographics and the aging of the workforce require your immediate attention and leadership on the issues of this Hearing. Getting this right will take the Congress and all of us working with you.

NCIL calls on Congress, as we did in a letter last fall to the U.S. House of Representatives Committee on Ways and Means, Subcommittee on Social Security, to mobilize a renewed focus and initiative on employment in the face of what is now an arrested Social Security Ticket to Work program.

NCIL presents four key recommendations for your Committee's review:

**Recommendation One**

Immediate Suspension of All Social Security Funded Evaluations of the Ticket to Work Program until Full Program Implementation

NCIL recommends that all formal evaluation proceedings prescribed and focused on the Ticket to Work Program, funded and commissioned by Social Security, be suspended immediately, and until such time as a national Ticket to Work Program is implemented and operationally in place, with diverse choice in providers in 50 states and the territories. Congress should exercise its oversight authority with the Bush Administration and the Social Security Administration to suspend these wasteful exercises using millions of tax payer dollars to evaluate a program that is not up and running as prescribed in the law.

Since early 2004 the Commissioner of Social Security, the Committee on Ways and Means of the House of Representatives and the Committee on Finance of the Senate have received ample reports and letters that the Ticket to Work Program is in crisis, is not working and is not attracting Employment Networks to the program in enough numbers and diversity to effectively evaluate the program.<sup>iii</sup>

The 1999 Ticket Act authorizes an evaluation of the Ticket to Work Program as it is implemented nationally. The legislative text clearly intends the evaluation for a program *being used*, and populated by enough service providers to warrant the detailed methodology criteria in the Ticket Act.<sup>iv</sup> It is cruel charade to pretend there is enough of a Ticket to Work Program to warrant the millions of dollars being spent evaluating it. It is not the case and everyone knows it. Your action on this one recommendation will signal to a wide community that a major national problem persists and that you plan to address it.

### **Recommendation Two**

#### **Funding and Statutory Reform for the Ticket Program and Employment Support Services**

Many would agree that Congress did not intend Ticket Act implementation to become just an internal Social Security project.<sup>v</sup> NCIL recommends that the Committee on Finance exercise its oversight responsibilities, convene added hearings, and initiate legislative amendments to Public Law 106-170 (the Ticket Act) to meet following minimum objectives:

1. Appropriate immediate, upfront funding to 1) re-launch the Ticket to Work program as a social insurance benefit in Social Security, or other appropriate social insurance financed venue;<sup>vi</sup> 2) fund related marketing needs for the program and other work incentives in and outside of Social Security; and, 3) increase and diversify the funding and the information services menu<sup>vii</sup> for critically needed community-based benefits planning, outreach and training services;
2. To support, to succeed at and to access funding sources for #1, *require* in law, not just encourage, that the Centers for Medicare and Medicaid Services, Social Security, the Department of Labor and the Department of Education, along with private health care and employment partners, coordinate programming, services and interactions to serve Americans as they might request employment support services related to the findings, the provisions and the outcomes sought in the Ticket Act.

Successful areas of Ticket Act implementation, such as supporting the growing field of community-based benefits planners, have been under funded since the beginning in 2000, and continue to be under funded. The Ticket Act made few if any benefit or health care rules easier to understand. Indeed the opposite has been the outcome, as there has been little to no substantive integration (that we are aware of) of Medicaid Infrastructure Grant, Medicaid buy-in and federal rule making initiatives related to benefit program interaction and employment outcomes. New and ever changing federal regulations related to the Ticket Act interact with a hodgepodge of different state rules on health coverage, Section 8, and vocational rehabilitation and other employment related rules (Goodman & Livermore, 2004).<sup>viii</sup> Social Security funded community-based benefits planner capacities to keep up with these complex rules has been fragile and strained at best since 2000, and weakened with delays in grants and training grants for benefits planners for the past 15 months. Community-based partner ties with Social Security have suffered across the country.

### **Recommendation Three**

Synchronize all SSI and SSDI Work Rules and Procedures into One Set of Rules

*NCIL recommends that Congress require Social Security to synchronize all of its SSI and SSDI work rules into one set of rules that can allow options (a NCIL position on these matters from the 1990s.) Improve SSI and SSDI work rules mindful of their important connections to accessing Medicaid buy-ins in the states and to employment services.*

SSI recipients who work and remain disabled become dual eligible, concurrent beneficiaries, potentially eligible for SSDI *and* Medicare.<sup>ix</sup> SSI work rules and the separate SSDI work rules routinely confound those with a Ph.D., and can encourage some to suppress earnings or avoid employment advancement opportunity rather than risk seamless access to their health coverage. Available data across all state Medicaid buy-in enrollment numbers show that the majority enrolled are SSDI beneficiaries or concurrent (dual) eligible beneficiaries on SSI and SSDI. Another cruel Ticket Act implementation reality since 1999 is the much increased availability of Medicaid buy-ins for those still confronted with and affected by the SSDI “cash cliff” when they gradually increase their earnings from lower paid employment categories.

### **Synchronization: Methodology and Objectives**

1. Raise the earned income disregard in SSI to the indexed Social Security Substantial Gainful Activity level (or SGA), \$900 and \$1,500 for the blind in 2007, to make work pay for many thousands of SSI very low wage earners, and to eliminate their fear and rampant confusion about SSI work rules amongst their service providers and natural supports;<sup>x</sup>
2. Raise the Trial Work Month earnings test dollar amount to SGA (with indexing) for those using current SSDI work rules;
3. Introduce a 2 for 1 (\$1 dollar reduction in cash benefits for every \$2 in earnings) in the SSDI program for earnings above SGA. Implement regionally or state by state if finances and operational efficiencies warrant. Allow SSDI beneficiaries

the choice of using current SSDI work rules, or the new benefit offset fully synchronized with SSI work rules as improved here in 1. and 2.<sup>xi</sup>

4. Require Social Security to craft one set of rules regarding when earnings were earned and when they were paid for use in both programs; require Social Security to implement and market one user friendly wage reporting procedure for both programs; promote, market and expand use of the Social Security Benefits Planning Query (BPQY) information sheet, available now to beneficiaries regarding their current benefits and prior use of work incentives.

#### **Recommendation Four**

Commission a Congressional Panel of Social Insurance and Employment Experts

NCIL urges the Committee to lead long-term transformational reform by commissioning a bipartisan experts panel to assist Congress with shaping solutions to decouple the two conflicting goals of the existing Social Security disability programs.<sup>xii</sup>

*“National public policy on employment and benefits remains stuck in a morass of confusing program rules and conflicting advocacy positions. Both the rule makers and the advocates are struggling with how to support employment while protecting health and income benefits for those who rely on them most. To sum up: “There is a terrible tension between eligibility to get benefits versus getting employment help.”<sup>xiii</sup>*

Within NCIL’s current policy framework on these matters, providing supports to help people prepare for, find and maintain a job would become a separate program of equal stature from providing income when people are physically or mentally unable to work. An Employment Support Insurance (ESI) program would provide health coverage through a new model of Medicare, benefits planning for those looking for work, and referrals to Ticket to Work program services, vocational rehabilitation, One-Stop, and other employment services. Improved Social Security ‘work incentive’ rules would be administered in the ESI program.

This Employment Support Insurance (ESI) program would operate under a social insurance model similar to the one that SSDI uses, with automatic FICA payroll deductions serving as premiums. ESI would provide better transitions between looking for work, employment, and having to go on SSI or SSDI. For those who are unable to work, the current SSDI program would maintain its successful earnings replacement components under the auspices of an Earnings Replacement Insurance (ERI) program. Current SSDI ‘cash cliff’ work rules would remain in the new ERI program for those whose transition back to full time work requires modest or little public support.

#### **Closing Comment**

We think it may be too convenient for some in government, and we know it is tragic for us on the outside to learn that the Office of Management and Budget and the Social Security Administration cannot come together in 2007 to resolve funding issues for crisis

level problems they have been informed on since before 2004. In a word, the arrested Ticket to Work Program today is about failure, a lost commitment to Americans with disabilities.

Senator Bob Dole said, and President Clinton agreed with him in the late 1990s, the Ticket Act is the "right thing to do." NCIL has learned a great deal since the late 1990s. These recommendations come to you after two years of NCIL discussion; we take these issues and our recommendations to you very seriously. Were the Committee on Finance to begin the action steps needed to implement them without another month of unconscionable delay, we are highly confident that the talented and expert stakeholders focused on employment, health care and full equality throughout the disability community will rally to your leadership. Many of us can provide your Committee and Congress the technical assistance to get employment back on track in the U.S. for beneficiaries of Social Security disability programs and for other Americans with a disability at earlier risk of losing their attachments to the workforce.

This is a painful letter for NCIL members. NCIL members from 1996 to 1999 devoted thousands upon thousands of pro bono hours to the hopes and the promise Congress first extended to us with the work incentives initiative that became the Ticket Act. We come back to you now on these matters with benefit of fresh, new thinking. We have a framework for you to consider and move forward with.

We implore you to listen and seize the moment. NCIL is ready to provide any details requested on matters in this testimony. NCIL members nationwide are ready to work with you to refocus Congress on the employment potentials of Americans with disabilities.

Thank you for your time and review of our recommendations. We look forward to working with you and your colleagues to enhance the employment opportunities and outcomes for American with disabilities and Social Security disability beneficiaries. Please do not hesitate to contact Deb Cotter, NCIL policy staff, with any questions.

Respectfully submitted:



John Lancaster  
Executive Director



Kelly Buckland  
President

## Endnotes

<sup>1</sup> A Disability System for the 21st Century, Social Security Advisory Board, 2006.

<sup>2</sup> SSI Disabled Recipients Who Work, 2006, Social Security Administration Office of Policy, Office of Research, Evaluation and Statistics, April 2007.

<sup>3</sup> Advice Report to Congress and The Commissioner of the Social Security Administration, The Crisis In En Participation—A Blueprint For Action, Ticket to Work and Work Incentives Advisory Panel, February 2004.

<sup>4</sup> Please refer to: Public Law 106-170: SEC. 101. [42 U.S.C. 1320b-19] ESTABLISHMENT OF THE TICKET TO WORK AND SELF-SUFFICIENCY PROGRAM. (d) Graduated Implementation of Program. (1) In general. (2) Requirements. (3) Full implementation. (4) Ongoing evaluation of program.— (A) In general. (B) Consultation. (C) Methodology.— (D) Periodic evaluation reports.

<sup>5</sup> Appropriated funding levels for Medicaid Infrastructure Grants to the states in the Ticket Act speak clearly to Congressional intent. Integration of services and supports funded by MIG grants with Social Security efforts to implement the Ticket Act have been accidental, ad hoc, uneven and unevenly measured, if occurring at all. MIG grants are important supports to states, should continue and be extended with better integration with federal initiatives.

