BARRIERS PREVENTING DISABILITY BENEFICIARIES FROM RETURNING TO WORK

HEARING

BEFORE THE

SUBCOMMITTEE ON SOCIAL SECURITY

OF THE

COMMITTEE ON WAYS AND MEANS
HOUSE OF REPRESENTATIVES

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CONTENTS

Page

Advisory of March 4, 1999, announcing the hearing 2

WITNESSES

Social Security Administration, Hon. Kenneth S. Apfel, Commissioner of Social Security; accompanied by Susan Daniels, Ph.D., Deputy Commissioner for Disability and Income Security Programs 13

U.S. General Accounting Office, Cynthia M. Fagnoni, Director, Income Security Issues, Health, Education, and Human Services Division; accompanied by Brett Fallavollita, Senior Evaluator 26

Consortium for Citizens with Disabilities, Social Security Task Force, Mary Gennaro 45

Johnson, Hon. Nancy L., a Representative in Congress from the State of Connecticut 5

Manic Depressive Association, and National Alliance for the Mentally Ill, Jim McNulty 54

National Association of Developmental Disabilities Councils, Mary Gennaro ... 45

National Association of Rehabilitation Professionals in the Private Sector, Jeffrey E. Carlisle 61

Ramstad, Hon. Jim, a Representative in Congress from the State of Minnesota 8

Services for Independent Living, Richard Blakley 40

SUBMISSIONS FOR THE RECORD

Corporation for Supportive Housing, New York, NY, John Rio, statement and attachment 67

San Francisco Network on Disability, Berkeley, CA, Jean Nandi, letter 71

Stark, Hon. Fortney Pete, a Representative in Congress from the State of California, letter and attachments 72

BARRIERS PREVENTING DISABILITY BENEFICIARIES FROM RETURNING TO WORK

MARCH 11, 1999

HOUSE OF REPRESENTATIVES,
COMMITTEE ON WAYS AND MEANS,
SUBCOMMITTEE ON SOCIAL SECURITY,
Washington, DC.

The Subcommittee met, pursuant to notice, at 10 a.m., in room 1100, Longworth House Office Building, Hon. E. Clay Shaw, Jr., (Chairman of the Subcommittee) presiding.

[The advisory announcing the hearing follows:]

ADVISORY

FROM THE COMMITTEE ON WAYS AND MEANS

SUBCOMMITTEE ON SOCIAL SECURITY

FOR IMMEDIATE RELEASE
March 4, 1999
No. SS–4

Contact: (202) 225–9263

Shaw Announces Hearing on Barriers Preventing Disability Beneficiaries From Returning to Work

Congressman E. Clay Shaw, Jr., (R–FL), Chairman of the Subcommittee on Social Security of the Committee on Ways and Means, today announced that the Subcommittee will hold a hearing on barriers preventing Social Security disability beneficiaries from returning to work. The hearing will take place on Thursday, March 11, 1999, in the main Committee hearing room, 1100 Longworth House Office Building, beginning at 10:00 a.m.

Oral testimony will be heard from invited witnesses only. Witnesses will include program experts, representatives of organizations promoting the self-sufficiency of people with disabilities, providers of services assisting return to work efforts, and consumers and potential consumers of those services. However, any individual or organization not scheduled for an oral appearance may submit a written statement for consideration by the Committee and for inclusion in the printed record of the hearing.

BACKGROUND:

Social Security's disability programs help protect workers and their families against financial hardship if workers experience disabling conditions that prevent them from working. Between 1988 and 1998, the number of working-age recipients on the Social Security and Supplemental Security Income (SSI) disability rolls increased 60 percent. Today, there are 4.7 million individuals receiving Social Security disability benefits and 4.3 million receiving SSI disability benefits. In addition, disabled recipients are staying on the rolls longer than in the past because of increased life expectancy, earlier onset of disability, and increased awards for mental impairments, which manifest at younger ages.

In 1996, fewer than six percent of new disability recipients were referred to State vocational rehabilitation agencies for services, and historically less than one-half of one percent of disabled recipients have left the rolls because of successful rehabilitation. These facts underscore the need for initiatives designed to encourage those disabled recipients who want to receive rehabilitation services and to re-enter the workforce.

To help Social Security and SSI disability recipients who want to return to self sufficiency, H.R. 3433, the "Ticket to Work and Self-Sufficiency Act," was introduced by then Subcommittee Chairman Jim Bunning and Ranking Minority Member Barbara Kennelly, and was passed overwhelmingly by the House by a vote of 410 to 1 during the 105th Congress. No action was taken by the Senate.

However, during the 106th Congress, S. 331, the "Work Incentives Improvement Act of 1999," has been introduced in the Senate and approved by the Finance Committee. Many of the provisions in H.R. 3433 are included in this legislation.

In announcing the hearing, Chairman Shaw stated: "Many individuals with disabilities can and want to work, but the current system offers barriers, not opportunities. Everyone should participate in, and benefit from, our booming economy. The time to act to provide real hope and opportunity for disabled workers is now."

FOCUS OF THE HEARING:

During the hearing, the Subcommittee will consider the views of program experts, consumers, and service providers on the barriers which prevent disability recipients from returning to work. The Subcommittee will also evaluate recommendations on what changes in the law are needed to remove those barriers.

DETAILS FOR SUBMISSION OF WRITTEN COMMENTS:

Any person or organization wishing to submit a written statement for the printed record of the hearing should submit six (6) single-spaced copies of their statement, along with an IBM compatible 3.5-inch diskette in WordPerfect 5.1 format, with their name, address, and hearing date noted on a label, by the *close of business*, Thursday, March 25, 1999, to A.L. Singleton, Chief of Staff, Committee on Ways and Means, U.S. House of Representatives, 1102 Longworth House Office Building, Washington, D.C. 20515. If those filing written statements wish to have their statements distributed to the press and interested public at the hearing, they may deliver 200 additional copies for this purpose to the Subcommittee on Social Security office, room B–316 Rayburn House Office Building, by close of business the day before the hearing.

FORMATTING REQUIREMENTS:

Each statement presented for printing to the Committee by a witness, any written statement or exhibit submitted for the printed record or any written comments in response to a request for written comments must conform to the guidelines listed below. Any statement or exhibit not in compliance with these guidelines will not be printed, but will be maintained in the Committee files for review and use by the Committee.

1. All statements and any accompanying exhibits for printing must be submitted on an IBM compatible 3.5-inch diskette in WordPerfect 5.1 format, typed in single space and may not exceed a total of 10 pages including attachments. Witnesses are advised that the Committee will rely on electronic submissions for printing the official hearing record.

2. Copies of whole documents submitted as exhibit material will not be accepted for printing. Instead, exhibit material should be referenced and quoted or paraphrased. All exhibit material not meeting these specifications will be maintained in the Committee files for review and use by the Committee.

3. A witness appearing at a public hearing, or submitting a statement for the record of a public hearing, or submitting written comments in response to a published request for comments by the Committee, must include on his statement or submission a list of all clients, persons, or organizations on whose behalf the witness appears.

4. A supplemental sheet must accompany each statement listing the name, company, address, telephone and fax numbers where the witness or the designated representative may be reached. This supplemental sheet will not be included in the printed record.

The above restrictions and limitations apply only to material being submitted for printing. Statements and exhibits or supplementary material submitted solely for distribution to the Members, the press, and the public during the course of a public hearing may be submitted in other forms.

Note: All Committee advisories and news releases are available on the World Wide Web at "http://www.house.gov/ways__means/".

The Committee seeks to make its facilities accessible to persons with disabilities. If you are in need of special accommodations, please call 202–225–1721 or 202–226–3411 TTD/TTY in advance of the event (four business days notice is requested). Questions with regard to special accommodation needs in general (including availability of Committee materials in alternative formats) may be directed to the Committee as noted above.

Chairman SHAW. Good Morning.

Today the Subcommittee will consider ways to provide new opportunities for individuals with disabilities to return to the work force and lead fuller, more productive lives. As we all know, this Subcommittee and the Full Ways and Means Committee have played a key role in this effort in recent years, leading up to the nearly unanimous passage last year of H.R. 3433, the Ticket to Work and Self-Sufficiency Act.

While that bill did not make it all the way to the legislative finish line, there is a real cause for confidence that we can reach our common goal this year. My predecessor, Chairman Jim Bunning and Ranking Member Barbara Kennelly, and the other Members of the Subcommittee, spent countless hours over several years holding hearings and refining what became last year's bill. For those who were not paying attention, that bill promised to ease the transition of disability beneficiaries into work by providing easier access to services and an additional 2 years of Medicare coverage.

I think we are all in agreement that this legislation will enable thousands of individuals with disabilities who want to work to do so. It preserves the Social Security and Supplemental Security Income Disability Programs, as a much needed safety net for people who are unable to work. As this Congress gets rolling, we have a fairly clear road map on how to proceed. I know there is some lingering disagreement as to some of the details, but these details are minor in comparison with the total bill.

For my money, the differences are just that: details that can and will be worked out as we proceed. Given how far we have already come together, I am confident we can make this work.

I welcome all of our witnesses and guests and look forward to hearing everyone's testimony this morning.

[The opening statement follows:]

Opening Statement of Hon. E. Clay Shaw, Jr., a Representative in Congress from the State of Florida

Today the Subcommittee will consider ways to provide new opportunities for individuals with disabilities to return to the workforce and lead fuller, more productive lives.

As we all know, this Subcommittee and the full Ways and Means Committee have played a key role in this effort in recent years, leading up to the nearly unanimous passage last year of H.R. 3433, the Ticket to Work and Self-Sufficiency Act. While that bill didn't make it all the way to the legislative finish line, there is real cause for confidence that we can reach our common goal this year.

My predecessor, Chairman Jim Bunning, and Ranking Member Barbara Kennelly and the other Members of this Subcommittee spent countless hours over several years holding hearings and refining what became last year's bill. For those who weren't paying attention, that bill promised to ease the transition of disability beneficiaries into work by providing easier access to services and an additional 2 years of Medicare coverage.

I think we are all in agreement that this legislation would enable thousands of individuals with disabilities who want to work to do so. And it preserves the Social Security and Supplemental Security Income disability programs as a much-needed safety net for people who are unable to work.

So as this Congress gets rolling, we have a fairly clear roadmap for how to proceed. I know there is some lingering disagreement as to some details. But for my money, the differences are just that—*details* that can and will be worked out as we proceed. And given how far we have already come together, I am confident we can make this work.

I welcome all our witnesses and guests, and look forward to hearing today's testimony.

Chairman SHAW. Mr. Matsui.

Mr. MATSUI. Thank you very much, Mr. Chairman. I really appreciate the fact that you are holding this hearing today. I would like to personally thank you, and your staff, for working together with Members of our side of the aisle on this particular issue. I understand we are still discussing the matter and I appreciate that opportunity.

If the Chair recalls, last year after the House had passed its Ticket to Work version of our legislation, the bill eventually died in the Senate before we were able to get it to the President. We adjourned. Mainly what occurred was Senators Jeffords and Kennedy introduced a bill that would have extended, for a longer period of time, the 2-year additional period of Medicare coverage. They recently, as those in the audience and others know, passed their version of the legislation on a 16-to-2 vote, out of the Senate Finance Committee. I think it was just last week, in fact.

I believe the issue again will be addressed in the conference, or perhaps on the House floor, or perhaps in the Full Committee. We all know that one of the most important things for those that are disabled is not only vocational rehabilitation opportunities, but also health care. Health care is an extremely critical component of making sure that people are given the opportunity for self-sufficiency.

So, it is my hope we can work together and see if we can, perhaps, move more in the direction of the Jeffords-Kennedy legislation as time goes on and as this legislation proceeds further. I believe there is bipartisan support for it, not only in the Senate, but also in the House.

Again, I think this hearing is extremely important. It doesn't have the visibility that many other hearings of the Congress have, but it will have a significant bearing on millions of Americans and their families.

Thank you, Mr. Chairman.

Chairman SHAW. Thank you, Bob.

We have as our first panel, Nancy Johnson and Jim Ramstad, two valuable Members of the Ways and Means Full Committee. As both of you know, we have your full statements. Without objection they will be made part of the record. You may proceed.

Mrs. Johnson.

STATEMENT OF HON. NANCY L. JOHNSON, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF CONNECTICUT

Mrs. JOHNSON of Connecticut. Thank you very much, Mr. Chairman. First of all, I thank you and Mr. Matsui and the Subcommittee for holding this hearing on what is really an extremely important bill. I am going to be introducing the bill that has been introduced on the Senate side, with Mr. Lazio, from Commerce and

many Democrats—I hope many from this Subcommittee—as well as Republicans, because there is a tremendous amount of support for this bill.