<sup>6</sup> “Congress should develop statutory language that clearly articulates its original intent that the Ticket Program’s outcome and milestone payments should provide additional resources to assist beneficiaries in attaining and retaining employment.” Advice Report to Congress and The Commissioner of the Social Security Administration, The Crisis In EN Participation—A Blueprint For Action, Ticket to Work and Work Incentives Advisory Panel, February 2004.

<sup>7</sup> Facilitate Beneficiary Choice – “Congress should authorize and direct SSA, the Rehabilitation Services Administration (RSA), the Centers for Medicare and Medicaid Services (CMS), the Department of Housing and Urban Development (HUD), and the Department of Labor Employment and Training Administration (DOLETA) to develop and implement an integrated benefits planning and assistance program that coordinates resources and oversight across several agencies that enables beneficiaries to access benefit planning services within multiple federal systems.” The Social Security Administration’s Efforts to Promote Employment for People with Disabilities, New Solutions for Old Problems, National Council on Disability, November 2005.

<sup>8</sup> For a full review of these complex program interactions, please see: The Effectiveness of Medicaid Buy-in Programs in Promoting the Employment of People with Disabilities, Goodman and Livermore, 2004, Briefing Paper Prepared for the Ticket to Work and Work Incentives Advisory Panel, Cornell University Institute for Policy Research, Washington, DC.

<sup>9</sup> An SSI recipient under the age of 24 can work part time a short 1.5 years with \$900 in gross earnings per quarter of the year and become eligible for SSDI from that short a period of paid work, and in today’s world, may not know about this new eligibility until after it happens.

<sup>10</sup> In the month of December 2006, 260,000 SSI recipients worked, reported earnings and received a lower partial SSI benefit check because of the earnings. These people worked at very low paying jobs with a significant disability. How many more would work if the work rules and the reporting rules were clear and easy to use for these workers? Data from SSI Disabled Recipients Who Work, 2006, Social Security Administration Office of Policy, Office of Research, Evaluation and Statistics, April 2007.

<sup>11</sup> The policy objective is one coherent set of work rules and reporting rules, with options as needed to suit variant employment objectives. The original NCIL objective from the 1990s was synchronization of two separate sets of arcane rules, not just a “2 for 1” sliding scale earnings plan for the SSDI program. Congress could look closely at current Social Security Ticket Act demonstration projects to assess if their directions suit such a policy objective.

<sup>12</sup> **Note well:** the Committee on Finance should include in their oversight a review of the May 2007 recommendations found in the Social Security Inspector General Organizational Review of the Office of Disability and Income Security Program (A-12-07-27162). Careful analysis and steps should be taken to insure that the reports’ recommended changes support employment as the core Social Security social insurance goal that it has become, and support reduction and then elimination of its orphaned, bankrupt status when it becomes pitted against Office of Operations responsibilities in other social insurance areas.

<sup>13</sup> William P. Molmen, General Counsel, Integrated Benefits Institute, San Francisco; quotes from Being American: the Way Out of Poverty, Poverty and Disability in the U.S., SUMMARY, Joshua Berezin, World Institute on Disability, an official NCIL Board policy position statement, available at [www.ncil.org](http://www.ncil.org) and [www.wid.org](http://www.wid.org), 2006.

**Statement of  
Peter Mead, Chair and  
Susan Webb, President**

**National Employment Network Association**

**Submitted to the Senate Committee on Finance**

**Hearing on  
"Barriers to Work for Individuals  
Receiving Social Security Disability Benefits"**

**June 21, 2007**

The National Employment Network Association (NENA) asserts that aggressive implementation and supplementary funding for the Ticket to Work & Work Incentives Improvement Act (TWWIIA) represent the simplest and most viable near-term solutions to eliminate Barriers to Work for Individuals Receiving Social Security Disability Benefits. NENA represents private-sector service providers who deliver employment support services to beneficiaries.

NENA's focus on near-term solutions does not detract from the importance of long-term enhancements. One valuable long-term proposal is a new payroll tax to fund an employment insurance program, proposed by the National Council on Independent Living. The proposal by Dr. David Stapleton of Cornell University for a "triage assessment" early intervention system also has excellent advantages. SSA's ongoing efforts to improve its disability determination process and reduce the disability claim backlog are also tremendously important to remove barriers to employment.

NENA's focus on near-term solutions is driven by our experience with beneficiaries since 2002, when the first Tickets were mailed. The original TWWIIA legislation itself offers many solutions that have not been adequately implemented. Before developing and implementing new solutions, it's incumbent on Congress to press for full development of the capabilities in the original legislation.

Whatever future solutions SSA undertakes to further reduce barriers to work, the Ticket Program will continue to provide a useful vehicle for the effort. It is the most immediate and efficient way to expand capacity to provide employment support services to SSA disability beneficiaries having the best prospects for employment. Under the proposed new program rules, State VR programs will continue to serve as many beneficiaries as possible, and could potentially increase their revenues. Private-sector service providers with proven track records will serve more beneficiaries. This increased service capacity comes with minimal upfront infrastructure investment by state or federal agencies.

NENA shares the sentiments of Senator Jim Bunning, who during the June 21 hearing commented, "All of the things that you have talked about here today were covered by the Ticket to Work Act." The original (and still current) program rules indeed covered a broad scope of needed reforms and program additions. Critical problems and limitations in the rules, however, made them a well-intended false start. The September 2005 proposed rules plus other program augmentations proposed by NENA can help the Ticket to Work Program achieve its full potential.

NENA recommends seven steps to ensure significantly better employment outcomes for SSI and SSDI beneficiaries.

1. Quickly implement the new Program rules, confirming SSA's commitment to disability beneficiaries, State VR agencies and private-sector providers.
2. Suspend programs to evaluate the Ticket to Work Program, until the Program begins producing outcomes under the new rules.
3. Fund mass media marketing by SSA targeted at beneficiaries to increase their awareness of work incentives and confirm SSA's desire to support their personal success.
4. Increase funding for Work Incentive Planning and Assistance services and technical assistance for WIPAs to facilitate Ticket Program marketing.
5. Authorize SSA to implement a 2:1 SSDI offset similar to SSI to eliminate the "earnings cliff" disincentive.
6. Fund SSA to develop and implement early intervention strategies to prevent needless SSDI claims by helping people maintain employment or find accommodations and new career paths.
7. Keep Ticket to Work operations in OESP, where they are the core mission, rather than allowing them to be consolidated into SSA Field Operations, where they would become tertiary.

Here follow the detailed rationale and data to justify NENA's seven recommendations.

### **1. Quickly Implement New Program Rules**

The Ticket Program rule changes proposed in September 2005 were the result of a blue-ribbon panel, the Adequacy of Incentives Committee. The September 2005 proposal itself was two years in the making, and SSA is now taking another two-years-plus to implement it, including another rule-making cycle to correct deficiencies in the September 2005 proposal. A four-year timeline to complete necessary rule changes is not a good way to develop awareness and momentum among beneficiaries and SSA's Ticket Program partners.

This is especially true for organizations that have suffered losses under the Ticket Program. They will be cautious to re-engage until SSA completes the appropriate changes and re-launches the program. Under the new program rules, many high-

potential community service providers could become an excellent resource for disability beneficiaries who want to use SSA work incentives.

Commissioner Astrue and interim Deputy Commissioner Vas deserve credit for acting quickly to advance the Ticket Program rule changes once they were aware of them. Another delay has occurred, however, during the Office of Management & Budget review of the new rulemaking cycle SSA wants to complete before implementing the September 2005 proposed reforms. It is past time to end the delays and push forward with a program re-launch that will communicate SSA's commitment to its disability beneficiaries and generate positive employment outcomes on a larger scale.

## **2. Suspend Ticket Program Evaluation**

Most Ticket Program participants can describe the program's shortcomings in detail, from their perspective. It's redundant and wasteful to spend more funds to continue to evaluate a troubled program's shortcomings when the solution of new program rules is in the pipeline. Any data generated by this program evaluation are now so skewed as to be worse than useless: they can yield false conclusions and confusion about the program and what outcomes to expect under the new rules. SSA should suspend these evaluations, stop wasting tax dollars now, and resume evaluations following the program's re-launch, when those tax dollars can be spent effectively.

## **3. Fund mass media marketing by SSA**

SSA must perform mass marketing regardless of anything employment networks do to recruit participation in Ticket to Work.

For some beneficiaries, the application experience and their personal reaction to it were so negative that risking their benefits and facing re-application must be avoided at all costs. But this is not the only experience and sentiment among SSA disability beneficiaries. Other beneficiaries had a less-negative experience, or have a more resilient desire to pursue employment, or both. These people represent a substantial minority among SSA disability beneficiaries who can succeed in employment. These people need a message from SSA to make them aware of work incentives and dispel any residual doubts about SSA's own commitment to their success.

In the most recent research available, 37 percent of beneficiaries surveyed in 2004 had career goals or work goals, 15 percent believed they could secure employment and become self-supporting in five years, and 7 percent believed they could achieve this in one year. (From the Third Ticket to Work Evaluation Report of the National Beneficiary Survey conducted for SSA under contract by Mathematica Policy Research.) Based on these figures, it's reasonable to assume that 10 percent of SSA disability beneficiaries are viable candidates to achieve self-support. That's more than one million people. Another two million SSA disability beneficiaries are interested in work.

These conclusions are supported by earlier research as well. In 1993, SSA surveyed SSDI beneficiaries, and 84,000 responded. Among these, 35 percent "expressed an

interest in receiving rehabilitation or other services that could help them return to work.” The March, 1997, GAO report *Social Security: Disability Programs Lag in Promoting Return to Work* also noted that “among working-age DI and SSI beneficiaries, one out of three is under the age of 40.” Younger beneficiaries have more current work skills and better prospects for return to work.

Among the 6.8 million people receiving SSDI benefits, if 35 percent desire to return to work, and if only one in three of those succeed, 785,000 people could return to work. Among the 3.4 million SSI beneficiaries, if 35 percent desire employment, but only one in five succeed, an additional 238,000 people would be employed, bringing the total number of substantially employable SSA disability beneficiaries to more than 1 million.

NENA Directors who manage active employment networks confirm from personal experience that many disability beneficiaries aren't waiting for a radically improved culture at SSA — they want to work today. One million SSA disability beneficiaries are candidates for self-support, and another two million more are strongly interested. Many of these people currently live in poverty. Failing to promote the work incentives keeps these beneficiaries in poverty needlessly, and deprives potential employers and co-workers of their contributions on the job.

Other improvements in Social Security disability programs eventually will increase the number of beneficiaries who can pursue substantial employment. That brighter future is no reason to maintain the current darkness for a million beneficiaries with real prospects for employment now. To achieve all the social and economic payoffs available through its work incentives, SSA must advertise the program on a massive, media-driven basis.