There is a key difference between the really outstanding work this Subcommittee did on the Ticket to Work bill last year, which is the predecessor, the parent, the core of what we need to do for the disabled, and the initiative that some of us have worked on. The key difference is in access to medical benefits. That is the bottom line.

As you well know, in the old days of welfare, if someone got a part-time job, they were off the program. Even if they could see that they could move up to full-time salary; if it wasn't a plan with health benefits and their children needed benefits, they often could not, in all good conscience, get off welfare. They could not afford to lose access to the Medicaid benefits. We have put our disabled people in exactly the same position.

There are many barriers to a disabled person getting into the work force. One is, you go $1 over the $500 threshold, you lose everything. So, they will get a part-time job and leave themselves in the position. This is so ironic. You have people come to you and sit down and tell you, I am working 10 hours at Stop-and-Shop. It's the Christmas rush. They want me to work more hours. I want to work more hours but I can't, because the government won't let me. If I work a little bit over that time, then I lose all of my benefits, both the monetary benefits and the health benefits.

Ticket to Work and the work of this Subcommittee had dealt with the issue of declining the benefits as salary grows. It has also dealt with the problem of letting someone who has left the program reenter the program if their circumstances change rapidly and easily. But we have dealt less well with maintaining access to health benefits. Particularly for people who are disabled as a result of mental illness, with the new drugs that are available which are wonderful, effective and very expensive, their independence and their ability to work depends flat out on their access to that drug benefit. They must be able to maintain access to Medicaid if they are going to work. This bill really does a lot to encourage States to open up Medicaid to their disabled population, even when that person is working. Neither level of government is still subsidizing their income. That is why Energy and Commerce have to do a lot of work on this in order for it to be an effective program.

We did increase access to Medicare benefits. We have to do it over a slightly longer period of time so there can be the confidence that not only will they be able to have access to health care, but they will be able to have it—in a sense—permanently. If we enlarge that access to 10 years, from the current 6 years—currently they have 4 years; we added 2 years; it's 6 years—we will give them the confidence over the course of that time that the problem of access to medical health benefits will be solved for us as a society, according to income.

That is really what many of us are focusing on. The issue of mental health benefits has brought that squarely to the fore. If a person is taking one of the very expensive, but very effective medications for schizophrenia or bipolar whatever, they can function very, very well. But they have two problems: access to that medication

and the problem of relapses. They have to be able to get back in the program and have that support for short periods of time if they have a problem.

I thank you for your good work in this area. I thank you for putting it high on your agenda. I hope we will have a good, solid bipartisan bill that will end up on the President's desk. Thank you.

[The prepared statement follows:]

Statement of Hon. Nancy L. Johnson, a Representative in Congress from the State of Connecticut

I want to commend Representatives Shaw and Matsui for organizing a hearing on this important issue of helping disabled people return to work. Under the leadership of Representatives Bunning and Kennelly, this subcommittee devoted considerable time and effort last session into identifying the barriers that prevent people on Social Security Disability and Supplemental Security Income from returning to work. As a result of their work, the House passed, with significant bipartisan support, the Ticket to Work Act. I am pleased that Chairman Shaw and Ranking Member Matsui have demonstrated their commitment to making this issue a priority again this session.

It is critical that we have federal disability programs to support people who have disabilities that prevent them from gainful employment. When the nature of those programs become barriers to those people returning to work when they are able, we need to identify and remove those barriers. The legislation put together by this subcommittee last year did this for many of the barriers within the cash assistance program, but it was not sufficient because it did not address the largest barrier: lack of affordable health coverage. By guaranteeing health coverage to someone on the system, but removing that access when they return to work, we have created a system that any rationale person would not want to leave.

I am very passionate about this issue because I have heard many true life stories directly from my constituents who are impacted. I have heard about a gentleman with mental retardation who works 10 hours a week in a community grocery store. The work is critical to his mental and emotional health because it gives him the chance to socialize and leave his home. His employer is very pleased with his work and would like to give him more hours. But the man is confronted with the reality that if he works more than 10 hours, he will earn more than $500 and lose his disability benefits all at once.

One of the meetings that caused me to be involved in this issue was with a group of people struggling with severe mental illness. They portray some of the most compelling reasons for this legislation. Returning to work is a significant task for these people, not only because of the financial concerns but also because of the uncertainty of their illness. The effectiveness of psychotropic drugs gives these people the ability to maintain mental and emotional health so they can perform consistently in a work environment. Without these drugs and therapy, returning to work is very difficult. So the most important thing for these people is having access to health coverage to help afford these treatments. In addition, a reoccurrence of their illness could happen at any time, so they need to be assured that the disability system will support and understand them during a relapse.

I have also heard from a young man who has had two organ transplants because of a bout with childhood diabetes. He requires significant health care services and relies on Medicare to provide them. Without the guarantee that he can continue to receive health coverage, returning to work is a no-win situation. He wants to work, but would have to earn a significant income to make up for the loss of his health insurance.

It is difficult to measure completely the impact that having a job makes in a person's life. It gives people a sense of personal value and identity, and there is something very powerful about being able to support oneself. When people return to work there are also positive impacts for our country. If only one percent of the 7.5 million SSI and SSDI recipients go to work and forgo cash payments from the Social Security Administration (SSA), this would result in a cash savings of $3.5 billion to the federal Treasury over the lifetimes of these individuals. If we factor in the income taxes these individuals would pay, their lack of need for food stamps, subsidized housing, and other forms of assistance, that $3.5 billion dollar figure would be even higher.

In this time of low unemployment, we also need to consider the positive benefit of having more workers in our economy. To stay strong, our economy needs access to a qualified and enthusiastic pool of potential workers. People currently on SSI

and SSDI are a tremendous untapped resource. Their enthusiasm alone would make a significant contribution to our workforce.

The Senate has taken the lead on this issue in the 106th Congress with broad-based bipartisan legislation. Their greatest contribution to the debate is their commitment to expanding health care coverage, through Medicare and Medicaid, for people returning to work. This is an important issue that will directly impact people who want desperately to return to work and become independent from government assistance. We should follow through on our work last session and work with the Senate to make sure that we address the critical need for health insurance. Thank you for the opportunity to testify this morning.

Chairman SHAW. Thank you.

Mr. Ramstad.

STATEMENT OF HON. JIM RAMSTAD, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF MINNESOTA

Mr. RAMSTAD. Thank you, Mr. Chairman and Members of the Subcommittee, for holding this important hearing to talk about the barriers which prevent people with disabilities from working.

This is an issue, Mr. Chairman, about which I feel passionately. It is an issue I have heard about from my friends with disabilities for 19 years. Since my first election into the Minnesota State Senate in 1980, I have had a Disabilities Advisory Committee. By far, the number one problem discussed by people with disabilities on the Risk Advisory Committee has been work disincentives within the Federal programs designed to assist people with disabilities.

The most compelling issues facing people who desperately want to work and contribute to society are the program rules that make working too costly and too complicated. Mr. Chairman, the legislation which was alluded to by Ranking Member Matsui and talked about by our friend, Nancy Johnson, has 54 cosponsors, already, in the Senate. Certainly, any time my two senators can agree on anything, it is a historic day. Two of the names on that bill are Paul Wellstone and Rod Grams. There is a bipartisan working group already sponsoring this legislation.

We have got to take steps to prevent abuses in the system. In so doing, however, we also have to tear down the barriers that prohibit Americans with disabilities from living up to their full potential. That is simply wrong. These programs, after all, were designed as safety nets, not steel cages.

Chairman Shaw, you have been a leader in passing the monumental and highly successful Welfare Reform legislation. I have heard you say many times, and I couldn't agree more, that preventing people from working runs counter to the American spirit. It is a spirit that thrives on individual achievements and societal contributions.

With our economy humming as it is and growing so rapidly, we need skilled workers. Individuals with disabilities are eager and highly qualified to meet the employment needs that are out there in the marketplace. This is the time to deal with this issue. It is not only the right thing to do, it is the cost-effective thing to do. Discouraging people with disabilities from working, as the present system clearly does, earning a regular paycheck, paying taxes, and moving off public assistance results in reduced Federal revenues.

This is something that has hit near and dear to home. One of my best friends, who happens to be a person with quadriplegia, Tom Habin, worked on my first congressional staff. A person who is quadriplegic needs catheters, attendant care, and can't take his or her own showers or go to the bathroom. Mr. Habin was employed on our staff. Given the limitations and the payscales we have, it was a very sad day—one of the saddest days in my life—when he came to me and he said, "Jim, I now risk losing my medical benefits. I can't work for you any more and you can't pay me enough to make it worth my while." That is wrong to have a built-in disincentive to a good, smart person who could contribute so much.

Now he spends most of his time in his apartment. He has to cling to those benefits. These people are scared, deathly scared, of losing those important, life-sustaining benefits. Those benefits enable them to have some dignity of independent living. That is why I feel so passionately about this issue. If there is anything we need to work on in a bipartisan way, it is this issue.

That is why I am so grateful you are sitting in that chair, Clay, and that we have the bipartisan spirit on this Subcommittee, and hopefully on the Full Committee and the Congress, to knock down these barriers. We need to do this so these people can truly enjoy the dignity of independent living and be contributors in the marketplace.

My own State of Minnesota is implementing a pilot program, right now, to help individuals to return to work. With the assistance of disability experts and advocates in Minnesota, Mr. Chairman, our State legislature is already working on limited legislation and wants Congress to pass the bill that Nancy and I are cosponsoring. They are in a position to react to any additional legislation that Congress passes.

Again, Mr. Chairman, thank you very much for holding this hearing today and for your leadership on this issue. I want to also thank your Subcommittee staff who have been very helpful in allowing my staff and me to work with them and you on these important issues. I am excited to continue our work together in helping people with disabilities return to work. As far as I am concerned, there is no higher calling for all of us as individual Members of Congress.

Thank you, Mr. Chairman.

[The prepared statement follows:]

Statement of Hon. Jim Ramstad, a Representative in Congress from the State of Minnesota

Mr. Chairman, I want to thank you and the Subcommittee for holding this important hearing to discuss those barriers which prevent people with disabilities from working.

The staff of the House Republican Caucus on Disabilities and I recently met with a number of advocates for people with disabilities—some of whom are in this room today—to talk about issues of importance to them. By far the number one topic discussed that day was work disincentives within those federal programs designed to assist people with disabilities. This is also one of the most important issues to the members of my own Disabilities Advisory Committee in Minnesota.

Like many of you, I have heard countless stories of frustrated individuals who desperately want to work and contribute to society but are literally prohibited from doing so because confusing federal programs and rules make working too difficult or expensive. Certainly, we must take steps to prevent abuse of the system. But in doing so, we must make sure our efforts do not prohibit Americans with disabilities

from living up to their full potential. After all, these programs were designed as safety nets, not iron cages.

Chairman Shaw, as a leader in passing the monumental and highly successful welfare reform legislation, you know how important it is for people to work. As I have said many times, preventing people from working runs counter to the American spirit—a spirit that thrives on individual achievements and societal contributions.

Realistically, we also know that our growing economy is in need of skilled workers. Certainly, individuals with disabilities are eager and highly qualified to meet those employment needs. In addition, creating work incentives for people with disabilities is not just humane public policy, it is sound fiscal policy. Discouraging people with disabilities from working, earning a regular paycheck, paying taxes and moving off public assistance results in reduced federal revenues.

Like everyone else, people with disabilities have to make decisions based on financial reality. Should they consider returning to work or even make it through vocational rehabilitation, the risk of losing vital federal health benefits often becomes too threatening to future financial stability. As a result, they are compelled not to work. Given the sorry state of present law, that's generally a reasonable and rational decision.

Eliminating the current barriers to work that so many individuals face is not just the smart thing to do, it is the right thing to do. That's why, in 1993, I worked with Rep. Stark on legislation to address the disincentives people with disabilities face in federal programs. Last year, I also strongly supported the efforts of this Subcommittee to pass legislation. While we were not successful in the 103rd or 104th Congress to enact meaningful legislation, I remain hopeful that we will get something done this year.

I am confident we can and will work out all the aspects of this important legislation. I am glad to report that my own state of Minnesota is enthusiastic about implementing pilot programs to help individuals return to work. With the assistance of disability experts and advocates in Minnesota, the state legislature is already working on limited legislation and should be able to react to any additional legislation this Congress passes.

Mr. Chairman, thanks again for holding this hearing today. Your Subcommittee staff continues to be very gracious in allowing me and my staff to work with you on these important issues, and I am excited to continue our work together in helping people with disabilities return to work.

Chairman SHAW. Thank you, Jim. I can see very clearly that you feel very passionately about your testimony, about the bill that you and Nancy are filing together. Hopefully, the young man that you referred to, the quadriplegic that used to be on your staff, can be welcomed back to your staff or some productive way of life. You spoke of both of your Senators. I can't help but ask how your Governor weighs in on this. [Laughter.]

You talk about a democracy.

Mr. RAMSTAD. Well, sir, I never presume to speak for my dear friend, Jessie Ventura, our distinguished Governor. Knowing that Jessie has a big heart and is also a smart man, given his sense of rationality and his feelings for people with disabilities, I would be willing to bet my last dollar that Jessie would support this legislation. I will get back to you on that by the end of the day. He has always been an advocate for people with disabilities and we have worked together on a number of events to raise money for people with disabilities. So, I am sure that Jessie is with us on this.

By the way, Mr. Habin, the gentleman I referred to earlier looks forward to coming out to testify on this bill and looks forward to meeting you.

Chairman SHAW. Very good, very good. We certainly look forward to welcoming him before the Subcommittee.

I have to tell you that one of things my new Governor in Florida, Mr. Bush, was looking forward to in going to his first Governors' conference was to meet Jessie. I think that was the high point.

Do any of the Members of the Subcommittee have any questions?

Mr. Matsui.

Mr. MATSUI. Thank you. Representative Johnson, I appreciate the fact that both you and Jim represent the laws you are going to be introducing in this bill. I think that is really great. I want to thank you very much for it. Is it my understanding that it will be a companion bill, exactly the same bill that the Jeffords-Kennedy bill is, or will there be some changes in it? Do you happen to know?

Mrs. JOHNSON of Connecticut. If any in this Subcommittee want to join, we generally don't ask Clay, as Chairman of the Subcommittee, and I doubt that Mr. Lazio actually asked you as Ranking Member on the Subcommittee, but we will talk about it afterward when we will have a broader base. Because the most controversial provisions are for Energy and Commerce, in terms of Medicaid access and putting some grant money out there to encourage the States to really open up their Medicaid Programs, we have yielded to the Energy and Commerce members to be the leads.

Mr. MATSUI. So it is a work in progress?

Mrs. JOHNSON of Connecticut. Yes. We will talk with you about it later in the day and update you on where that is. Sometimes that takes a little longer than it does on our Subcommittee.

Mr. MATSUI. Thank you.

Mrs. JOHNSON of Connecticut. I would just like to make one additional comment. It is something I have gotten from talking to people who are profoundly affected by this legislative proposal. I have certainly understood the importance of disabled people having the right to work and what it did for them personally and what it does for our society. But I did not understand what we do to them when we let them into the system part way. Then they become a part-time employee who cannot participate in any emergency of the business.

There is a flood or a Christmas rush. Everyone else works a little overtime, but they can't. We finally put them in a position of always being the employee who says no. Even though, actually, they are the employee who wants, more than almost anyone else, to work more. We sock them in and, thereby, we keep them labeled. We keep them at odds with the people around them. We keep them unable to accept their fair share of any new workload that comes up. What we do to them to keep them identified as other and less competent, even after we let them into the work force under the current plan, is positively criminal. I am very proud of the work that this Subcommittee and our Ways and Means Committee did last year on this issue. I think if we can go forward rapidly, we can get the health benefit issue addressed, as well.

Chairman SHAW. Do any of the Members—yes?

Mr. HULSHOF. Mr. Chairman, just a brief statement. First of all, I also applaud you for holding the hearing. I think you have opened yourself up to the label compassionate conservative. I happen to think that is a very positive label. Certainly, Mr. Ramstad, we appreciate your work as far as the caucus on disabilities and the lead

you have taken. I am proud to be a member of that caucus with you. Thank you for being here.

Mr. Chairman, and for Mr. Matsui's benefit as well, we have got a bill we have been working on that is actually a blend of Ticket to Work and the Kennedy-Jeffords bill. Mr. Chairman, you hit it right on point saying that, I think, we are all in agreement on where we need to be—but some of the details—for instance the bill that we are working on. We are concerned about the sunset provision in Kennedy-Jeffords on the Ticket portion. That is, it sunsets the program by 2004. There is a vocational evaluation provision in the House bill that is eliminated in Kennedy-Jeffords. Some things like that we are really trying to blend together. We want to have the best product available. We are glad to have you here, Mr. Chairman.

Mr. RAMSTAD. Mr. Chairman, may I respond briefly? There was an oversight on my part, along with Ms. Johnson and Mr. Lazio, nobody has worked harder on this than Mr. Hulshof. That was an oversight on our part, certainly. We appreciate your great input on the caucus and also in working on this legislation. You have certainly played a major role, to date. I know you will continue to do so.

Mrs. JOHNSON of Connecticut. I would like to say, too, that I really appreciate Mr. Hulshof's leadership and dedication to this and getting into the details—the little differences—between the bills. Many of us have been, sort of, a little more focused on getting the other Committee mobilized and moving forward. This does have to be a Joint Committee effort this year. Last year we were able to bring it through our own Committee, but we really have to broaden that base. Mr. Hulshof, you have really done yeoman's work on this and we appreciate it very much.

Chairman SHAW. Mr. Doggett.

Mr. DOGGETT. Well, I would just like to add a second to that broadening the base part. I share the passion both of you have voiced, largely from working on related issues at the State level for much of the last 25 years. I am afraid that if we don't deal more comprehensively with the health insurance barrier, we will do the very thing that you, Mrs. Johnson, indicated that we do not want to do. That is, to just put them in part way and create false expectations that we are addressing this issue when, in fact, that health insurance barrier remains so very severe. One would think, Jim, if you can get that kind of agreement among your senators in Minnesota, we ought to be able to reach across all parts of the aisle and get it over here in the House and make some bipartisan progress to deal with this matter in a comprehensive fashion, rather than in a piecemeal fashion.

Mr. RAMSTAD. Certainly, we are not ignoring your side. We are trying to get our act together first. We want a broad bipartisan support for this bill, like they have in the Senate. We are going to get it, with your help.

Mrs. JOHNSON of Connecticut. There is the assumption in this bill, that Medicare is going to find a way to provide, at least, critical prescription drugs. We don't specifically address that in this bill. But if Medicare fails to do that, we will have to come back and specifically address that because it is so critical to many who are

disabled. The issue of Medicaid coverage is extremely important because that is the only health program in the Nation, public or private, that covers personal assistance care. For many people, without that kind of help in getting out the door every morning and getting back and other workplace support, we can't do this. This has to be a much broader-based approach in terms of health benefits. We were able to mobilize the last Congress.

Chairman SHAW. Any further Members?

[No response.]

I want to thank this panel. You have certainly brought something to us that we are going to be taking a really hard look at. Let us not forget that we need to pay for the legislation, so I hope you will have some recommendations for us in that way. What you are asking for, I can see, is very badly needed.

I have been advised that we may have as many as six votes on the floor. We will return as quickly as we possibly can. Everyone has plenty of time to go walk around in the hall for awhile, if you want to. We will commence this hearing just at the conclusion of the last vote. We stand in recess.

[Recess.]

Chairman SHAW. The Subcommittee will come back to order.

For our next witness we have Kenneth Apfel, Commissioner of Social Security. He is accompanied by Dr. Susan Daniels, Deputy Commissioner for Disability and Income Security Programs.

STATEMENT OF HON. KENNETH S. APFEL, COMMISSIONER OF SOCIAL SECURITY, SOCIAL SECURITY ADMINISTRATION; ACCOMPANIED BY SUSAN DANIELS, PH.D., DEPUTY COMMISSIONER FOR DISABILITY AND INCOME SECURITY PROGRAMS

Mr. APFEL. Thank you Mr. Chairman, Mr. Ranking Member, and Members of the Subcommittee for inviting me to speak with you today about initiatives to help Social Security and SSI, supplemental security income, disability beneficiaries return to work. Joining me today is Dr. Susan Daniels, our Deputy Commissioner for Disability and Income Security Programs, who has been a tireless supporter of efforts to promote work.

Mr. Shaw, Mr. Matsui, I believe the best element of welfare reform has been changing the dynamic about work. Ever since my first graduate degree in rehabilitation counseling nearly three decades ago, I have believed in work as a pillar, a well to drink from, for people and for families. As a nation, we are best served when all of our citizens have the opportunity to contribute their talent, ideas, and energy. This can and should be the year in which we make significant progress toward this goal for disabled Americans.

Today, I would like to provide a brief overview of the Administration's efforts to help return Americans with disabilities to work and also outline some specific proposals now before Congress. Historically, only a small number of our approximately 10 million Social Security and SSI, supplemental security income, disability beneficiaries attempt to return to work each year—in fiscal year 1998, about 10,000 beneficiaries. But many more individuals with disabilities want to return to work. It is the Administration's fundamental goal to remove barriers to work.

Last year, the President established a National Task Force for Employment of Adults With Disabilities to create an aggressive, coordinated, national policy to promote gainful employment. As part of the task force, Vice President Gore announced last September the awarding of grants by SSA to nine States, totaling $4.4 million, to develop innovative return-to-work projects. In January we announced that SSA will fund a Disability Research Institute that will help provide policymakers with pertinent information and research data. In February we announced a proposal to increase the amount that disabled adult beneficiaries can earn while still remaining eligible for benefits. The proposed regulations would increase the amount from $500 to $700 per month, and may affect as many as one-quarter of a million beneficiaries with disabilities.

I also want to note that later today I am releasing a report on how my agency can improve its disability process through improved decisionmaking, stronger safeguards for program integrity, increased research into disability and, of course, better return-to-work policies. My staff will be available shortly to brief you on the report.

Mr. Shaw, Mr. Matsui, and Members of the Subcommittee, the cornerstone of our return-to-work strategy at SSA remains our commitment to the Ticket to Work Program first proposed in 1997, and again included in the fiscal year 2000 budget. For too long our disability programs have been seen, in part, as tickets out of the work force. It is clear that the cash support for our disability program provides essential support in needy times for millions of Americans. Millions of our beneficiaries will never be able to return to work.

But the Ticket to Work proposal will help some people get off the disability rolls and back to the work force. We believe that the Ticket to Work proposal will result in many more opportunities for beneficiaries to receive return-to-work services. The proposal represents a public-private partnership designed to provide its customers with control and flexibility in securing rehabilitation and employment services. It is fiscally responsible since it focuses on outcomes. Providers would only be paid for results. It is innovative, recognizing that the customary ways of doing business have not yielded satisfactory results.

Under the Ticket to Work program, all disabled Social Security and SSI beneficiaries, except those for whom medical recovery is expected, will be eligible to participate. Beneficiaries can use the tickets to obtain services from any enrolled public or private provider of their choice. Vocational rehabilitation agencies can participate on the same basis as any other provider. The provider of services would be paid only after the beneficiaries return to work and no longer receive a cash benefit under the Social Security or SSI Programs.

We steadfastly believe in the value of the Ticket to Work proposal which incorporates some of the more effective initiatives already underway and builds upon their strengths. For example, 5 years ago this month, SSA amended its vocational rehabilitation regulations to broaden the providers of rehabilitation services that are available. As of this week, we have been able to sign contracts with 419 alternative vocational rehabilitation services providers

across the country. We are encouraged by the results of our initiatives in this area. We believe a fully realized Ticket to Work Program would make a meaningful difference in helping individuals with disabilities return to work.

The Administration is also seeking support for a legislative proposal that provides beneficiaries who attempt to work the assurance that cash and health benefits can be restored in a timely fashion if they must stop working. Let me also say, I believe the assurance of continued health benefits is central to any initiative in helping return severely disabled individuals to work.

When I travel around the country, people tell me it is the fear of losing health care benefits and coverage that would most likely dissuade people from attempting to return to work.

I want to take this opportunity to thank the Members of the Subcommittee for their support of the Ticket over this past year, as well as your support in passing an extension last year of the demonstration authority of section 505(a) of the Social Security Disability Amendments of 1980. Unfortunately, it was not enacted and the Administration is seeking a permanent extension of demonstration authority so that we can initiate new projects for researching return-to-work strategies.

In conclusion, let me say that the Social Security Administration looks forward to working with you and other Members of the Congress to enact fiscally responsible legislation that can help more Americans with disabilities to successfully return to work. It is a goal that is supported not only by our disability beneficiaries, but, I believe, by all Americans.

Thank you. We would be happy to answer any questions that you may have at this time.

[The prepared statement follows:]

Statement of Hon. Kenneth S. Apfel, Commissioner of Social Security, Social Security Administration

Mr. Chairman and Members of the Subcommittee:

Thank you for inviting me here today to discuss initiatives to assure that the Social Security Administration's (SSA) beneficiaries with disabilities who want to work have the opportunity to do so. I am accompanied today by Dr. Susan Daniels, Deputy Commissioner for Disability and Income Security Programs.