#### **4. Increase funding for WIPAs.**

Work Incentive Planning and Assistance (WIPA) contractors play an important role for disability beneficiaries. They are at the core of SSA's existing plans to promote the Ticket Program. WIPA counselors plan a safety net of benefits, work incentives and supports to help beneficiaries achieve their personal employment goals. These expert counselors have no financial interest in a beneficiary's decision to pursue self-support, and provide valuable, objective services.

A total of approximately 104 contractors carry the responsibility for the entire country, with a total budget of \$26 million. In many states, a single WIPA contractor serves the entire state, often from a single office. This makes face-to-face contact with beneficiaries in more distant or rural areas difficult or nearly-impossible.

The network of state WIPA agencies is seriously underfunded compared to the potential demand for services if SSA promotes its work incentives. A conversation with Amina Donna Kruck, the Director of the WIPA contractor in Arizona, identified operating conditions that are typical for many WIPA agencies:

- a ratio of one counselor for every 18,000 beneficiaries in the state;
- several counselors are part-time and some must travel to meet with beneficiaries;

- in most cases, counselors have only completed the initial counseling with beneficiaries, and don't yet carry the additional time-demand of follow-up service;
- the WIPA organization is already operating at or near capacity, despite the low level of Ticket activity;
- when Ticket activity picks up, additional counselors will be needed but aren't in this organization's budget, due to limitations of the contract with SSA.

In addition to counseling beneficiaries (the core of the historic mission under the former five-year contract) WIPAs now must also support SSA's Ticket to Work marketing program. This was initially estimated to require 10 percent of the WIPA hours, although no additional funding was provided for this, compared to the former contract.

Clearly, WIPA funding must increase to support the marketing and beneficiary service goals of SSA's Employment Support Programs.

#### **5. Authorize a \$2-for-\$1 benefit offset for SSDI**

Many SSDI beneficiaries say it's a challenge to transition off cash benefits, when they go from full benefit to no benefit after their last month of grace period. SSI beneficiaries, however, don't face this "cash cliff." They have a benefit offset that gradually reduces benefits: for every \$2 earned, cash benefits are reduced by \$1.

SSA has conducted pilot projects to research the impact of providing a similar benefit offset to SSDI beneficiaries. These demonstrations followed a more complicated formula than NENA would recommend. SSA should configure the SSDI benefit offset program toward three primary goals: 1) end the cash cliff disincentive to beneficiaries; 2) administrative simplicity; 3) incent increased earnings. Administrative simplicity will create more value than complicated formulae yielding only marginal additional incentives to increase earnings.

In addition to configuring the benefit offset for administrative simplicity, benefit calculation and payment also can be automated with a software system to reduce staff demands. SSA conducted a demonstration project to investigate the accuracy of a system for automating the SSI benefit offset. The accuracy was found acceptable. Such a system could be applied to both SSI and SSDI benefit offsets. The broader the application of such a system, the better the staff cost reduction and the greater the feasibility of using benefit offsets.

#### **6. Fund SSA to Develop and Implement Early Intervention Strategies**

A 2004 article in the *Journal of Vocational Rehabilitation*, *Program and Benefit Paths to the Social Security Disability Insurance Program*, by Todd C. Honeycutt from Rutgers University describes how other disability-related benefits programs routinely transfer claimants from their systems to the SSI/SSDI system rather than providing vocational services that might have potential to avoid SSI/SSDI applications altogether. Honeycutt cites research that 34 percent of long-term disability (LTD) recipients became DI

beneficiaries. Indeed, Tom Foran, Director of Product Development for Wellpoint, a recognized expert in LTD plans, asserts that most LTD plans *require* their claimants to immediately apply for SSDI as a condition of receiving LTD benefits.

SSA has convened discussions and designed feasibility efforts to test various early intervention strategies providing return-to-work services even before a claimant qualifies for DI benefits. Private-sector research consistently shows that providing return-to-work services earlier in the process makes it more likely a claimant will return to work sooner. Inversely, the longer a claimant remains on benefits, the less likely he or she is to return to work.

Many different insurance systems (including LTD, workers' compensation and TANF) routinely seek SSDI coverage to offset their costs. NENA recommends SSA be authorized and funded to partner aggressively to deliver return-to-work services in partnership with these other systems *before* that cost-offset occurs. This would reduce Trust Fund payouts, reduce SSA administrative costs and achieve better quality of life for Americans with disabilities.

#### **7. Keep Ticket Operations in OESP**

In an Organizational Review of the Office of Disability and Income Security Programs (ODISP), the SSA Inspector General made a tentative recommendation to remove Ticket Operations from the Office of Employment Support Programs (OESP) and place it under SSA's "operational components" (the organization including field offices). The recommendation was contingent on completing the implementation of the new program rules and assessing the impact of the new rules on the Ticket Program.

This recommendation is consistent with SSA's pattern of separating different functions (such as policy and operations) into different organizational units. Despite this, the Inspector General recognized special factors may be at play in Ticket Operations warranting at least a temporary exception. To this we heartily assent, and we encourage a permanent exception.

SSA isn't unique in attempting to end inappropriate dependence on disability benefits. Major corporations have pursued this goal for two decades and more. In a "typical" corporation, employees have access to numerous support programs during disability events. These programs must be aligned to create a single, simple path back to work, otherwise employees can "fall into the cracks between programs" and remain dependent on benefits. To align or integrate these programs, corporations usually have a single manager with oversight of all programs, including policy and operational functions.

Most corporate initiatives to integrate diverse disability management programs begin with the recognition that these programs are fragmented and operate at cross purposes. The Ticket Program must succeed in aligning even more component programs than a typical corporate disability management initiative. Fragmenting the Ticket Program into multiple organizational units would defeat its ability to align component programs. It's important to retain the current integration of the Ticket Program in OESP.

**CONCLUSION**

A significant subset of approximately one million Social Security disability beneficiaries are good candidates to pursue employment leading to self-support, and another two million are interested in employment. Further improvements to SSA's disability determination process and other disability program components may well increase that number. The number of beneficiaries already interested in employment is sufficient, however, to mandate aggressive implementation of all work incentives and employment supports provided in the Ticket to Work Program. Even the most ambitious of NENA's seven recommendations – early intervention and benefit offsets – have already been investigated by SSA. It's time to get aggressive with implementation of the Ticket Program and all its innovative components and commit resources to aggressively inform beneficiaries about the work incentives, as Congress originally intended, so that SSA work incentives can reach their maximum potential in helping SSA disability beneficiaries achieve self-support, build a comfortable retirement and avoid poverty.

Statement of Monica Nagle Newton  
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Submitted to the Senate Committee on Finance

Hearing on

"Barriers to Work for Individuals Receiving Social Security  
Disability Benefits"

June 21, 2007

My name is Monica Nagle Newton. I am the New Hampshire Delegate for "Voices for Work", which developed out of the Atlanta Summit "Voices for Change: Beneficiaries Paving the Way to Work" sponsored by the Social Security Ticket to Work and Work Incentives Advisory Panel last February. I have been an advocate for people with disabilities for 34 years. I am going to tell you from my own personal experience why we need to make it possible for people with disabilities to be able to go to work without risking the loss of their SSI and SSDI benefits: their financial and medical benefit safety net.

Without this safety net I would not be alive today. When I am well you would never know I have a disability, what you don't see is how hard I have worked to stay well and the fact that the nature of my disability leaves me in a place where I never know when I may have a relapse. I was diagnosed with a brain disorder in 1974 at the age of 17. This was discovered after I was hit by a car while riding a horse by a drunk driver. I started to become symptomatic after the accident and we didn't know why. This led to my first hospitalization. I spent the next 20 years in and out of the mental health system searching for a recovery path. I've been hospitalized 13 times during the course of my life. My current diagnosis is bi-polar and PTSD. The arts through music, performance and poetry saved my life. They were my wellness tools until I was able to discover a formal recovery program. It wasn't until many years later that I was introduced to the work of Mary Ellen Copeland and her WRAP (Wellness Recovery Action Plan) program. Since then I have learned great recovery tools that have helped me discover a road to overall health. I became a wellness educator, WRAP facilitator, WRAP trainer and helped Mary Ellen edit the "One Step Up: a Teen Program for Walking into Wellness" to coincide with her Adolescent Depression workbook. Because of the nature of my disorders relapse, which is influenced by stress, is always a real possibility.

I have been able to work on and off through out the years depending on the state of my health and the number of relapses I was experiencing. Even though I have gone through severe trauma and abuse, the suicide of my first husband and a violent crime at the age of twenty, where I was kidnapped and brutally raped, I have managed to do more than survive my life. This would not have been possible without my faith, my resiliency, my support systems and my willingness to transcend difficulty, while at the same time reaching out to others with a spirit of hope and triumph over adversity. This has allowed me to experience a great deal of success in my life.

Testimony of Monica Nagle Newton - Page Two

I have raised two beautiful girls, who have grown up to be successful, loving individuals; I have gone back to graduate school and achieved a degree in community and community economic development. I became the Director of Arts and Humanities for the New Hampshire YMCA, worked as a managing Editor for a national literary arts magazine called "Bone and Flesh", performed as a successful folk singer and guitarist for over twenty years, including touring three years in Brazil. All of this work took place with a spirit of determination, as my disability continued to cause many relapses that left me to experience periods of extreme suffering, poverty, homelessness and grief. I navigated my way alone through the complicated, unfair and extremely impersonal Social Security System. I managed to survive through my ingenuity and willingness to reach out and search for resources that seemed at best hidden and at worst non-existent.

Several years ago I worked very hard with the New Hampshire Department of Vocational Rehabilitation and designed a successful self employment and PASS plan in New Hampshire, which helped me to expand an award winning prevention program called "The Art of Living Center". My program design was a small business model that collaborated with non-profits using community arts as a drug, alcohol, tobacco and high risk prevention tool to help over 750 teens live healthy creative lives. This later led to me being hired as the Program Director for Newfound Area Nursing Association and Coalition Coordinator for the Newfound Region's "Make Art Not Smoke" tobacco prevention coalition. This job helped me to finally realize an incredible income of \$50,000.00 a year, obtain life and health insurance and a 401-k retirement plan. I met my wonderful second husband, built a beautiful log home and seemed to have really made my dreams come true.