Since President Clinton took office, the American economy has added nearly 18 million new jobs; and unemployment is the lowest in three decades. The unemployment rate among all working-age adults with disabilities, however, is nearly 75 percent. According to current estimates, about 16 million working-age adults have a disability that leads to functional limitations and 14 million working-age adults have less severe but still significant disabilities. In addition, individuals with disabilities also face multiple barriers to work, which include: Lack of adequate health insurance, higher costs of work, a disconnected employment service system, and inaccessible or unavailable technology. Not only is it more difficult for people with disabilities to work; when they do work, their earnings are lower.

As a nation, we are best served when all our citizens have the opportunity to contribute their talents, ideas, and energy to the workforce. There are a number of initiatives underway both at SSA and in Congress which promise to make this year one in which we see significant progress in doing just that. Today I will discuss the Clinton Administration's ongoing efforts to help people with disabilities participate in the workforce.

CLINTON ADMINISTRATION INITIATIVES

I would like to tell you briefly what we have done and what we would like to do. As part of this Administration's continuing commitment to the return to work effort, President Clinton established the National Task Force on Employment of Adults

with Disabilities on March 13, 1998 by Executive Order 13078. This high-level task force includes the Secretaries of Labor, Education, Veterans Affairs, Health and Human Services (HHS), as well as the Administrator of the Small Business Administration, the Chair of the Equal Employment Opportunity Commission, the Chair of the National Council on Disability, and the Commissioner of Social Security.

Briefly stated, the purpose of the task force is to create an aggressive and coordinated national policy to bring adults with disabilities into gainful employment at a rate that is as close as possible to that of the general adult population. This involves studying existing policies to determine what changes are necessary to remove barriers to work, to develop health insurance options, and analyze the outcomes of programs related to employment for young people with disabilities. The final report of the task force is due to be issued in July 2002, with the first interim report issued last month.

As the first activity launched by the task force, Vice President Gore announced last September that SSA, in a collaborative effort with the Departments of Health and Human Services, Education, and Labor, would award grants to 12 States initially totaling over $5 million to develop innovative projects to assist adults to reenter the workforce. It is expected that the new approaches now getting underway in these States will create Federal/State partnerships and serve as models for other States to replicate. This is one of many activities recommended by and acted upon by the Administration. In fact, as of January, actions had been initiated on every recommendation in the Task Force's Interim Report.

Last July, the President announced his commitment to enact affordable, feasible legislation to help people with disabilities maintain their health care-coverage and return to work.

In January, I announced that SSA will fund a Disability Research Institute to help provide policy makers with information and research data in the disability policy area, including ways to strengthen return-to-work policies for people with disabilities. The Disability Research Institute should be operational by the end of the year.

On February 12th we announced SSA's proposal to increase the amount that adult beneficiaries with disabilities can earn while still remaining eligible for benefits. The proposed increase, from $500 to $700 per month, may affect as many as 250,000 Social Security beneficiaries with disabilities.

This year the President continues his commitment to improving opportunities for disabled Americans. The President's fiscal year (FY) 2000 budget contains a package of new initiatives that will remove significant barriers to work for people with disabilities. This three-part initiative, which invests over $2 billion over five years, includes: (1) The Work Incentives Improvement Act, which was introduced in the Senate by Senators Jeffords, Kennedy, Roth and Moynihan and includes the Ticket to Work proposal enacted by the House last year; (2) a new tax credit of $1,000 annually for workers with disabilities to help defray the monetary or in-kind costs incurred by people with disabilities who need transportation, special job equipment, or other assistance to return to work; and (3) expanded access to information and communications technologies. With these new proposals, the Administration will have taken action on every recommendation made in the President's Task Force on the Employment of Adults with Disabilities.

As a further incentive to encourage beneficiaries to return to work, the Administration has developed a legislative proposal to assure cash and health benefits can be restored in a timely fashion for former beneficiaries who must stop working but continue to meet the disability standards. These individuals, whose entitlement was terminated because of work, could request reinstatement without filing a new application as long as it is within 5 years of the termination, and receive provisional benefits—cash and Medicare or Medicaid, for up to 6 months while SSA is making a determination.

TICKET TO WORK PROVISION

In 1997, the Administration first proposed its "Ticket to Independence," which was later included in the President's FY 1999 Budget. Last year, based on the Administration's proposal, two former members of this Subcommittee, Representatives Bunning and Kennelly, introduced the "Ticket to Work and Self-Sufficiency Act," which was passed overwhelmingly last year in the House and is a key part of this year's Senate Work Incentives Improvement Act. This proposal is included in the President's FY 2000 Budget.

We believe that the Administration-proposed "Ticket" will result in many more opportunities for our beneficiaries to receive the services they need in order to work. The "Ticket" is a public-private partnership to give people receiving disability pay-

ments what they want and need—the control and flexibility to secure services tailored to their individual requirements from their choice of providers. The "Ticket" maintains fiscal discipline, since providers would be paid only for results.

The ticket would enable an SSI and SSDI beneficiary to go to either a public or a participating private provider. Providers who accept the ticket would have more flexibility in selecting their preferred reimbursement.

The Ticket proposal included in the President's Budget is based on the following fundamental principles:

Customer Choice: We believe that beneficiaries desire and need maximum flexibility and choice in pursuing services which will help them to become gainfully employed. Beneficiaries with disabilities must be able to choose a participating public or private employment or rehabilitation provider to receive the services that they need to participate in the workforce.

Paying for Outcomes: Beneficiaries and providers alike should focus on the goal of stable employment. A focus on outcomes and milestones is best achieved by linking it to financial rewards. Our goal is to reward success while using public funds in an accountable and targeted way.

Encouraging Innovation: We believe the competitive spirit in the proposed legislation will encourage innovations in the private and public sectors by creating opportunities for State agencies, local non-profit and for-profit providers, employers, and beneficiaries.

The Administration-proposed "Ticket" is designed to bring new service providers into this process. We want to develop new and innovative ways to bring beneficiaries with disabilities to the workforce based on actual outcomes, working with capable and committed service providers, and providing a strong infrastructure of information and support services. Many of these concepts are currently underway at SSA, and I would like to take this opportunity to discuss some of our initiatives.

SSA Initiatives

Historically, a very limited number of our approximately 10 million Social Security, Old Age, Survivors and Disability Insurance (OASDI) and Supplemental Security Income (SSI) disability recipients leave the disability rolls each year because of successful rehabilitation. In fiscal year (FY) 1998, SSA paid State VR agencies about $102 million for their services provided to approximately

10,000 beneficiaries with disabilities who worked at least 9 months at the substantial gainful activity level. Although this was a record year for reimbursements, I believe we can do better.

Based on our experience and extensive collaboration with professional groups and advocates, we have learned that many more individuals with disabilities want to work and will do so if they have access to the rehabilitation services they need to reenter the workforce. We recognize the myriad of complex and sensitive issues that must be addressed to remove barriers to participation in the workforce.

With this in mind, we have made progress on a number of other initiatives in the return-to-work arena which I would now like to share with you.

Alternate Provider

It is clear that there are many providers in the private sector who are willing to help. In March 1994, SSA amended its VR regulations to provide more opportunities for people with disabilities to receive the employment and rehabilitation services they need to return to work or enter the workforce for the first time.

These regulatory changes allowed SSA to refer Social Security Disability Insurance (SSDI) beneficiaries and SSI recipients who are blind or disabled to VR service providers in the public or private sectors. The option of serving the beneficiary continues to be offered first to the states; however, if SSA does not receive notification that the state VR agency has accepted a beneficiary for services by the end of the 4th month after the month of referral, we may arrange for an alternate provider of rehabilitation services to serve that individual. Usually, these providers come to us from the private sector. (Of course, this process would change with passage of the "Ticket.")

To further expand the pool of alternate providers, we have released two RFPs, the second of which will remain open continuously. It is important to note that this is not a competitive procurement with limits on the number of the contracts awarded. We are interested in expanding the pool of providers who can serve our beneficiaries and will award contracts to all providers who qualify. Through the first week of March, we have signed contracts with 419 VR service providers nationally.

Some of these providers have begun to work with our beneficiaries. We just authorized payment for the first successful case, with several other cases soon to ma-

ture for payment. Alternate providers, like current VR providers, are reimbursed only after an individual has been working at the SGA level for at least nine months.

PROJECT RSVP

Our experience with Project RSVP (Referral System for Vocational Rehabilitation Providers) will help us better understand the concept of using a program manager to oversee service providers. The objective of Project RSVP is to assure that return to work services are more readily available to SSA-referred individuals while improving the administration and cost-effectiveness of the program. RSVP is a 3-year demonstration project to test the advantages and the cost-effectiveness of contracting out certain administrative functions under SSA's VR referral and reimbursement programs, and assist in managing the alternate providers. On September 27, 1997 a contract was competitively awarded to Birch & Davis Associates, Inc. of Maryland. Birch & Davis is marketing the project to potential VR providers. In addition, a toll-free number to provide technical assistance and respond to questions from beneficiaries and providers as well as the contractor's bulletin board to refer individuals to alternate providers is in place.

SELF-REFERRAL INITIATIVE

With the assistance of the RSVP contractor, we are expanding ways to provide SSDI and SSI recipients with disabilities or blindness increased access to rehabilitation and employment services to help them go to work. Under this process, these individuals have the opportunity to self-identify their interest in receiving return-to-work services by calling a toll-free number. Our contractor will obtain information from the caller, combine it with information supplied by SSA and transmit a referral to the State VR agency and/or the alternate provider(s) serving the individual's area of residence. We believe this initiative helps to support our intent to offer beneficiaries a more pro-active role in assessing services at a time that is most appropriate to their circumstances.

Through all of these provider initiatives, we have and will continue to gain valuable insight and experience that we will use to ensure the success of the proposed legislation. We are encouraged by the results. We have learned that many highly skilled, outcome-focused agencies and professionals are eager to assist our diverse population to return to work. And, we have learned that individualized planning and support is essential to successful work re-entry.

DELIVERY OF WORK INCENTIVE INFORMATION

We are working with the Virginia Commonwealth University to develop and test a decision support software package called WorkWorld for use in assisting consumers and service providers in determining the effects of work on their entitlement to SSA benefits as well as other federal/state benefits, such as food stamps. This will allow our beneficiaries to make more informed choices regarding employment opportunities.

We have created an attractive education kit called, "Graduating to Independence" (GTI), that is aimed specifically at youth in transition from education to employment and their families. The kit is designed for use by educators or professional organizations to instruct young beneficiaries and their families about SSA's work incentives. This multimedia kit contains a videotape and several computer disks, in addition to written materials, that combine facts with motivational examples. We have been very aggressive in distributing the GTI kits, sending them to school districts across the country, and handing them out at national conferences.

Additionally, we publish a number of other training and public information materials on work incentives. These materials are provided in multiple formats and have been designed with significant consumer input to be user-friendly. And, we have developed an Internet website which contains information about work incentive provisions, access to our publications, and information on our rehabilitation and employment programs.

Finally, SSA Operations and Program Offices are working together to assess our policies and procedures relative to our work incentive service delivery. Through this process, we are exploring ways we can improve the accuracy and timeliness of work incentive information in our field offices. Beyond that, we plan to develop methods to speed "on-demand" information to customers and stakeholders.

DEMONSTRATION AUTHORITY

The demonstration authority of section 505(a) of the Social Security Disability Amendments of 1980 expired June 10, 1996. I want to thank the members on this Committee for their support for an extension passed by the House last year, which unfortunately was not enacted. In order to initiate any new projects under the SSDI program for researching return-to-work, the Administration seeks a permanent extension of demonstration authority so that we can test new approaches to accomplish our goals in this area. With this renewed authority, SSA can develop a comprehensive strategy that integrates earlier intervention, and identification and provides necessary assistance in removing barriers to work for applicants and beneficiaries.

With renewed authority we will pursue other projects that bring us closer to our goal of supporting the active participation of our beneficiaries with disabilities in the workforce.

HEALTH CARE

Finally, although I would defer to HHS on the details, I would like to mention the issue of health care coverage, which is addressed in the President's legislative package and is part of S. 331, "The Work Incentives Improvement Act." Fear of losing health care coverage is frequently cited as the most common reason many disabled beneficiaries do not attempt to return to work. These initiatives would expand Medicare and Medicaid so that people can retain their health benefits coverage when they return to work. Under the proposal, Medicare coverage for disabled beneficiaries who return to work during the next 10 years would continue so long as they remain disabled and States would be permitted to allow disabled individuals to buy insurance through Medicaid. In many cases, people returning to work either work part-time and are not eligible for employer based health insurance or work in jobs that do not offer insurance. These health options, included in the President's budget, are essential complements to the Ticket to Work and other policies to remove barriers to work for people with disabilities.