Relapse set in again and I was able to use my wellness plan to intervene but, because I asked for time off work to be well, go into the hospital to make a medication adjustment, even though my employer knew of my disability, I was given an award one day and fired the next, because of my disability. My professional reputation was ruined when I was fired and my relapse got worse after I lost my job. It took me a year to get my SSDI benefits back, putting me in peril of not being able to support myself, pay my mortgage and maintain the stability I had worked so hard to obtain. The only way I survived was to cash in my only 401-K retirement plan. I was able to qualify for Medicaid and food stamps, but as soon as I got married, because of the marriage penalty, I lost my Medicaid and food stamps benefits. Still on the advice of the New Hampshire Disability Rights Center I chose to fight the employment discrimination from my former employer and my case has been with the New Hampshire Commission on Human Rights for two years. Because I had no financial resources, I could not afford to hire an attorney and there were no funds in the available non-profit legal arena to take my case. As a result I struggled through all of my own legal paperwork and have been waiting on a long over due ruling.

I am currently on SSDI and in the middle of my trial work period. I have a part time job that pays only twelve dollars an hour and barely covers the cost of my insurance, co-pays and medicine. I have been working on a book about recovery through the arts called The Poet, The Poem, The Pill "An Artist's Recovery from Bi-polar Disorder and Other Revolutionary Concepts". I also have been working through New Hampshire Vocational Rehabilitation on a new self-employment and PASS plan to enable me to do disability advocacy work. If I don't make enough money by October, when my trial work period will end, I am going to be in real financial trouble.

Testimony of Monica Nagle Newton - Page Three

Without social security I would not have been able to get the medical and financial support I needed to accomplish any of the things I have done. I am hoping to climb out of the relapse hole once again. I want to work and continue my career. We need to make it easier for people to get the help they need in navigating their way through the system. I did it on my own. It was very difficult and I'd hate to think what would have happened to me if I didn't have the fortitude to overcome the hundreds of barriers I found to get my needs met. We need to help people go back to work without losing their medical benefits. I need my benefits in order to be well enough to work and be a contributing member of society. I deserve a good quality of life, like everyone else. I suffered in many ways needlessly because we need to improve the Social Security System. Expedited reinstatement and approval for disability benefits has to be humane. The fear is so great if you have an illness that is life long, but changes in its severity impeding your ability to work due to relapse. This must be taken into consideration realistically. We have to want to make it better for all people out there with disabilities. We all deserve a better quality of life. People with disabilities are so underestimated in our culture. We have so much to contribute to our communities and the world. We want to work. We want to give of our gifts. We want to be part of the solution, but the way the system is set up now, the risks of peril are too high and the fear of survival is much too realistic. Still, I will never give up.

My involvement as the New Hampshire Delegate with "Voices for Work" is bringing me a lot of hope that our growing beneficiary organization will be able to collaborate with the Social Security System and Congress to improve the programs that will ultimately make going to work a reality for people with disabilities. I am currently a member of our steering committee and chair the funding committee. During the Atlanta Summit the delegates from "Voices for Work" came up with several recommendations for the Social Security Ticket to Work and Work Incentives Advisory Panel. The beneficiaries have the answers to improve the current system. We live it every day, so we know what does and doesn't work. The following are our top three recommendations:

#1: Raise the SGA amount to \$1,800, and keep COLA (cost of living adjustment). Adjust earnings and asset limits to today's dollars with COLA. Raise the SSI resource limit to at least double (\$7,000/\$10,000 with a COLA) with more asset exclusions (allow asset development, savings and retirement).

#2: Allow people with disabilities on SSI/SSDI to work and keep some of their cash and medical benefits. Allow beneficiaries to keep health care when they go back to work, including self-employment.

#3: Develop and implement a Work Support Program to allow people with disabilities to go back to work and gradually cut back benefits. Beneficiaries need to be involved in the development and implementation of the Work Support Program

I appreciate you taking the time to read my story.

Sincerely and from my heart,  
Monica Nagle Newton

New Hampshire Task Force on Women and Addiction

# Women's Leadership Institute

## Facilitator's Training

### Certificate of Completion

is hereby granted to

*Monica Nayle*

135

to certify that she has completed

### Training of Facilitators

and have been granted 13.5 hours of continuing education that have been pre-approved by  
The NH Board of Alcohol and Other Drug Abuse Counselors Professional Practice.  
Categories of Competence: 1, 3, 4, 5, 6, 7, 8, 15, 17, 18  
Performance Domains: I, II, III, IV, V

Granted: February 25, 2005

  
Niki Miller, Executive Director



## Hustling the Music

For Monica Nagle, the East Windsor singer and songwriter, there's no time to lose in promoting her repertory of original jazz, blues and folk tunes

IN CONCERT



As a college student, Ms. Nagle was torn between music and equestrian medicine. She has been writing poetry since she was 6 and playing the guitar since she was a teenager.

BY ANGELA DELLI SANTI

**T**RY keeping tabs on Monica Nagle, the East Windsor singer-songwriter who totes three appointment calendars just to keep up with herself.

An attractive 30-year-old whose mane of curly brown hair explodes around her shoulders and face, Ms. Nagle has decided her time has come. She is ready to "actualize" her music.

Determined to make it in the cut-throat entertainment business — without compromising her music or herself — Ms. Nagle lugs a worn blue suitcase from record producer to club owner trying to land new gigs. The overnight bag bulges with lyrics, news clippings, cassette tapes and flyers — all tools in the game of self-promotion that struggling musicians play.

"In 1988, it doesn't matter how good you are. If you don't have your foot in the door, if you don't know somebody who knows somebody else, you can spend weeks and weeks, months and months, just playing saloon after saloon."

Ms. Nagle has grown accustomed to hustling her talents to would-be employers, be it a big Manhattan-based record company or a local tavern owner. "I'm original music," she said. "It's very hard to walk into a place with a tape and say, 'I'm going to bring you business.'"

Nonetheless, when she showed up at John and Peter's, the New Hope, Pa., club, one afternoon last fall, Ms. Nagle landed a booking in 30 seconds. Her repertory of original songs contains

jazz, blues and folk tunes, sung in a sweet, emotion-charged voice that has never been refined through formal training.

She has been compared to Joni Mitchell, Bonnie Raitt and Rickie Lee Jones, though she shrugs off these comparisons in a firm gesture of her individuality.

"It's a wonderful, exciting time in my life," the Buffalo, N.Y., native announced with a smile. "I really didn't think I'd be here until I was 40. So I'm 10 years ahead of myself."

"Arriving" on the entertainment scene takes persistence, diligence and an iron will to succeed — characteristics that the Twin Rivers resident possesses in abundance. What sets her apart from other would-be celebrities, though, are the reasons she is so driven to succeed.

"My purpose in life is not to become a star," she stressed. "I'm not on this earth to become a zillionaire. It's really irrelevant how many people know my name. What's relevant is how many people I help."

Through her performances and her unselfish lifestyle, Ms. Nagle hopes to "reverse the universal law that says get everything you can for yourself. Instead of 'all for one and one for all,' it should be 'all for all and none for one.'"

The title of the song she just finished may best sum up her philosophy: *I Want to Make a Million Dollars so I Can Give It All Away*. Thus, much of Ms. Nagle's performing time is devoted to benefit shows, like the ones she has done for Alpha House for girls in Camden, the Carrier Foundation in Belle Mead and for Princeton University's Women's Center.

Her jam-packed schedule of upcoming events includes "A Concert for Life," the proceeds of

which will be split between Alpha House, United Cerebral Palsy and the National Federation of Parents for Drug Free Youth (NFDY). The benefit is tentatively planned for May and will likely take place in Princeton.

The mother of two young daughters, Wynter Ashley, 7, and Alexia Dusquin, 3, Ms. Nagle and her Brazilian-born husband, Renato Bontempo, juggle a hustling domestic life with Ms. Nagle's crazy professional schedule. She, in fact, runs out of fingers before listing all the projects in which she is engaged.

Planning to record her first record album later this year, Ms. Nagle is in the process of incorporating a new for-profit company, New Rising Sun Productions Inc., and a non-profit subsidiary that will channel funds to a host of charitable causes.

She is about to shoot a video to *Power Old Joe*, a song about a man who couldn't say no to various vices in his life. Once packaged, NFP may market the 5-minute video, she said.

She has also been solicited to write the score to the film *Dreamers*, a project on which she is collaborating with several other musicians. And, as if her schedule is not cluttered enough, Ms. Nagle is planning to co-write a children's book with her artist-mother, Barbara Crickshank, beginning this summer.

Then there is the international tour, which Ms. Nagle and her band, *Dream Peace*, plan to launch in 1989 or 1990. The tour is expected to make stops in 14 countries, including Israel, Egypt, Nicaragua, Peru, Poland and Russia. While on the road, Ms. Nagle hopes to meet with diplomats from the various nations to talk about world peace, one of her many activist endeavors.

Sure it's stressful: "I don't have any privacy or any time right now. When I go to sleep, I dream this stuff. But that's OK — I'm coming up with some really great ideas in my sleep."

She also gets inspired in the car, as is evident by *Can't Shoot Me Down*, a song that "came to me" one night on the way home from a performance. Ms. Nagle actually pulled over to the side of the road to jot down the lyrics. The resulting blues-rock tune is a tribute to slain ex-Beale John Lennon.

Ms. Nagle has been writing poetry since she was six and playing guitar since she was a teenager. "I knew when I was born I was going to do this," she said of her passion for making music, which is rivaled only by her lust for horses.

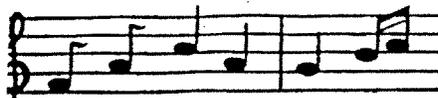
As a college student, Ms. Nagle agonized over her future career, torn between music and equestrian medicine. Finally, a professor told her she had to make a choice. "I can't," she told the instructor. "I would rather just sing and play guitar to my horses and make them feel better."

She writes music religiously and claims to have collected more than 2,000 original songs, which are stashed in boxes, scribbled on scrap paper or tucked in that worn suitcase. "I'm a gold mine for a any record company," she said; then quickly she added, "I would sign with a record company, but I wouldn't conform."

In other words, Monica Nagle won't dress in leather, and you'll never catch her on MTV.

Ms. Nagle will be performing every Saturday in February at the *Great American Saloon and Eatery*, 101 S. Main St., Hightstown. She will also appear at *PJ's Cafe*, 154 Nassau St., Princeton, Feb. 12, from midday to 3 a.m.

# 'Actualizing music' — inner strength



By Doug Sachs  
Staff Writer

**EAST WINDSOR** — Monica Nagle's love of singing and playing the guitar and her love of mankind has earned her through joy, adversity and 30 years of life experience:

From living on a commune as a child in the 1960s, through a troubled first marriage that ended with the suicide of her husband, through a concert tour of Brazil, through the birth of two daughters and into her second marriage, she has maintained her spirit by her love of people and her love of writing and performing music. Adorned in jewelry reflecting natural and supernatural images, Ms. Nagle discusses her life and her musical career with energy and enthusiasm. Animated hand gestures and constant shifting from the front to the back of her chair accent the highlights of the many tales of her young life.

Ms. Nagle, a Twin Rivers resident, plays guitar and sings every Saturday night the month at the Great American Saloon and Eatery, 101 S. Main St. in Hightstown. Her passion for playing the guitar began many years ago, when she moved from a commune in British Columbia, Canada, to Jamesburg.

Ms. Nagle found herself living on the commune when she was 12. It was 1969, and her mother, who was raising Monica and her four siblings on her own, decided to leave their home in Buffalo, N.Y., with a group of graduate students and begin a new life in Canada.

"We were going to get away from the Vietnam War and all the craziness back home," Ms. Nagle says.

The utopian dream lasted a year for Ms. Nagle's family, but they had to leave when her mother could no longer obtain Canadian resident status. But the year represented an important growing experience for Ms. Nagle, as it gave her the opportunity to pursue her love of poetry and expand her horizon.

"I was exposed to a whole other life style," she says. "People were living in hippies — just your classic '60s commune situation."

After leaving the progressive lifestyle of communal living, Ms. Nagle found herself back in small-town America. The culture change and feelings of alienation led her to begin playing the guitar, and eventually she began adopting her poetry to music.

Her interest in the guitar developed further when, at age 15, she moved to California to attend a school for American Indians established by graduates of the University of Stanford.

"That's when I really started playing," she says. "I picked up the guitar and never put it down. It was the answer to my emotional and spiritual void."

Her experiences in California went beyond learning to play the guitar. She also expanded her passion for horses, which helped her develop greater self-confidence and inner strength, she

says, where she explored the terrain on the back of an Arabian horse. She ended up becoming lost and searched for three days before finding her way back to the commune.

"I had lots of experiences like that," she says of the semester in California, "where you had to find your own way out."

At 16, she returned to Jamesburg wanting to share her inner feelings and deeper appreciation of herself with a peer group interested mainly in smoking marijuana and following the latest fashion trends. She was not pleased.

"To me, it didn't matter what shoes you were wearing," she says.

And for marijuana, Ms. Nagle says drugs held no interest for her when she was in high school, and she continues to oppose drug use.

In order to make that connection with her classmates that could not come from drugs or fashion, Ms. Nagle turned to an element of her life she knew had true significance.

"My music was a way for me to be accepted by people — a way of connecting with my peers," she says.

After graduating from Jamesburg High School, she lived in Princeton and played at many of the clubs and colleges in the area. During this time, she met the man whom she married when she was 20.

Her husband worked as a sound engineer, and together they went to Los Angeles to seek Ms. Nagle's singing fame. After six months and two unsuccessful interviews, Ms. Nagle left both the Hollywood scene and her husband to return to the East.

"I knew, in the spiritual sense, I wasn't ready to handle the life of a star anyway," she says.

She moved to Maryland where she lived with her father, an engineer for NASA. Her husband also returned to the East, and together they had Ms. Nagle's first daughter, WYNNE ASALE.

But her husband committed suicide in 1982, she said. Ms. Nagle says the incident affected her, but she continued to play and perform.

While still living in Maryland, she met her current husband and together they had Ms. Nagle's second daughter, ALEXIS. Her husband, a Brazilian, took Ms. Nagle to Brazil where she performed there to receptive audiences in Rio de Janeiro and smaller towns.

"Anything American, they love down there," she says.

Her tour of Brazil was not all fiestas and adoring audiences. She especially was affected by the disparity of wealth between the haves and the have-nots.

"The shock of Brazil was going and seeing the children with nothing to eat," she says. "The children would stand outside the bakeries begging for food, but the streets were full of new cars."

The family left Brazil and moved to East Windsor when Ms. Nagle's husband



Staff photo • Lorraine B. Keenan

Monica Nagle emphasizes her life experiences and her music mesh in an unusual way which keeps her enjoying life and spreading music.

got a job offer. Now Ms. Nagle must balance the demands of being a wife and a mother with need to write and perform.

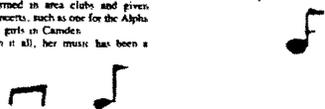
"It's tough trying to juggle all this," she says. "I want to be a good mom, but my music is something I must actualize."

Since returning from Brazil, Ms. Nagle has performed in area clubs and given benefit concerts, such as one for the Alpha House for girls in Camden.

Through it all, her music has been a

motivating and sustaining force.

"My music expresses the joy and love I have inside and want to share with the world," she says. "I know that's my reason I'm here."



# ARTS AND LEISURE

Recreation • Theatre • Music • Lectures • Artworks

## Teens make Room for arts

By OLIVIA GARFIELD  
COURIER STAFF

LITTLETON—For teenagers who would rather play music, write poetry or draw than play sports, life can be unfulfilled. Up until recently, they might have gathered in someone's house or in a church hall, but, at best, it wasn't enough. But that's all changed now.

Thanks to the Art of Living Program, which is supported by the SAU 35's Student Assistance Program, kids now have a place of their own to perform, to show artworks, to dance, have fun and, along the way, to learn. The program draws students, grades 9-12, in all high schools in the SAU: Lisbon, Profile and Littleton.

Eleventh grader Gordon Boddington said, "It started with an empty room, the second floor of the old Deacon's Bench building. We really didn't know what we were doing, but we did know what we wanted."

The objective was to start a coffeehouse/cafe where students could perform, show artworks and otherwise express themselves through their own and others' creative energies.

Guided by Art of Living director and creator, Monica Nagle-Reed of Bristol, who had started a similar coffeehouse/cafe, the kids converted that empty 1600 square foot room into a gallery,

a stage, a dance floor and a gallery where snacks and sodas could be served.

Called simply The Room, students produced the first coffeehouse last October.

Jason Blodgett, a senior said, "We had no idea whether anyone would come. But there was a big crowd. It was amazing. Totally cool."

Eighty students showed up to listen and to perform. Lisa Brown, Student Assistance Coordinator, said, "The kids were hesitant at first and said they wouldn't come. But they were curious and they loved it when they got there. It really took off."

She said students now make it happen by organizing themselves into committees which meet regularly to hash out the many details of how to put on the coffeehouses. They have a food committee, a curator to encourage artists and an active entertainment committee.

Since the first coffeehouse, the Art of Living Program has grown with students visiting other Art of Living coffeehouses, getting to know one another and trading ideas and support. In Littleton there have been six coffeehouse evenings and another is coming up April 11.

Nagle-Reed, whose energy and enthusiasm for the program seems boundless, has worked as a performing artist, singer, guitarist and writer as well as an

arts administrator. She says her interest in economic community development inspired her to "create a bridge-building program that use the arts as a tool to instill positive values in young people."

Program objectives are lofty. They include providing a safe place for young people to experience performance, encourage artistic self-expression to promote and enhance learning, offer an alternative to drug and alcohol experimentation and create a positive attitude towards community service.

Students performing at the cafe/coffeehouses receive credit toward school grades relating to the nature of their performance, whether it be creative writing, music, art or social issues.

Student Assistance Coordinator Rebecca Summers described the program as "an outstanding prevention program...in every sense of the word."

"No matter how skilled or non-skilled you are, says Nagle-Reed, "you need a place to tune up, to circulate talent."

**BACKBEAT**/Randy Alexander

## A chartered course to folk fame

After 13 years as a professional singer-songwriter, Monica Nagle can't wait to become an overnight success.

The 30-year-old East Windsor resident is a woman who knows where she's going in the music business and has mapped out a meticulous plan to get there.

She has a 1,000-song catalog, a voice likened to early Joan Armatrading, a style often compared to Rickie Lee Jones and Joni Mitchell and all kinds of projects in simultaneous development. Better yet, Nagle has just the right chutzpah to pull it all off.

"I'm basically a gold mine for a record company," says Nagle over a light bite at the Great American Saloon in Hightstown, where she's performing her brand of jazz-tinged folk blues with partner Charlie Wight every Saturday in April and May, Wednesday. Nagle will be backed by her Dream Peace band, guitarists Wight and Harry Warner, at John & Peter's in New Hope.

"I'm a good performing artist," she says. "There's that electricity that exists on stage. It's my soul that's out there. The reason I perform is the exchange that happens."

**YOU CAN'T** ignore Nagle's joy of life that keeps her in perpetual motion. If she's not writing, she's hustling a business deal or spending time with her husband and two children.

She's quite proud of acquiring that business sense, because she's learned, after so many years in the biz, to be an artist who "listens twice and speaks once." Here's what she has to show for it.

Of the 1,000 songs she's written, she believes 150 of them could be recorded "tomorrow" for an album. The album's coming, she promises, but not before Nagle records and produces a master of "The Story of Poor Ol' Joe," a song about a man who couldn't say no to life's vices, at Tom Marolda's Songgram Studios in Mercerville. There will be an accompanying video, she promises, and she's toting around the storyboard as proof of her inclinations. If a major label doesn't take them, Nagle will put them out herself.

She's been asked to score a "metaphysical nature film" called "Dreamers," written by Danielle McCall and currently in negotiation for major release. Collaborating on the score are Dream Peace bandmates plus local musicians Bruce Foster, Greg Merkle and Marcus Dagan.

Then there are plans for a children's book, "Mothers and Daughters," which Nagle's writing with her mother, poet and former activist Barbara Cruckshank, to be accom-



Monica Nagle and Dream Peace perform Wednesday at John & Peter's in New Hope, Pa.

**NAGLE ALSO** plans to mount a world tour with Dream Peace in 1988. Again, if a major label backs her, fine. If not, she'll do it anyway. Meanwhile, folk, blues and jazz festivals are seeking her out, as Nagle moves further from the coffeehouse circuit.

How does she do it all? "I'm a delegator of responsibility and keeping within the realm of the arts," she says. "It's all the same, really."

"I'm not a fake. I'm for real. I write my own material and I have a beautiful, raw, untrained voice. It's raw. It's there. The soulfulness comes through no matter what."

"And everything I write about is something I truly believe and feel. I'm not afraid to write about who I am."

...and she's in a "therapeutic

# Teens, Parents, Artists Celebrate at Festival in Alton

By RAY CARBONE  
Staff Writer



Dancers from the Boston Conservatory of Music perform to the music of the Martin Luse Collection during "The Art of Living" New Hampshire Festival held at the Alton Bay Pavilion Saturday. The all-day festival, sponsored by the New Hampshire YMCA, allowed high

age — to see the arts positively. Another goal, according to Nagle, is to help youngsters see the arts as an important part of their lives. Open stage cafes have been held in Laconia, Gilford and Gilmanton and Nagle hopes to expand the program to Belmont, Littleton and Wilton soon.

Nate Jasper, 18, of Gilford — who was the first to perform with his band Vacant Lot — enjoyed the show.