CONCLUSION

Mr. Chairman, I want to assure you that the Social Security Administration stands ready, willing, and able to work with lawmakers on both sides of the aisle to enact fiscally responsible legislation to help thousands of Americans with disabilities, who with appropriate services and support, can be successful in obtaining or continuing to work. People with disabilities can bring tremendous energy and talent to the American workforce, but institutional barriers often limit their ability to work. We need new and innovative approaches so that Americans with disabilities can work. The President's three-part budget initiative in addition to the other initiatives I have discussed today represent not only new approaches, but also a continued commitment to make every effort to enrich the lives of people with disabilities and to help those who want to work do so.

I would be happy to answer any questions.

Chairman SHAW. Mr. Matsui.

Mr. MATSUI. Thank you, Mr. Chairman.

I would like to thank Dr. Daniels and you, Commissioner Apfel. I just want to ask one question.

You reviewed the Jeffords-Kennedy legislation that passed the Senate Finance Committee, last week, on a 16-to-2 vote, I believe. Does the administration support that version of the Ticket to Work proposal?

Mr. APFEL. We support the ticket proposal and we support the health care provisions. The Administration supports both. There are a series of minor differences that have been raised that we will need to work through in the months ahead. We believe all of those issues are entirely resolvable. We fully support the ticket and the health care provisions.

Mr. MATSUI. Thank you very much. And in both the health care and the ticket provisions?

Mr. APFEL. Yes.

Chairman SHAW. If I might expand on that, the health care provisions, are you also endorsing the revenue raisers on that, or have you had a chance to really take a position on that?

Mr. APFEL. I think you are out of my territory on that one, Mr. Chairman.

Chairman SHAW. For the purposes of the record, you are speaking only on the health care provisions and you are not commenting on the balance of it.

Mr. APFEL. I am not commenting. I don't know the answer on the revenue proposal.

Chairman SHAW. That is certainly fair enough. Do any of the other Members have any questions?

Mr. Hulshof.

Mr. HULSHOF. To follow up on Mr. Matsui's question, Commissioner, the Work Incentives Improvement Act—I think it's the official term of the Kennedy-Jeffords bill that passed the Senate Finance Committee last week—requires implementation begin within 1 year of enactment, full implementation within the following 3 years. As you know, the ticket bill that we talked about, and you testified about last time, gives Social Security Administration more of a gradual implementation. Is there some concern, on your part, on that particular provision? That is one of the discrepancies between the two bills. I would like your comments.

Mr. APFEL. It is one of the discrepancies; 6 years in the provision in last year's House bill; 3 years in the Senate. We think we can work somewhere in the range of those two and come up with something that would be perfectly reasonable. We don't, at all, oppose the Senate provision of 3 years. We think we will be making very strong progress in all areas by 3 years. What exactly full implementation is in 3 years is for the future. We expect 3 years would be fine. If we could work out something a little bit clearer, that would be fine also.

Mr. HULSHOF. As they say in wedding ceremonies, Speak now, or forever hold your peace.

Mr. APFEL. Absolutely.

Mr. HULSHOF. OK. I know I was expecting GAO to testify before you, but I am glad to have you here. Let me ask you to comment on GAO's testimony. In their testimony they talk about the income cliff recipients face if they return to work. Under law those who do want to go to work can make as much as $500 from work, on top of the $500 or so in benefits, but no more than that or they lose benefits all together. Is that your understanding as well?

Mr. APFEL. I think the cliff needs to be addressed. I think it is one of the more important elements of the reform legislation. We have really two answers to that. One is that I have promulgated draft regulations to raise the $500 monthly amount to $700, to enable more work. We expect about one-quarter of a million individuals to benefit from that. Also, as part of our demonstration authority, we would be able to look at a phasedown where benefits would be reduced by $1 for every $2 in earnings, which is closer to what happens in the SSI Program. This is absolutely the right

thing to do. We strongly support that provision in the bill. We would like to be able to conduct major efforts in this area to determine the cost, the efficacy, and the importance of such an approach.

Mr. HULSHOF. Thank you for your testimony.

Thanks, Mr. Chairman.

Chairman SHAW. Mr. Cardin.

Mr. CARDIN. Thank you, Mr. Chairman. It is a pleasure to have you here, Mr. Apfel.

We have been talking a great deal about the obstacles in the way of disabled individuals being able to work. Let me talk a little bit about the vocational rehabilitation programs themselves. This change seems like a win-win situation. We are allowing the person that is disabled to have a ticket to get rehabilitation services from a much broad ranger of providers, but the reimbursement is limited to only if the provider succeeds in getting the person to work 9 months. The Chairman, in announcing this hearing, points out the very low number of people who are disabled who return successfully to the workplace. Is there interest out there among the providers in participating in these programs and getting people into rehabilitation services, knowing the risk that reimbursement is limited to whether they succeed in rehabilitating the individual to work? Is there interest out there?

Mr. APFEL. I think there is enormous interest. We have over 400 alternate providers under our current system, so there is a lot of interest. What we need is the financing mechanism that the Ticket provides.

I believe that focusing on outcomes is centrally important here. Rather than reimbursing for services only, we need to be able to ultimately focus on outcomes. I think focusing on outcomes almost always makes sense. In this case, paying for outcomes is essentially important. We would like to see the legislation have a provision included that would allow payments or milestone payments—because I think milestone payments make sense—only if a person has returned to work, rather than milestone payments before the individual has returned to work. We believe the alternate providers, the whole provider network, the employment networks will be able to, given the extra payment system, provide a big difference for individuals. Going away from just funding services is centrally important. Focusing on the outcome—the outcome is work and the payment is tied to work—will create great incentives for our providers to move people to work. That is one change we would like to see in the legislation.

Mr. CARDIN. Just one last question. With the State vocational rehabilitation services, could you talk a little bit about the capacity and why there is need to go beyond just the traditional State programs?

Mr. APFEL. Some of our research in the past with the old 505 demonstration authority showed us that there were many organizations, whether it be ARC, sheltered workshops, or Goodwill Industries, that would love to be able to help our client population return to work. The vocational rehabilitation system has done a good job. About 10,000 people last year moved through that system and returned to work. We provided about $100 million last year for that

activity. Broadening the program to give individuals choice beyond the traditional State vocational rehabilitation system creates, I think, incentives for our vocational rehabilitation system to do better, as well as provides other vehicles for other organizations to do more. We don't think this is going to hurt the vocational rehabilitation system. We think this is going to strengthen the vocational rehabilitation system, giving vocational rehabilitation agencies the capacity to also be involved with the Ticket. It creates a more competitive environment with individuals having more choice. We think that is good for our beneficiaries. We think it is good for the service network.

Mr. CARDIN. Let me just reinforce that. I think it is our vocational rehabilitation services at the State level that want to be able to expand and allow their clientele to be able to have a broader base of providers. So, everything we have heard, I think, makes a great deal of sense. I appreciate the fact that you want it based upon outcome which is an accountability where it should be. It seems to me we can do a lot better job in helping people with rehabilitation services, directly, in addition to removing the obstacles that are currently in the way for a person to be able to be gainfully employed. You are doing it from both points of view: Provide the services that they need; give them the training; give them the help, and then remove the barriers. It seems to me that it is a well-balanced program.

Thank you, Mr. Chairman.

Chairman SHAW. Mr. Doggett.

Mr. DOGGETT. Thank you. Thank you for your testimony. You mentioned that under the alternate provider program, I believe, through last week you had signed up about 419 vocational rehabilitation service providers. About how many beneficiaries have actually signed up for services at this point?

Mr. APFEL. Very few. I don't have the exact number. What is needed is the reimbursement system. We have a well of organizations that are interested in providing services. But without the ticket, there is very little ability to match up individuals and need with the organization. What is needed to see a significant increase is the ticket.

Ms. DANIELS. I would like to add something to what you said, Commissioner. Mr. Doggett, the program is fairly new and required us to develop a whole infrastructure: A way to sign up providers, a way to run a bulletin board. We are just really beginning to put all of that into place. So, we only have a few people, now, actually signed up with a particular provider. But we expect that over time that will pick up dramatically.

Mr. DOGGETT. Now you consider vocational rehabilitation at the time of the initial disability determination. Do you also, if it is not the appropriate thing to do at that point, have a process by which you raise it again later in the process?

Ms. DANIELS. Not at this time. The current alternate provider program must follow the current statute which says that we have to refer individuals to vocational rehabilitation first and wait for vocational rehabilitation to serve them or not serve within a certain window. Then we can refer these individuals on to other providers. We are beginning to explore the opportunity for people to

self-refer to alternate providers, but we have to work within the constraints of the current statutes. The ticket would give us more flexibility in offering more opportunity to current beneficiaries who are already on the rolls, not just people who just applied.

Mr. DOGGETT. As this legislation was proposed last time, would it have the flexibility to consider vocational rehabilitation referrals at a later point after someone had been on the disability rolls for some time? Because I think there is some literature that suggests that there is merit to doing it other than just at the initial determination.

Ms. DANIELS. My understanding of the ticket is that we would be able to issue tickets to all beneficiaries, not just to those who recently entered the rolls. So, all of our beneficiaries, no matter how long they have been on the rolls, could make the choice to seek services.

Mr. DOGGETT. I think this is evident, Commissioner, from your initial testimony. I gather it is your view from the work that you have done that unless we address this health insurance issue as it is addressed in the Kennedy-Jeffords bill, we are going to leave out tens of thousands of people out there who would like to work, who would like to be participating in the economy for themselves and for the benefit of the taxpayer as well, and would like to be taxpayers. They are going to be left out if we don't address the health insurance issue and just leave it part way in progress in this area.

Mr. APFEL. Mr. Doggett, I totally agree. Every time I am speaking to disablility groups, to individuals who are on our rolls, the major issue is a fear of the unknown. That fear of leaving the program and losing health care coverage is the absolute biggest concern. I think it is the fundamental issue.

I would also point out that the provision that we think is very important in the Senate bill is what is called the easy on provision. Basically, it enables an expedited eligibility process if someone goes off the rolls.

Right now, the decision to move to employment and go off the rolls triggers, under current law, the need to reapply all over again. That provides enormous disincentives for moving into work. So, we need a system, and again the Senate bill does address this, that enables an easy on. An individual who leaves our rolls through work can come back on automatically and then, within 6 months, we would conduct a disability review to determine whether there is still a disabling condition. That means the individual immediately has access to health care, and is immediately able to come back on the rolls. That eliminates both the major barriers of access to health care as well as concern that you are never going to get back on the rolls. Ultimately, the notion of health care coverage is central to our future successful efforts in this area.

Mr. DOGGETT. Thank you. Thank you, Mr. Chairman.

Chairman SHAW. Mr. Portman.

Mr. PORTMAN. Thank you, Mr. Chairman. I commend you for having the hearing and for doing all you can to move this legislation forward this year—kind of unfinished business from last go around.

I have found this morning just listening and reading this testimony, I have been around here too long already. I feel like I am

still a freshman, but I guess I have been here a few years, and, as the archivist of the Subcommittee, I have to make the comment that I worked with then-Chairman Bunning and Mrs. Kennelly, the Ranking Member on this starting in 1997, and, although I am delighted that the Administration has this in their proposals, I see here that it was based on the Administration's proposal. They actually came up with that initially out of this Subcommittee, and I think it was creative work, and I think that it deserves to be credited to the former Chairman and Ranking Member. So, just that quick comment.

I really appreciated the testimony earlier, also, from Ms. Johnson and Mr. Ramstad and the commitment that I am hearing on both sides of the aisles in wanting to move this forward this year with the additional Medicare and Medicaid provisions to be sure that health is covered.

I have two quick questions, if I might. One is this notion that we were hearing last year from the State folks which we need to be sure that SSA is encouraging work at the earliest opportunity, and that there is early intervention. We heard this from the State administrators, the vocational rehabilitation people, and my question to you is, are your efforts successful? Is SSA promoting employment possibilities at the earliest possible point? Initial disability determination, for instance—and is that working well for you?

Mr. APFEL. It is not working well for us yet. But we believe it is the ticket that will help us to be able to do that.

There is another thing that would help us, too, which this Subcommittee and this Committee has helped us do, which is to extend our demonstration authority which we would like to have extended on a permanent basis——

Mr. PORTMAN. In a pilot program——

Mr. APFEL. One of the things that we would like to test is whether for someone, even before getting on the disability rolls there is a way to do an intervention at the point before benefits start. We would need our demonstration authority to test that. It is one of the reasons why we would like to have that demonstration authority.

But, ultimately, the goal of the ticket, and of our demonstration authority, is to test ways to intervene earlier and earlier.

Mr. PORTMAN. Another good reason to get this done this year and to include that authority.

The USA accounts that the President has proposed in the State of the Union, and we haven't seen specifics of yet, might effect individuals with disabilities, and I wanted to ask you about that. Do you know whether folks would be able to make withdrawals from these USA accounts if they became disabled?

Mr. APFEL. As you point out, Mr. Portman, the details on the USA accounts are not yet available, but that is also the Treasury Department's issue as opposed to the Social Security Administration. So, I don't have an answer to that question.

Mr. PORTMAN. Would you support that?

Mr. APFEL. I think that is a tough issue. It is a tough issue on a couple of different fronts.

One, if we are creating retirement savings for the future as a supplement to a major base of adequate support, then having the

ability to utilize supplemental resourcese while disabled potentially could be beneficial. But, depending on the adequacy of the retirement plan out there, if the individual account becomes a large part of what a person has for retirement, and if that money gets consumed before getting to retirement age, then that is putting a person very much at risk.

So, I really am of two minds as to whether that retirement account should be available at disability, and there are——

Mr. PORTMAN. The other question is, what effect would that have if that were available on the likelihood of disability claims being increased or decreased into the future? And I just think that it is something to think about as you are putting together this proposal. I assume the Treasury Department is coming to you for advice on this since it is related to both of your programs, disability and retirement.

Mr. APFEL. They are, sir, and I will take that under advisement.

Mr. PORTMAN. Both of the hats that you wear.

Thank you, Mr. Chairman.

Mr. APFEL. Mr. Portman, if I could add for the record, that the Administration first proposed the ticket in 1997, and had been working very closely with the Chairman and Mrs. Kennelly.

Mr. PORTMAN. I'm told that the Bunning bill was September 1996. I hate to be the historian around here. I've only been here since 1993.

Chairman SHAW. But, also, in order to clarify the record, too, the Ranking Member there was Andy Jacobs who was a cosponsor.

Mr. PORTMAN. That is correct. Andy Jacobs was the first Ranking Member.

Chairman SHAW. We will all leave Congress someday, and we would like to be remembered.

Mr. PORTMAN. There you go. I am doing it for the benefit of all of us.

Mr. APFEL. Well, it is my hope and expectation that we will all be remembered in a very positive light when this legislation is adopted. And, if we look back in a bipartisan fashion, the Administration and Congress will all realize that we made a major contribution.

Chairman SHAW. Well, as President Reagan said, there is no end to what you can accomplish if you don't worry about who gets credit for it. And there is plenty of credit to go around on this. This is a great piece of legislation, and hopefully, we can get it going this time.

I want to thank this panel. I don't believe there are any more questions at this time.

Mr. APFEL. If I could, Mr. Chairman, add——

Mr. PORTMAN. Yes, please.

Mr. APFEL [continuing]. A couple of other issues in the Senate bill I would like to mention. I think that it is important to establish a mechanism for dispute resolution, as the Senate bill does, and to fund the protection and advocacy system. We ought to be able to figure out a way to work together to determine how to do that.

Also, the Senate bill has a 5-year sunset on the overall bill which I think is going to create some disincentives for the providers to really get behind this legislation. They may be concerned that cap-

ital improvements potentially could go away in 5 years. I think that the sunset is a mistake. I think that we clearly will need to do research to determine the efficacy of the program, but whether creating a 5-year sunset would potentially lead to inhibitions to fully develop systems would be a good question to ask providers.

Another issue would be the advisory panel. Last year's bill had some fairly prescriptive advisory panel language where the advisory panel would actually be involved in piloting sites, determining sites, and so forth. Our recommendation is to be a little less prescriptive in that area so that the overall guidance would be provided by an advisory board, which I think is good. Having the advisory board involved in the actual site selection and other operational issues really is what my job is and Susan's job, and I would hope we would have a little more flexibility in that area.

The other big fundamental difference between last year's bill and this year's bill, as Mr. Matsui, Mr. Cardin, and Mr. Doggett pointed out, is the health care provision is centrally important. As we heard from the first panel—the ability of disabled individuals to be able to return to work without that health care provision would be severely limited. It is a fundamental issue for people with disabilities. I don't know if Susan wanted to add anything.

Ms. DANIELS. I just want to add, personally, that I was a Social Security beneficiary myself, and the program was enormously important to me and allowed me to finish my education and provided me with needed support. But, for so many people it has become a trap, especially when they cannot replace the health care. I look to the future myself and hope that I will not be in a difficult position to secure health care for myself. I empathize a lot with the problem. I hope we all think that each one of us could be vulnerable to the very same problem, and that we empathize with that situation.

Thank you very much.

Chairman SHAW. Thank you, Dr. Daniels, and I thank both of you for being with us this morning.

Mr. APFEL. We are honored to be here.

Chairman SHAW. Yes, sir. And congratulations on getting out of here in record time. [Laughter.]

Mr. APFEL. In 2 hours?

Chairman SHAW. After your last stay.

Mr. APFEL. That was 3 hours. [Laughter.]

Chairman SHAW. All right. Our next witness is Cynthia Fagnoni who is the Director of the Income Security Issues, Health, Education, and Human Services Division of the U.S. General Accounting Office. We have your full statement which will be made a part of the record, and we invite you to proceed as you see fit. Welcome.

STATEMENT OF CYNTHIA M. FAGNONI, DIRECTOR, INCOME SECURITY ISSUES, HEALTH, EDUCATION, AND HUMAN SERVICES DIVISION, U.S. GENERAL ACCOUNTING OFFICE; ACCOMPANIED BY BRETT FALLAVOLLITA, SENIOR EVALUATOR

Ms. FAGNONI. Thank you, Mr. Chairman.

I have with me today Brett Fallavollita, who is a senior evaluator at GAO who has done quite a bit of work on the disability-return-to-work issues.

Mr. Chairman and Members of the Subcommittee, I am pleased to be here today to testify on factors affecting the return to work of beneficiaries in the Social Security Disability Program. Over the years, the Congress has enacted various work incentive provisions designed to safeguard beneficiaries' cash and medical benefits to encourage them to test their ability to work. Despite these statutory provisions, as well as medical and technological changes that have afforded greater potential for some beneficiaries to work, not more than 1 of every 500 DI, disability insurance, beneficiaries has left the rolls by returning to work.

To help improve return-to-work outcomes, Members of Congress and advocates for people with disabilities have recently proposed various reforms such as allowing working beneficiaries to keep more of their earnings, safeguarding medical coverage, and enhancing vocation rehabilitation.

Today, I would like to focus my remarks on three issues: Structural and operational weaknesses in the current DI and SSI Programs that impede return to work; factors that working beneficiaries believe are helpful in becoming and staying employed; and tradeoffs and challenges that exist in improving work incentives. My testimony is based on a series of GAO reports on Social Security Disability Program design and implementation, as well as a report on factors facilitating work for a group of DI beneficiaries.

Regarding the first issue, program weaknesses that impede return to work, we have found that the DI and SSI Programs' design and operational shortcomings do not encourage beneficiaries to maximize their work potential. Program eligibility and requirements and a disability application process encourage people to focus on their inabilities, not their abilities. Because the disability decision results in either a full award or a full denial of benefits, applicants have a strong incentive to establish their inability to work and, thus, qualify for benefits.

Work incentive provisions that are complex, difficult to understand, and poorly implemented further impede return-to-work efforts. Because SSA has not promoted them extensively, few beneficiaries have been aware that work incentives exist, and, despite providing some financial protection for those who want to work, work incentives do not appear to be sufficient to overcome the prospect of a drop in income for those who accept low-income employment.

Let me now describe the factors that disabled beneficiaries themselves have told us help them return to work. The most frequently cited factors were health interventions and encouragement from friends and family. Health interventions, such as medical procedures, medications, physical therapy, and psychotherapy helped beneficiaries by stabilizing their conditions and helping them function better.

These health interventions were viewed as important precursors to work, as well as important to maintaining ongoing work efforts. For example, one person we interviewed who had cancer and was working as a financial consultant told us that all of his treatments,

chemotherapy, radiation, and eye surgery, helped him get well and enabled him to work. Another individual with bipolar disorder who is an administrative support worker told us that a combination of medications and therapy helped her function in a work environment.

Beneficiaries also told us that they received encouragement from family, friends, health professionals, supervisors, and coworkers. A beneficiaries who is HIV positive told us that his doctor is very supportive, going as far as writing a letter to his employer explaining his condition and capabilities. A beneficiary with epilepsy noted that his supervisor checks from time to time to make sure that everything is OK and that he is not burning out, even suggesting that he take days off.

Now, let me turn to our third point: tradeoffs and challenges in improving work incentives. Changing work incentives may or may not increase the work effort in current beneficiaries depending on their behavior and response to the type of change and their capacity for work and earnings. For example, allowing people to keep more of their earnings would make the program more generous and could cause people who are currently not in the program to enter it. Also, improving the work incentives could keep some in the program who might otherwise have left. Allowing people to keep more of their earnings would also mean they would not leave the program, as they once did, for a given level of earnings. Such a decrease in this exit rate could reduce overall work effort because people on the disability rolls tend to work less than people off the rolls.

The cost of proposed reforms is difficult to estimate with certainty because of the lack of information on such entry and exit efforts.

Mr. Chairman, this concludes my oral statement, my oral remarks. Of course, we have submitted a full statement for the record, and I would be happy to answer any questions that you or the Members might have.

[The prepared statement and attachment follow:]

Statement of Cynthia M. Fagnoni, Director, Income Security Issues, Health, Education, and Human Services Division, U.S. General Accounting Office

Mr. Chairman and Members of the Subcommittee:

Thank you for inviting me to testify on return-to-work issues facing the Disability Insurance (DI) and Supplemental Security Income (SSI) programs. The Social Security Administration (SSA) pays out about $5.1 billion in cash payments to DI and SSI beneficiaries each month. While providing a measure of income security, these payments, for the most part, do little to enhance work capacities and promote beneficiaries' economic independence. Yet, as embodied in the Americans With Disabilities Act (ADA), attitudes have shifted toward goals of economic self-sufficiency and the right of people with disabilities to full participation in society. Moreover, medical advances and new technologies now provide more opportunities to work than ever before for people with disabilities.

The DI and SSI programs, however, have not kept pace with the trend toward returning people with disabilities to the work place. Fewer than 1 percent of DI beneficiaries, and few SSI beneficiaries, leave the rolls to return to work each year. Yet, even relatively small improvements in return-to-work outcomes offer the potential for significant savings in program outlays. For example, if an additional 1 percent of the working-age SSI and DI beneficiary population was to leave SSA's disability rolls by returning to work, lifetime cash benefits would be reduced by an esti-

mated $3 billion.[1] To help improve return-to-work outcomes, Members of the Congress and advocates for people with disabilities have recently proposed various reforms—such as allowing working beneficiaries to keep more of their earnings, safeguarding medical coverage, and enhancing vocational rehabilitation.

Today, I would like to focus my remarks on (1) structural and operational weaknesses in the current DI and SSI programs that impede return to work, (2) factors that working beneficiaries believe are helpful in becoming and staying employed, and (3) challenges that exist in improving program incentives to work. My testimony is based on a series of GAO reports on Social Security disability program design and implementation as well as a report on factors facilitating work for a group of DI beneficiaries. (A list of related GAO products appears at the end of this statement.)

In summary, program eligibility requirements and the application process encourage people to focus on their inabilities, not their abilities. Moreover, work incentives offered by the programs do not overcome the risk of returning to work for many beneficiaries, and the complexities of work incentives can make them difficult to understand and challenging to implement. Also, there is little encouragement to use rehabilitation services, which are relatively inaccessible to beneficiaries seeking them. Some DI beneficiaries who work despite these program weaknesses cited improved ability to function in the work place, resulting from successful health care, and encouragement from family, friends, health care providers, and coworkers as the most important factors helping them find and maintain work. Finally, our analysis of some of the proposed changes to work incentives—such as gradually reducing the DI cash benefit level as earnings increase—indicates that there will be difficult trade-offs in any attempt to change work incentives. Moreover, determining the effectiveness of any of these proposed policies in increasing work effort and reducing caseloads would require that major gaps in existing research be filled.

BACKGROUND

DI and SSI—the two largest federal programs providing cash to people with disabilities—grew rapidly between 1988 and 1998, with the size of the working-age beneficiary population increasing from about 4.4 million to 7.6 million. Administered by SSA and state disability determination service (DDS) offices, DI and SSI paid cash benefits totaling about $61.3 billion in 1998. According to the law, to be considered disabled by either program, an adult must be unable "to engage in any substantial gainful activity by reason of any medically determinable physical or mental impairment which can be expected to result in death or has lasted or can be expected to last for a continuous period of not less than 12 months."[2] Moreover, the impairment must be of such severity that the person not only is unable to do his or her previous work but, considering his or her age, education, and work experience, is unable to do any other kind of substantial work nationwide.