"It's good," he said. "It's hard to find a real combination of people with different musical things together like this... I think it's cool."

Chuck Macchire, another member of Vacant Lot who served as emcee for the show, said that among the group called the Rhythmic Jukes were at the show.

"They're a really good band," Macchire said.

But some observers — including Alton Police Officer Steven Holly — said that some of the things they saw at the festival were not what they were talking to some kid and he said to me, "But you're not 18, you don't care." That's one of the reasons that I'm here, to show the kids that I

ARTS, Page 8

ALTON — Students, parents and artists from all over New England gathered at the Alton Bay Pavilion Saturday for the New Hampshire YMCA's "The Art of Living" New Hampshire Festival.

The festival program was an outgrowth of a grant that the organization has been operating in the Lakes Region recently. High-school age poets, dancers, comedians, singer-songwriters, bands and other artists performed while adult artists acted as both mentors and colleagues.

The festival is every aspect of festival production, including staging, sound and promotion, according to Monica Nagle, director of Arts and Humanities for the New Hampshire YMCA.

Continental Cablevision taped the show and highlights will reportedly be shown on the "The Art of Living" program. Students assisted with the taping and will be helping during the production stage of the broadcast.

"The Art of Living" is aimed at building community partnerships while encouraging students — of both high school and middle school

words. "There will always be kids who break the rules and they wanted to say that it was not the space for something like that," Nagle related. "I was not the space for those kinds of things, that's not what we're about."

Nagle said that 125 people attended the event and admitted that drawing a crowd for the festival was more difficult than she had imagined.

"We're competing with (Alton's) friends-making," she said.

it anyway." Frank Kuman, an artist from Plymouth who served as a mentor for the project, was asked to comment on the student's remarks.

"I think it shows that they're artists," Kuman said. "It's important to speak for itself. If you're asking me to judge it, I'm not going to."

Nagle said that the words disturbed her. Later, a number of teens who regularly work on the cafes got together and changed the artwork.

On a floor illustration students were asked to write on, one student wrote "I'm not going to be an artist." Another student wrote "I'm not going to be an artist." Another student wrote "I'm not going to be an artist."

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Monica Nagle.

### Dream Peace Headlines At Princeton Benefit

The jazz/blues/folk ensemble, Monica Nagle and Dream Peace, the new age instrumental guitarist Greg Merkle, singer/songwriters Marcus Dagan, Jeffrey Folmer and Lisa Cornelio, the eclectic 12 string guitarist/vocalist Jim Hickey, and the new age jazz artist P.J. Lorenz, will join forces for a benefit concert May 13 at Princeton University.

Three charities will benefit from this wide-ranging show—United Cerebral Palsy, the Alpha House of Camden, and the Dream Peace Foundation. Dream Peace is a newly formed nonprofit organization that channels funds to various charities itself, including the peace movement group Beyond War, and the National Federation of Parents for Drug Free Youth.

Guy Ciarcia, an artist from Hopewell, has designed a special set design entitled "Peace Piece," which will add a visual element to the event.

The Women's Center and the Student Volunteers Council of Princeton University are sponsoring the event. Corporate and private donations are being sought to make the concert a financial success.

Tickets (\$10, or \$8 for students) are available at the Richardson Auditorium Box Office, P.J.'s Pancake House in Princeton, the Whole Earth Center in Princeton, the Princeton University Women's Center, and The United

Auditorium, Alexander Hall, on the Princeton campus.

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Executive Director  
January 28, 2005

*Richard M. Coughlin*  
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January 28, 2005

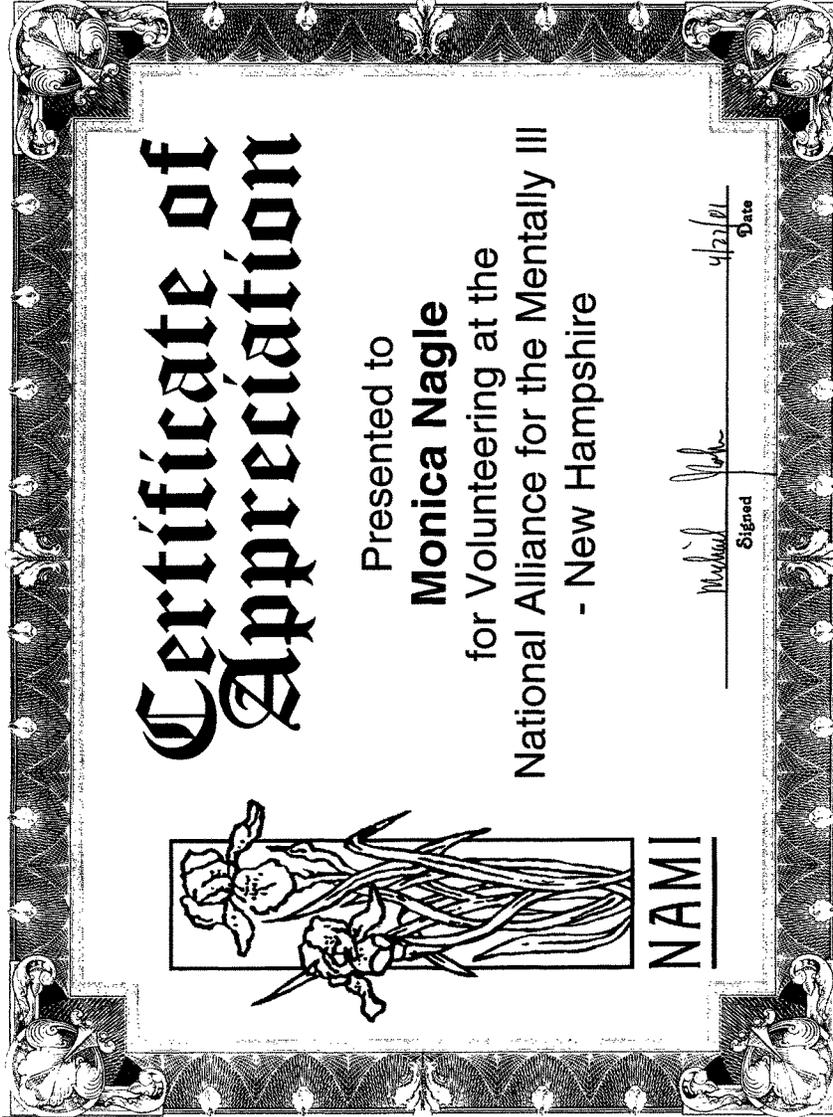
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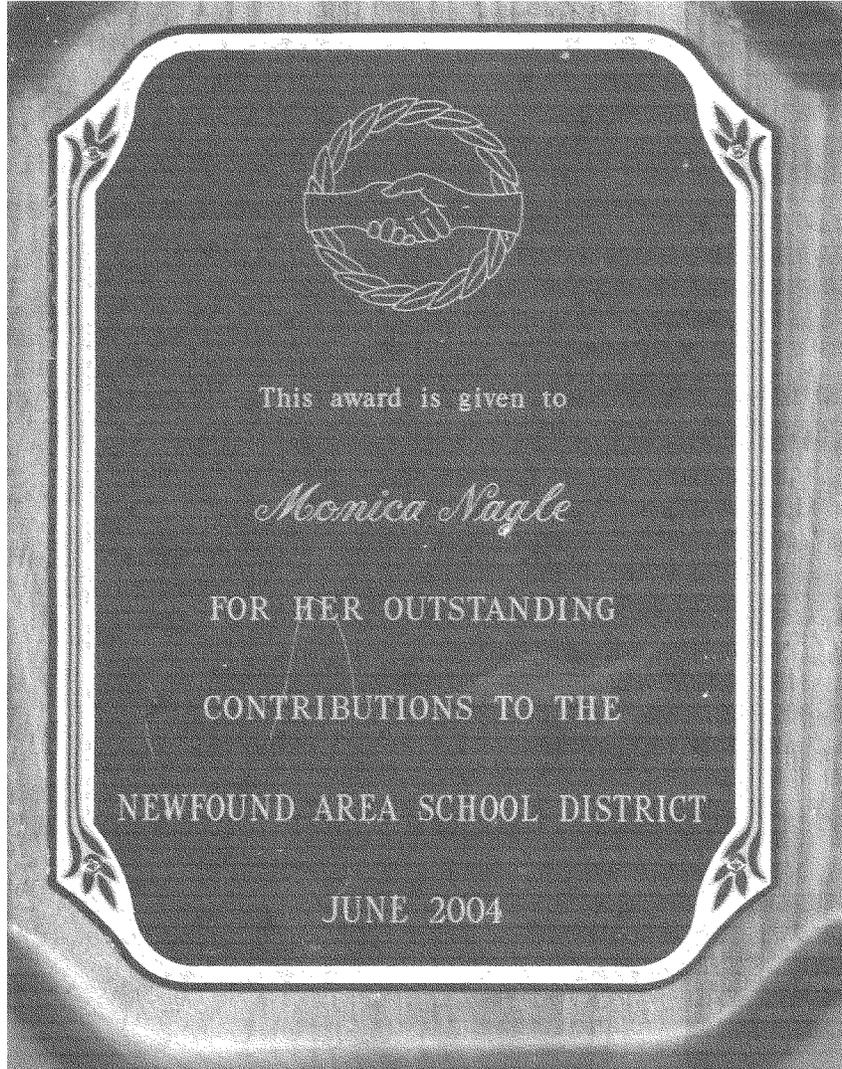
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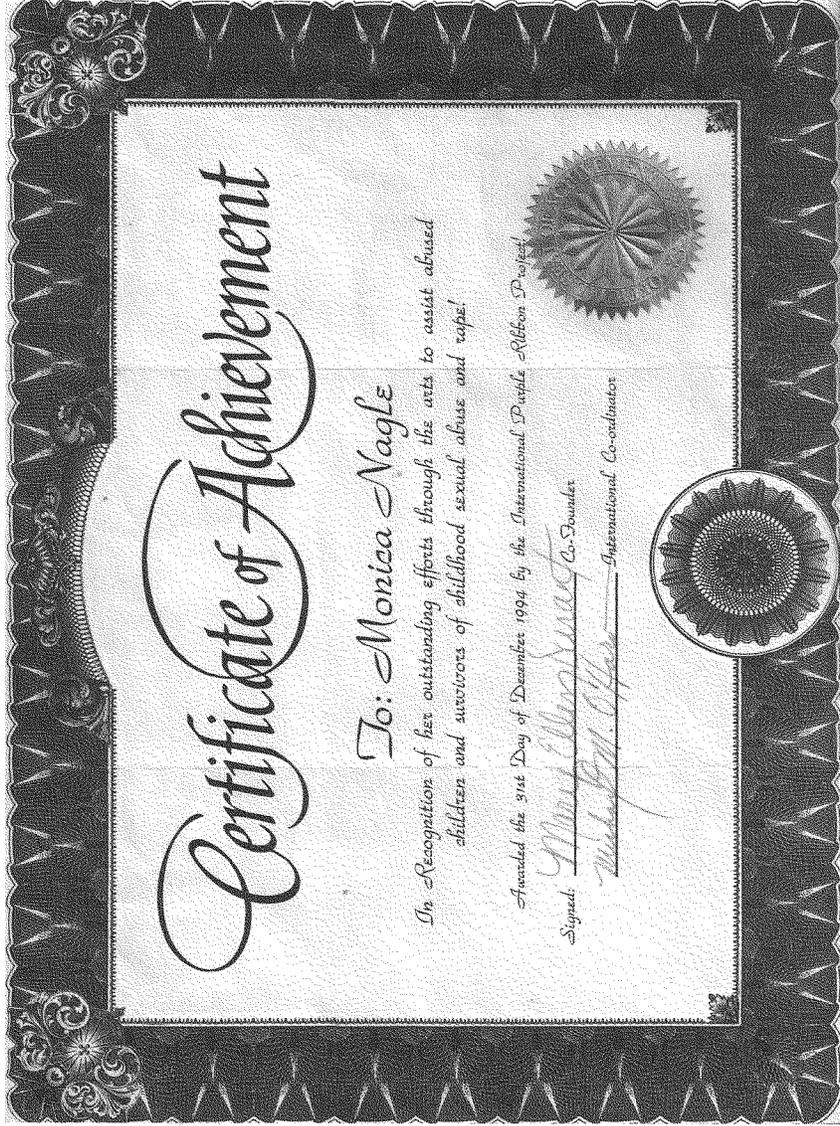
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The Afterschool Alliance