Established in 1956, DI is an insurance program funded by Social Security payroll taxes. The program is for workers who, having worked long enough and recently enough to become insured under DI, have lost their ability to work—and, hence, their income—because of disability. In addition, Medicare coverage is provided to DI beneficiaries after they have received cash benefits for 24 months. About 4.7 million working-age people (aged 18 to 64) received about $39.9 billion in DI cash benefits in 1998.[3]

In contrast, SSI is a means-tested income assistance program for disabled, blind, or aged individuals regardless of their prior participation in the labor force.[4] Established in 1972 for individuals with low income and limited resources, SSI is financed from general revenues. In most states, SSI entitlement ensures an individual's eligibility for Medicaid benefits.[5] In 1998, about 3.6 million working-age people with dis-

[1] The estimated reductions are based on data provided by SSA's actuarial staff and represent the discounted present value of the cash benefits that would have been paid over a lifetime if the individual had not left the disability rolls by returning to work. These reductions, however, would be offset, at least in part, by rehabilitation and other costs that might be necessary to return a person with disabilities to work.

[2] Currently, individuals with disabilities are considered to be engaging in substantial gainful activities (SGA) if earnings exceed $500 per month. The monthly SGA level for persons who are blind is $1,110 per month.

[3] Included among the 4.7 million DI beneficiaries are about 720,000 beneficiaries who were dually eligible for SSI disability benefits because of the low level of their income and resources.

[4] References to the SSI program throughout the remainder of this testimony address blind or disabled, not aged, recipients.

[5] States can opt to use the financial standards and definitions for disability they had in effect in January 1972 to determine Medicaid eligibility for their aged, blind, and disabled residents,

Continued

abilities received SSI benefits; federal SSI cash benefits paid to these and other disabled beneficiaries amounted to $21.3 billion.[6]

The Social Security Act states that people applying for disability benefits should be promptly referred to state vocational rehabilitation (VR) agencies for services in order to maximize the number of such individuals who can return to productive activity.[7] Furthermore, to reduce the risk a beneficiary faces in trading guaranteed monthly income and subsidized health coverage for the uncertainties of employment, the Congress has established various work incentives intended to safeguard cash and health benefits while a beneficiary tries to return to work.

STRUCTURAL AND OPERATIONAL WEAKNESSES IN DI AND SSI IMPEDE RETURN TO WORK

In a series of reports, we have discussed how DI and SSI design and operational weaknesses do not encourage beneficiaries to maximize their work potential.[8] The cumulative impact of these weaknesses, summarized in table 1, is to understate beneficiaries' work capacity and impede efforts to improve return-to-work outcomes.

Table 1. Summary of Program Design and Implementation Weaknesses

Weakness	Description
Work capacity of DI and SSI beneficiaries may be understated..	Medical conditions alone are generally a poor predictor of work incapacity. While impairment has some influence over capacity to work, other factors—vocational, psychological, economic, environmental, motivational—are often considered to be more important determinants of work capacity.
Disability determination process may encourage work incapacity..	"All-or-nothing" decision gives incentive to promote inabilities and minimize abilities. Lengthy application process to prove one's disability can also erode motivation and ability to return to work.
Benefit structure can provide disincentive to low-wage work..	The prospect of losing cash and health benefits can reduce motivation to work and receptivity to VR and work incentives, especially when low-wage jobs are the likely outcome. People with disabilities may have less time available for work than others, further influencing a decision to opt for benefits over work.
Work incentives are ineffective in motivating people to work..	Few beneficiaries are aware that work incentives exist. Regardless, work incentives are complex, difficult to understand, and poorly implemented, and they do not overcome the prospect of a drop in income for those who accept low-wage employment.
VR plays limited role in disability programs..	Studies have questioned the effectiveness of state VR agency services. Access to VR services through DDS referrals is limited. Restrictive state VR policies limit categories of people referred by DDS offices, the referral process is not monitored (reflecting its low priority and removing incentive to spend time on referrals), and the success-based VR reimbursement system is ineffective in motivating VR agencies to accept beneficiaries as clients. In addition, applicants and beneficiaries are generally uninformed about and not encouraged to seek VR, affording little opportunity to opt for rehabilitation and employment.

rather than making all SSI recipients automatically eligible for Medicaid. Often, the Medicaid financial standards used by states are more restrictive than SSI's.

[6] This amount represents payments to all adult SSI blind and disabled beneficiaries, including those age 65 and over.

[7] State VR agencies also provide rehabilitation services to people not involved with the DI and SSI programs.

[8] SSA Disability: Program Redesign Necessary to Encourage Return to Work (GAO/HEHS–96–62, Apr. 24, 1996); *SSA Disability: Return-to-Work Strategies From Other Systems May Improve Federal Programs* (GAO/HEHS–96–133, July 11, 1996); and *Social Security: Disability Programs Lag in Promoting Return to Work* (GAO/HEHS–97–46, Mar. 17, 1997).

In recent years, SSA has made efforts to better promote return to work. Also, the Congress and others have proposed various alternatives at program reform.

Work Capacity of DI and SSI Beneficiaries May Be Understated

The Social Security Act requires that the assessment of an applicant's work incapacity be based on the presence of medically determinable physical and mental impairments. SSA maintains a listing of impairments for medical conditions that are, according to SSA, ordinarily severe enough in themselves to prevent an individual from engaging in any gainful activity. About 50 percent of new awardees are eligible for disability because their impairment is listed or meets the severity of a listed impairment.[9] But findings of studies we reviewed generally agree that medical conditions are a poor predictor of work incapacity.[10] As a result, the work capacity of DI and SSI beneficiaries may be understated.

While disability decisions may be more clear-cut in the case of people whose impairments inherently and permanently prevent them from working, disability determinations may be much more difficult for those who may have a reasonable chance of work if they receive appropriate assistance and support. Nonmedical factors may play a crucial role in determining the extent to which people in this latter group can work.

PROGRAM WEAKNESSES IMPEDE EFFORTS TO IMPROVE RETURN-TO-WORK OUTCOMES

Because a disability determination results in either a full award of benefits or a denial of benefits, applicants have a strong incentive to overstate their disabilities to establish their inability to work and thus qualify for benefits. Conversely, applicants have a disincentive to demonstrate any capacity to work because doing so may disqualify them for benefits. Furthermore, many believe that the documentation involved in establishing one's disability can create a "disability mind-set," which weakens motivation to work. Compounding this negative process, the length of time required to determine eligibility can erode skills, abilities, and habits necessary to work.

In addition, VR has played a limited role in the DI and SSI programs, in part because of restrictive state VR policies and limits on alternatives to providers in the state VR system. Beneficiaries have generally been uninformed about the availability of VR services and have been given little encouragement to seek them. Moreover, the effectiveness of state VR services in securing long-term financial gains has been mixed, at best.

Work incentive provisions that are complex, difficult to understand, and poorly implemented further impede return-to-work efforts. Because SSA has not promoted them extensively, few beneficiaries have been aware that work incentives exist. Despite providing some financial protection for those who want to work, work incentives do not appear to be sufficient to overcome the prospect of a drop in income for those who accept low-wage employment.

For example, DI work incentives provide for a trial work period in which a beneficiary may earn any amount for 9 months (which need not be consecutive) within a 60-month period and still receive full cash and health benefits. At the end of the trial work period, if a beneficiary's countable earnings are more than $500 a month, cash benefits continue for an additional 3-month grace period and then stop, causing a precipitous drop in monthly income from full benefits to no cash benefits.[11] SSA researchers have noted that such a drop in income is a considerable disincentive to finishing the trial work period as well as to beginning work. It may be more financially advantageous for beneficiaries—especially those with low earnings—to continue to receive disability payments by not working or by limiting earnings than to earn more than $500 a month in countable income.

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[9] This percent is based on DI and SSI decisions made at the initial level of determination by the DDS offices and subsequent decisions made by administrative law judges on appealed cases from September 1992 through April 1995.

[10] For example, S. O. Okpaku and others, "Disability Determinations for Adults With Mental Disorders: Social Security Administration vs Independent Judgments," *American Journal of Public Health*, Vol. 84, No. 11 (Nov. 1994), pp. 1791–95; and H. P. Brehm and T. V. Rush, "Disability Analysis of Longitudinal Health Data: Policy Implications for Social Security Disability Insurance," *Journal of Aging Studies*, Vol. 2, No. 4 (1988), pp. 379–99.

[11] For 36 months after the trial work period ends, cash benefits will be reinstated for any month in which the person does not earn more than $500 a month in countable income; this is referred to as the extended period of eligibility.

Numerous Program Reforms Have Been Proposed

Our work has called for SSA to develop a comprehensive, integrated return-to-work strategy that includes intervening earlier, providing return-to-work supports and assistance, and structuring benefits to encourage work. SSA has agreed that there are compelling reasons to try new return-to-work approaches.

Recently, SSA told us that it has (1) contracted with over 400 public and private VR providers, (2) trained state VR agency staff on SSA work incentives and reimbursement procedures, and (3) positioned itself to contract with state agencies to research ways to improve service integration for beneficiaries attempting to return work. In addition, SSA has proposed to demonstrate the effectiveness of vouchers (or "tickets") for beneficiaries to obtain VR services from public or private providers reimbursed on an outcome basis. SSA has also proposed increasing the substantial gainful activities level for beneficiaries, thereby allowing them to have a higher earned income before leaving the disability rolls.

In addition to SSA's proposed reforms, the Congress and advocates for people with disabilities have offered various reforms. Such reforms have proposed allowing working beneficiaries to keep more of their earnings, safeguarding medical coverage, and using tickets to enhance vocational rehabilitation.

MULTIPLE FACTORS ASSIST BENEFICIARIES' MOVEMENT INTO THE WORKFORCE

To understand how DI beneficiaries overcome the challenges and disincentives to work, we conducted survey interviews with 69 people who were receiving DI benefits and working in one of three metropolitan areas.[12] The working DI beneficiaries we interviewed cited a number of factors as helpful to becoming employed (see table 2). The two most frequently reported factors—health interventions and encouragement to work by family members and others—appear to have been the most critical in helping beneficiaries become employed. First, health interventions—such as medical procedures, medications, physical therapy, and psychotherapy—reportedly helped beneficiaries by stabilizing their conditions and, consequently, improving functioning. Not only were health interventions perceived as important precursors to work, they were also seen as important to maintaining ongoing work attempts. Encouragement to work from family, friends, health professionals, and coworkers was also critical, according to respondents.

Although other factors were reported less frequently, any single factor can be the key determinant in an individual's becoming employed. These factors include a flexible schedule (particularly to have time off to visit a health professional), job-related training and vocational rehabilitation services (especially job search and on-the-job training), the trial work period and extended period of eligibility, and high self-motivation. To a somewhat lesser extent, religious faith, job coaches, assistive devices and equipment, and ADA provisions were useful. In general, similar proportions of respondents with physical impairments and those with psychiatric impairments cited these factors as helpful to being employed. However, people with physical impairments found coworkers and the trial work period more helpful than did those with psychiatric impairments.

Table 2. Factors That Facilitated Working DI Beneficiaries' Employment, by Frequency of Reporting

Factor	Description	Significance
Primary:		
Health intervention	Health interventions provided medical stabilization and improved functioning.	Early return to work without health intervention may be difficult for some
Encouragement	Family, friends, coworkers, and health professionals provided encouragement and emotional support.	Desire to work can be influenced positively, and possibly negatively, by social forces

[12] Our findings from these interviews are reported in *Social Security Disability Insurance: Multiple Factors Affect Beneficiaries' Ability to Return to Work* (GAO/HEHS–98–39, Jan. 12, 1998). Because neither the metropolitan areas selected nor the people we interviewed constituted a random sample, our results are not generalizable to the entire population of working DI beneficiaries.

Table 2. Factors That Facilitated Working DI Beneficiaries' Employment, by Frequency of Reporting—Continued

Factor	Description	Significance
Secondary:		
Flexible work schedule	Number of hours and work schedule were responsive to respondents' needs and capabilities.	Typical 5-day, 40-hour work week may be unrealistic for some beneficiaries
Job-related training and services.	Training and services were directly related to finding and performing a job.	This factor has implications for retaining workers in the labor force who otherwise might apply for Social Security disability benefits
Trial work period/extended period of eligibility.	SSA provisions allowed beneficiaries to test their work capacity without jeopardizing benefits and to ease their transition to the workforce.	Trial work period reported as useful, although some felt that 9 months is too short and $200 earnings level is too low
High self-motivation	Respondents strongly wanted or needed to work, especially compared with disabled peers without jobs.	Motivation to work may develop over time, as about 3 in 10 did not expect to work upon program entry
Tertiary:		
Religious faith	Religious faith reported as providing source of strength and guidance.	Interview did not specifically address religious faith; it may be more important than reported
Job coaches	On-site job coach or similar specialist taught work skills.	This factor has implications for retaining workers in the labor force who otherwise might apply for Social Security disability benefits
Assistive devices and equipment.	Among most frequently mentioned items were back and leg braces, canes and crutches, adapted computers and keyboards, and wheelchairs.	Usefulness of assistive devices and equipment is largely limited to people with physical impairments
Provisions provided by ADA.	Respondents reported that ADA provided rights, accommodations, and hiring opportunities.	About one-third were aware of ADA, and over one-half of those who were aware said ADA was not helpful

Note: Factors are categorized into three groups—primary, secondary, and tertiary—on the basis of how often all respondents reported them. In some instances, we combined related areas of support and services in developing the factors and assigning relative importance.