October 8, 2003









July 2, 2007

Robin Renshaw  
Nevada Delegate, "Voices for Work"  
6312 Cromwell Ave.  
Las Vegas, NV 89107

Senate Committee on Finance  
Attn. Editorial and Document Section  
Rm. SD-203  
Dirksen Senate Office Bldg.  
Washington, DC 20510-6200b

RE: Hearing on Barriers to Work for Individuals Receiving Social Security Disability Benefits / June 21, 2007, at 10:00 am in 215

Dear Senate Committee on Finance:

My name is Robin Renshaw. I'm a native of Nevada, born & raised in Las Vegas. I have a disability which is Cerebral Palsy (C.P.) since birth. In addition to having C.P., I attracted an illness at age fourteen which put me in a wheelchair. Yet my disability has never held me back. I received my Associates of Arts Degree in Business Management and working towards my Bachelor's of Science Degree in Education from the University of Nevada, Las Vegas. I have 17 years of experience with non-profits of which the last 8 years, I have been a Transition Specialist with an advocacy organization serving children with disabilities and their families. Today I come to you not only as a person with a disability, but as a strong advocate for the rights of persons with disabilities. I educate family members, educators, service providers, and other professions on disability rights.

As a post-recipient of SSI and a current recipient of SSDI, I know first hand how difficult it is to be at the mercy of assistance while at the same time trying to succeed in life. All of my adult life when I have worked, I constantly have to check myself to see that I don't go over my income limit for fear of losing my benefits. My personal and professional experiences qualified me to be one of the delegates nationwide to participate in the Social Security Summit, 2007. The purpose of summit was to offer suggestions to improving programs. There were many recommendations from the delegates ranging from providing insurance to early childhood to providing insurance to those with disabilities who are working. These recommendations are listed towards the end of this letter. But first, I would like to share my thoughts with you.

The Ticket to Work/Work Incentive Improvement Act gives states the option of expanding Medicaid coverage to employed people with disabilities. As you know, the goal of the grant is to provide employed people with disabilities the opportunity to

maintain Medicaid coverage. In the fall of 2000, the Center for Medicare and Medicaid Services awarded Nevada a Ticket to Work-Medicaid Infrastructure Grant. Soon after, I was appointed to its Advisory Group. Before the tickets were rolled out to those qualified, details of the program were hammered out by this group to ensure people with disabilities who access the program could participate in competitive employment. To date almost 62,000 tickets were mailed statewide in Nevada. Unfortunately though, just over 1,100 are being used.

A couple of years later, Nevada's version of the Medicaid Buy-in program, Health Insurance for Work Advancement (HIWA) was initiated. The program provides employed people with disabilities the opportunity to maintain Medicaid coverage. Today two and half years after implementation, there are only 19 people enrolled. These programs have the potential of integrating more individuals with disabilities into the community and increasing level of self-sufficiency. In addition, the program will improve lives of persons with disabilities so that they not only can be included in the workforce but they can improve their personal lives as well. However, as a person with a disability, I can attest that people with disabilities are hesitant on going to work for fear of losing their insurance benefits. Consequently, people choose not to enroll.

To ensure that the legislature would approve funding for HIWA, we had to set an unearned income cap at \$699.00 a month to qualify. This is one of the main reasons enrollment is low. Which ever program an individual chooses to enroll in, there is usually an income cap attached to it. Therefore, many people with disabilities, including myself play the "gainful employed" game in which we work to a point in which not to exceed this amount. Because I'm on SSDI, I can only make \$899.00 a month. Because of this, I only work 20 hours a week.

Aside from income caps, there are other factors as to why persons with disabilities are fearful of going to work. These are as follows: 1) Rate Hike of Insurance Companies - If a person with a disability finds employment and decides to get off of Medicaid/Medicare, and want to obtain health insurance through their employer, most insurance companies will increase their premium as soon as they find out that there is a person with a disability employed. 2) Employment Longevity - A lot of jobs that persons with disabilities acquire do not last due to resources. Because of this, as soon as a person becomes unemployed, he/she has to apply again for benefits which may take a few months. 3) Income Gap - Partly because people with disabilities are more likely to hold part-time jobs, their earnings are lower than those of their non-disabled peers. In 1995, working men with disabilities earned on average only 72.1 percent of the amount non-disabled men earned annually, according to data from the SIPP, while working women with disabilities made 72.6 percent as much as those without disabilities. I think these numbers scream out with clarity and illustrate the dilemma persons with disabilities are faced with. It raises the question, "can we afford to work at the risk of losing our benefits?" Most people with disabilities know that even though they want to work, they know they really can't because of health care. Therefore, they continue receiving Medicaid/Medicare.

Medicaid and Medicare spend millions every year to eligibility workers to keep track of us to make sure we don't make too much money. We don't need an incentive to work. We already have that within us! What we need is a viable program that will allow us to work without playing the game. The following are our recommendations.

- Raise the SGA amount to \$1,800, and keep COLA (cost of living adjustment). Adjust earnings and asset limits to today's dollars with COLA. Raise the SSI resource limit to at least double (\$7,000/\$10,000 with a COLA) with more asset exclusions (allow asset development, savings and retirement).
- Allow people with disabilities on SSI/SSDI to work and keep some of their cash and medical benefits. Allow beneficiaries to keep health care when they go back to work, including self-employment.
- Develop and implement a Work Support Program to allow people with disabilities to go back to work and gradually cut back benefits. Beneficiaries need to be involved in the development and implementation of the Work Support Program.

Years ago when the Americans with Disabilities Act (ADA) of 1990 was enacted, prohibiting discrimination against individuals with disabilities in employment, housing, education, and access to public services, people were excited and thought it would give us more opportunities. I must agree it did, it gave us ramps into buildings, wider door ways, lowered telephone booths, etc. However, it did not give us equality. Until we are given an opportunity to work without stipulations, we will never be able to fully achieve our goals in life. I know that I'm not alone among my fellow delegates in saying that I hope you will consider these recommendations and know they truly will enhance our lives!

Thank you,



Robin Renshaw  
Delegate; Social Security Summit, 2007

June 21, 2007 Barriers to Work for Individuals Receiving Social Security Benefits.

Joseph Steffy, KS age 21

I graduated from high school at age 18. I have multiple complex disabilities but my greatest disability is LES, Low Expectation Syndrome. My IEP team at school said I would live in a group home, go to a workshop and thought my parents were in denial of the significance of my disabilities. It was not a good environment and the three years from 18 - 21 would not have benefited me.

Through Partners in Policymaking training in Kansas my parents heard a presenter on "Entrepreneurship for Individuals with Disabilities." My parents knew my strengths and my need to be active. There were opportunities for me if I were to build on my ABILITIES.

Vocational Rehabilitation agreed to work with me to start my business. My mom attended First Step Fast Track Program in Kansas City and wrote a feasibility plan for Poppin Joe's Kettle Korn. This was completed and became the business plan combined with 1) the PASS plan (Plan for Achieving Self Support), 2) the grant application to the Kansas Council for Developmental Disabilities and 3) vocational rehabilitation business support. These all worked together to form Poppin Joe's Kettle Korn in April 2005. I am the sole proprietor.

I pop at events and festivals in the area. I have a small weekly route where I sell my four products in convenience stores. By January 1, 2006 Poppin Joe's had done well enough, I was no longer eligible for SSDI.

I am a part of my community where I contribute and am valued. I do not live in a group home. I do not go to a workshop to pass time with little or no pay. My mom calls workshops the American legalized sweat shops, whatever that means.

As Poppin Joe, I hire six part time employees. There are several parts to my work. I work at one of the tasks until I need to change jobs. My employees work accordingly. I pay taxes.

My community is interested in what I am doing. At a recent Rotary Club in Overland Park, KS I spoke. The first comment was, "I am sure glad to hear of a government program that works."

This has been possible because of the support of the Kansas Council for Developmental Disabilities, the PASS Plan, Vocational Rehabilitation, and the First Step Program that gave mom the skill to write a business plan. All put together it gives me the opportunity to be all I can be. I have a place in my community. I belong.

You see all the records say I have down syndrome, autism, that I am non-verbal, a hearing loss, ADHD, epilepsy, obsessive-compulsive behaviors. My records say nothing about my strengths and abilities.

Please know the opportunity to own my own business successfully is only because of what is in place. The PASS is the best kept secret there is to support us. Agency personal do not know how powerful a tool they have to offer, and people with disabilities do not know it is there to be asked for.

Visit my website: [www.PoppinJoes.com](http://www.PoppinJoes.com).

Sincerely, joe steffy KS

**Statement of  
Berthy De La Rosa Aponte, Chair**

**Ticket to Work and Work Incentives Advisory Panel,  
Social Security Administration**

**Submitted to the Senate Committee on Finance**

**Hearing on  
“Barriers to Work for Individuals Receiving Social Security  
Disability Benefits”**

**June 21, 2007**

As Chair of the Ticket to Work and Work Incentives Advisory Panel (the Panel), I respectfully submit the following statement on behalf of the Panel. We appreciate this opportunity.

The topic of today’s hearing, “Barriers to Work for Individuals Receiving Social Security Disability Benefits,” represents one of the core issues to which the Panel has been devoting much of its work since Congress established the Panel in 2000 as part of the Ticket to Work and Work Incentives Improvement Act of 1999 (the Act). The Panel will continue to focus on this issue through our sunset date of December 2007.

At each of the Panel’s meetings, we have heard from diverse stakeholders, including beneficiaries who have shared their perspectives and advice on the need for immediate improvements to current programs under the Act, as well as approaches to more comprehensive, systemic changes to policy and system design. We have also conducted extensive policy research, consulted both nationally and internationally with experts in the field of return to work, and provided the President, Congress and the Commissioner of the Social Security Administration (SSA) with recommendations and counsel for enhancing the return to work efforts of disability beneficiaries.

Beneficiaries’ perspectives and recommendations have played a primary role in the development of Panel advice and will continue to play a critical role as we develop the recommendations in our Final Report, which will be released at the end of 2007. Beneficiaries have affirmed to the Panel that most people with disabilities want to work but are challenged by system fragmentation and complexity, fear of loss of health care benefits and overpayments, and well intended policies that have the effect of limiting economic security and advancement. It is estimated that, in 2005, 104,100 non-employed SSI beneficiaries were actively looking for work, and 103,200 non-employed SSDI beneficiaries were actively looking for work.<sup>1</sup>

Over the years, the Panel has provided recommendations related to SSA's work incentives, health care programs, administrative and programmatic operations and budgetary issues, as well as the work of other federal programs charged with the responsibility of removing barriers to employment and economic self-sufficiency for individuals with disabilities. Below are key recommendations that the Panel has made and that we reiterate now as you consider strategies and approaches for removing barriers to work.

Our recommendations are organized into the following categories: 1) Ticket to Work and Self-Sufficiency Program-Related Issues; 2) Marketing and Outreach on Work Incentives; 3) Improving/Simplifying Specific Work Incentives; and 4) Training for Work Incentives Specialists.

#### **Ticket to Work and Self-Sufficiency Program-Related Issues**

On September 30, 2005, SSA published a Notice of Proposed Rule Making called "Amendments to the Ticket to Work and Self-Sufficiency Program." These proposed amendments incorporated many of the Panel's priority recommendations. We were particularly pleased that the proposed amendments accounted for and addressed the multi-step nature of returning to work by calling for a new payment system for Employment Networks (ENs), offering more frequent and earlier payments.

The Panel was hopeful that the proposed changes would improve the program. Unfortunately, SSA has not yet published the final regulations, and the program continues to face significant problems. In fact, the number of active ENs working with Social Security beneficiaries has been in a statistical decline for the past eight months.

The Panel continues to hold hope for a demand-driven approach to supporting beneficiaries in going to work; however, without significant enhancements and aggressive outreach, we fear the Ticket Program will not recover from initial design flaws and ongoing beneficiary and EN disenchantment.

Specifically, the Panel recommends:

- All SSI and SSDI adult beneficiaries, including those designated as medical improvement expected, should be eligible to participate in the Ticket Program.<sup>2</sup>
- Payments to ENs should be more frequent and earlier to reduce ENs' financial risk. One caution is that SSA should review the lump sum milestone payment provisions to ensure Tickets retain sufficient value so beneficiaries continue to be able to negotiate for needed services later in their return to work efforts.<sup>3</sup>
- SSA should rewrite the regulations and modify transmittal 17 to make it clear that:
  - Beneficiaries' eligibility for vocational rehabilitation (VR) service or the scope of those services should not be adversely affected by where they assign their Ticket.

Eligibility for VR services and VR client status should not dictate when or where beneficiaries can use their Ticket.

- ENs should receive payments from SSA for beneficiaries who, with EN assistance, continue in employment above substantial gainful activity (SGA) after VR has been paid under the traditional cost reimbursement system.<sup>4</sup>
- Transition-aged youth should be eligible for Tickets.<sup>5</sup>
- Request Commissioner of SSA's support of Panel's recommendation to Congress to extend Ticket continuing disability review (CDR) protection to any and all beneficiaries who are participating in an approved program of VR services, employment services, or other employment support services.<sup>6</sup>
- Explicitly state that a person entitled to benefits pursuant to expedited reinstatement is immediately eligible for a new Ticket.<sup>7</sup>
- Amend statute to permit the Ticket Program to increase the sum of payments for serving SSI beneficiaries to a level equal to the sum of payments for serving SSDI beneficiaries.<sup>8</sup>
- Beneficiaries should be eligible for more than one Ticket in a period of entitlement for SSDI/SSI benefits when their disability is likely to require some indefinite supports to remain employed (including self-employment).<sup>9</sup>

#### **Marketing and Outreach on Work Incentives**

A coordinated marketing and substantial nationwide public education campaign, targeted to beneficiaries, their families and disability service providers, is needed to increase awareness of SSA's work incentives and to debunk some of the widely held misperceptions about the negative consequences of work for beneficiaries. As referenced earlier, there are substantial numbers of disability beneficiaries actively engaged in looking for work who could face greater likelihood of success if they knew what supports were available and how existing work incentives could provide an important safety net in their return to work.

Specifically the Panel recommends:

- SSA should immediately develop a national marketing and public education campaign to explain available programs.<sup>10</sup>
- Expand resources available to broaden the impact of the work incentives planning and assistance network.<sup>11</sup>
- Expand resources available to broaden the impact of protection and advocacy services and supports.<sup>12</sup>

**Improving/Simplifying Specific Work Incentives**

Across the board, SSA needs to reduce the complexity and improve the consistency of work incentives for both the SSDI and the SSI programs. We are pleased to announce that the Panel, in consultation with national experts, is preparing an advice report for the President, Congress, and SSA on work incentives utilization. We will be deliberating on this report during our July 2007 quarterly meeting, and plan to publish it this summer.

This Panel is considering ten themes or high level recommendations that form an overall basis for increasing the utilization of work incentives, and more importantly, improve the employment status of beneficiaries with disabilities.

1. Increase awareness of beneficiaries about work incentives (including better understanding and expanding outreach efforts).
2. Improve the collection, organization, and use of data about work incentive utilization for decision making.
3. Improve SSA customer service and the knowledge base of accurate information (training and technical assistance to SSA personnel) delivered to beneficiaries.
4. Integrate planning and delivery of work incentive programs across the myriad of federal programs involved.
5. Increase the number of trained work incentive planning specialists dedicated to assisting beneficiaries.
6. Conduct studies and create demonstration projects to exemplify improved work incentives utilization.
7. Increase the limits on liquid cash and assets for the purposes of future security for beneficiaries.
8. Assure accessible health care as work incentives are utilized.
9. Reduce the risk of overpayments for beneficiaries.
10. Ensure that work incentives accommodate the dynamic nature of disability.

**Training for Work Incentives Specialists**

The Panel has continued to recommend that Congress appropriate funds for training of SSA staff and work incentives specialists to explain work incentives to beneficiaries, and is currently reviewing how beneficiary support is provided within the current field office structure.

The Panel has also supported funding private organizations to provide work incentives training and support, beginning with the Benefits Planning, Assistance, and Outreach Program and now the Work Incentives Planning and Assistance Program as well as the Protection and Advocacy for Beneficiaries of Social Security Program.

Specifically, the Panel recommends:

- Congress should direct SSA to spend more on public education and field training.<sup>13</sup>

#### **Next Steps for Panel**

The Panel's three goals are driving our work: 1) Goal 1 – Elevate and Incorporate the Beneficiary Perspective; Goal 2 – Improve Implementation and Marketing of the Ticket to Work and Work Incentives Improvement Act; and Goal 3 – Develop A National Employment Investment Strategy to Transform Approaches to Assets, Income, Health Care, and Supports for People with Disabilities that is Person-Centered, Culturally Competent, and Respectful of Each Person's Values and Experiences

The recommendations we have offered to date are part of our continuous improvement goal, and our forthcoming advice report on work incentives utilization will provide more detailed recommendations for increasing utilization of work incentives.

The Panel will also be publishing two other reports in line with our other goals. These reports will feed into our Final Report.

1. Beneficiary Summit Report – “Voices for Change: Beneficiaries Paving the Way to Work”

This report will include the Beneficiary Summit recommendations. In addition, the Panel will be developing recommendations for ensuring beneficiary input for future policy development separate from this report.

2. National Employment Investment Strategy Report

The Panel recognizes that more will need to be done outside the current structure to more substantially remove barriers to work for people with disabilities. This report will lay out a comprehensive approach to promoting employment for people with disabilities – today and in the future.

#### **Conclusion**

It is essential that SSA act sooner rather than later to decrease the complexity of work incentives, to improve the consistency of work incentives for both the SSDI and the SSI programs, and to remove barriers to work. Social Security beneficiaries with disabilities have waited far too long for improvements. This urgency applies particularly to youth who are transitioning from school to work. Now is the time for SSA to integrate a return-

to-work philosophy and culture into its service to the public, especially for new beneficiaries.

Thank you for this opportunity.

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<sup>1</sup> Houtenville, A. J., Erickson, W. A., Lee, C. G. (2007, March 16). Disability Statistics, from the American Community Survey (ACS). Ithaca, NY: Cornell University Rehabilitation Research and Training Center on Disability Demographics and Statistics (StatsRRTC). Retrieved June 7, 2007 from [www.disabilitystatistics.org](http://www.disabilitystatistics.org).

<sup>2</sup> Final Advice Report on Ticket Program Notice of Proposed Rule Making, July 2001.

<sup>3</sup> Annual Report: Yr. 6, Advisory Letter to Commissioner Re. NPRM September 2005.

<sup>4</sup> Annual Report: Yr. 6, Advisory Letter to Commissioner Re. NPRM September 2005.

<sup>5</sup> Annual Report: Year Two; Aug. 2002.

<sup>6</sup> Advisory Letter to Commissioner Re. NPRM Aug. 2003 on Continuation of Benefit Payments.

<sup>7</sup> Advisory Letter to Commissioner Re. NPRM Oct. 2003 on the Reinstatement of Entitlement to Disability Benefits (EXR).

<sup>8</sup> Advice Report on Employment Networks; Feb. 2004.

<sup>9</sup> Annual Report: Yr. 6, Advisory Letter to Commissioner Re. NPRM Sept. 2005.

<sup>10</sup> Annual Report: Year Three; May 2003.

<sup>11</sup> Letter to Sue Suter, Associate Commissioner, SSA's Office of Employment Support Programs, Feb. 11, 2005.

<sup>12</sup> Letter to Congressman Shaw and Senator Grassley, Nov. 20, 2003.

<sup>13</sup> Annual Report Year 2.