Beneficiaries' comments illuminate the importance of these factors in helping them return to work. For example, Carol, an administrative support worker in her thirties with a manic depressive disorder, pointed to encouragement and medical intervention as factors that enabled her to continue working:

> My family members . . . encouraged me to go to work and not rely on disability income. They were helpful to me in assessing the merits and benefits of potential job offers. . . . I am using a combination of Prozac and lithium medications to control my condition and [enable] me to work regularly where I don't use my sick days. Therapy with my counselor for over 4 years has really allowed me to work and function in a work environment.

Similarly, Mark, a maintenance worker in his thirties with epilepsy, said

> Medications for [my] epilepsy help keep [my] condition under control, which minimizes seizures and the risk of getting fired. . . . [My supervisor] checks from time to time to make sure everything is okay [and] even suggests taking days off.

Stephen, a bartender in his thirties with HIV, identified various individuals in the community who support him:

> [My] infectious disease doctor [is] encouraging and is very supportive. He wrote a letter to [my] employer explaining [my] condition and my capabili-

> ties. [My] parents are very supportive [and my] medications have made me physically able to work. [Coworkers are] providing emotional support.

Yvonne, a cashier in her forties with an anxiety disorder, found—in addition to medical intervention and community support—ADA helpful:

> Psychotherapy and group therapy [have] been helpful. Also, medication has been helpful. . . . My psychotherapist has gone out of his way to help me. I can call him at any time. The pastor of my church has also counseled me. At the college I attended, a director of the disabled talks to my professors and tells them about my condition so that they can take this into account when assigning work and evaluating my performance. . . . ADA has helped because I believe that [my employer] would not have hired me because of my problems.

Longer Term Work Decisions Were Also Affected by Health Concerns

Not surprisingly, personal health appears to be an overriding issue as beneficiaries consider their future status in the DI program and at the work site. Among the 44 respondents without employer-based health insurance coverage, 29 plan to stay on the DI rolls into the foreseeable future or are unsure of their future plans. In contrast, 15 of 24 respondents with such coverage plan to exit the rolls. Moreover, when asked if anything would make it harder to work, about one-half of the 46 respondents who responded affirmatively said that poorer health would inhibit employment. Similarly, some said that improved health would facilitate work. We found little difference in future work and program plans between people with physical and psychiatric impairments.

Work Incentives and SSA Staff Played Limited Role

DI program incentives for reducing risks associated with attempting work appear to have played a limited role in beneficiaries' efforts to become employed. Although the trial work period was considered helpful by 31 respondents, others indicated it had shortcomings or were unaware that it existed. For instance, several respondents indicated the amount signifying a "successful" month of earnings ($200) was too low, an all-or-nothing cutoff of benefits after 9 months was too abrupt, and having only one trial period did not recognize the cyclical nature of some disabilities.[13] Respondents' mixed views of the design of the trial work period suggest that while they value a transitional period between receiving full cash benefits and losing some benefits because of work, they might be more satisfied with a different design. Finally, over one-fifth were unaware of the trial work period and therefore may have unknowingly been at risk of losing cash benefits.

Moreover, many respondents were unaware of other work incentives as well. Consequently, fewer respondents reported these incentives as helpful than might have had they been better informed. For example, 41 respondents were unaware of the provision that allows beneficiaries to deduct impairment-related work expenses from the amount SSA considers the threshold for determining continued eligibility.[14] Using the deduction could make it easier for a beneficiary to continue working while on the rolls without losing benefits. Moreover, 42 respondents were unaware of the option to purchase Medicare upon leaving the rolls. As a result, some of these beneficiaries may have decided to limit their employment for fear of losing health care coverage, while others who planned to leave the rolls may have thought they were putting themselves at risk of foregoing health care coverage entirely upon program termination.

Generally, respondents told us that SSA staff with whom they interacted provided neither much help in nor were much of a hindrance to return-to-work efforts. Fifty-nine respondents answered "no" when asked if people from SSA assisted them in becoming employed. However, 52 of the 69 respondents told us that they did not have experiences with SSA that made it difficult to become employed. For the 17 people reporting difficulties, the most common examples cited were the limited assistance offered and poor information provided by SSA.

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[13] Similarly, some beneficiaries noted that the $500 monthly earnings threshold used in the formula to determine if a person with a disability other than blindness is working at a gainful activity level (and therefore no longer eligible for benefits) is set too low.

[14] Examples of expenses likely to be deductible include attendant care services performed in the work setting, structural modifications to a vehicle used to drive to work, wheelchairs, and regularly prescribed medical treatment or therapy that is necessary to control a disabling condition.

DIFFICULT CHALLENGES AND TRADE-OFFS INVOLVED IN IMPROVING WORK INCENTIVES

Because the current work incentives have either impeded or played a limited role in helping beneficiaries return to work, the Congress and others have recognized the need to reform the current work incentives, particularly those in the DI program. However, our work has found that changing the work incentives involves difficult challenges and tradeoffs. Because of the complex interactions between earnings and disability benefits, some types of work incentive changes may help some beneficiaries more than others. Moreover, tradeoffs exist between trying to increase the work effort of beneficiaries without decreasing the work effort of people with disabilities who are not currently receiving disability benefits.

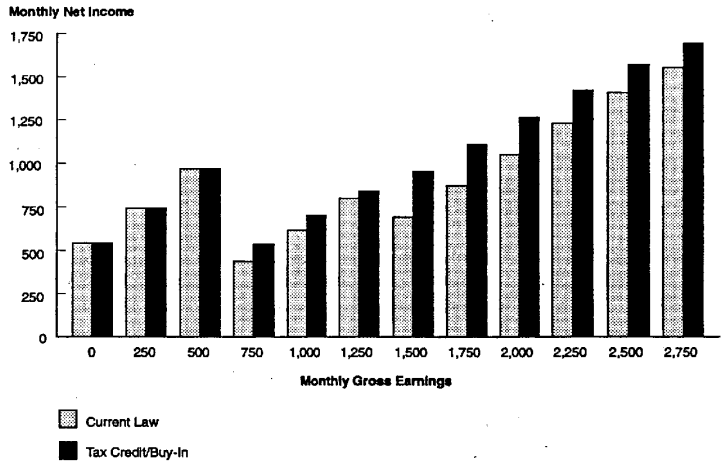
Two illustrations using data from Virginia Commonwealth University's Employment Support Institute underscore the complex interactions between earnings and benefits.[15] For example, figure 1 shows that under current law, a DI beneficiary's net income may drop at two points, even as gross earnings increase. The first "income cliff" occurs when a person loses all of his or her cash benefits because countable earnings are above $500 a month and the trial work and grace periods have ended (which, in figure 1, occurs when the individual earns $750 a month). A second income cliff may occur if Medicare is purchased when premium-free Medicare benefits are exhausted (which, in figure 1, occurs when the individual earns $1,500 a month).

Figure 1 also illustrates what happens to net income when a tax credit is combined with a Medicare buy-in that adjusts premiums to earnings.[16] In this particular example—although the tax credit may cushion the impact of the drop in net income caused by loss of benefits—it does not eliminate the drop entirely. However, as figure 2 shows, the income cliff is eliminated when benefits are reduced $1 for every $2 of earnings above the substantial gainful activity level.

[15] The Employment Support Institute at Virginia Commonwealth University developed WorkWORLD software, which allows individuals to compare what happens to their net income (defined as an individual's gross income plus noncash subsidies minus taxes and medical and work expenses) as earnings levels change under current law and when work incentives are changed.

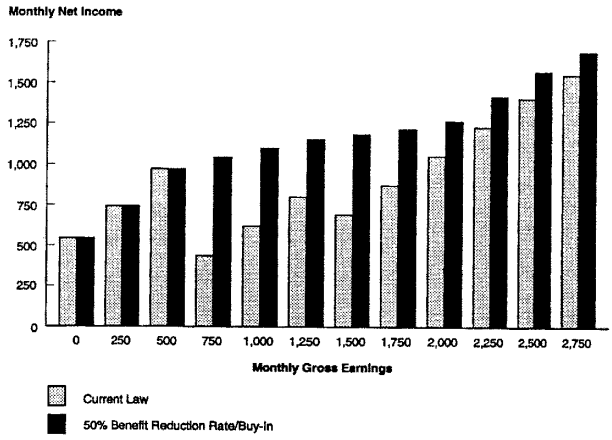
[16] The tax credit used in this example assumes that the credit is refundable and supplements the existing Earned Income Tax Credit.

Figure 1: Comparison of Net Income for DI Beneficiaries Under Current Law and Under Proposed Tax Credit and Sliding Scale Medicare Buy-In



Source: Employment Support Institute, Virginia Commonwealth University.

Figure 2: Comparison of Net Income for DI Beneficiaries Under Current Law and Under Proposed 50-Percent Benefit Reduction Rate and Sliding Scale Medicare Buy-In



Source: Employment Support Institute, Virginia Commonwealth University.

In addition, changing work incentives may or may not increase the work effort of current beneficiaries, depending on their behavior in response to the type of change and their capacity for work and earnings. But even if changes in work incen-

tives increase the work effort of the current beneficiaries, a net increase in work effort may not be achieved. This point is emphasized by economists who have noted that improving work incentives may make the program attractive to those not currently in it.[17] Allowing people to keep more of their earnings would make the program more generous and could cause people who are currently not in the program to enter it. Such an effect could reduce overall work effort because those individuals not in the program could reduce their work effort to become eligible for benefits. Moreover, improving work incentives by allowing people to keep more of their earnings could keep some in the program who might otherwise have left. Decreases in the exit rate could reduce overall work effort because people on the disability rolls tend to work less than people off the rolls. The extent to which increased entry occurs and decreased exit occurs will affect how expensive these changes could be in terms of program costs.

The costs of proposed reforms are difficult to estimate with certainty because of the lack of information on entry and exit effects. Although our work sheds additional light on this issue, the lack of empirical analysis with which to accurately predict outcomes of possible interventions reinforces the value of testing and evaluating alternatives to determine what strategies can best tap the work potential of beneficiaries without jeopardizing the availability of benefits for those who cannot work.

Mr. Chairman, this concludes my prepared statement. At this time, I will be happy to answer any questions you or the other Members of the Subcommittee may have.

RELATED GAO PRODUCTS

Social Security Disability Insurance: Factors Affecting Beneficiaries' Return to Work (GAO/T–HEHS–98–230, July 29, 1998).

Social Security Disability Insurance: Multiple Factors Affect Beneficiaries' Ability to Return to Work (GAO/HEHS–98–39, Jan. 12, 1998).

Social Security Disability: Improving Return-to-Work Outcomes Important, but Trade-Offs and Challenges Exist (GAO/T–HEHS–97–186, July 23, 1997.)

Social Security: Disability Programs Lag in Promoting Return to Work (GAO/HEHS–97–46, Mar. 17, 1997).

People With Disabilities: Federal Programs Could Work Together More Efficiently to Promote Employment (GAO/HEHS–96–126, Sept. 3, 1996).

SSA Disability: Return-to-Work Strategies From Other Systems May Improve Federal Programs (GAO/HEHS–96–133, July 11, 1996).

Social Security: Disability Programs Lag in Promoting Return to Work (GAO/T–HEHS–96–147, June 5, 1996).

SSA Disability: Program Redesign Necessary to Encourage Return to Work (GAO/HEHS–96–62, Apr. 24, 1996).

PASS Program: SSA Work Incentive for Disabled Beneficiaries Poorly Managed (GAO/HEHS–96–51, Feb. 28, 1996).

Social Security Disability: Management Action and Program Redesign Needed to Address Long-Standing Problems (GAO/T–HEHS–95–233, Aug. 3, 1995).

Supplemental Security Income: Growth and Changes in Recipient Population Call for Reexamining Program (GAO/HEHS–95–137, July 7, 1995).

Disability Insurance: Broader Management Focus Needed to Better Control Caseload (GAO/T–HEHS–95–164, May 23, 1995).

Social Security: Federal Disability Programs Face Major Issues (GAO/T–HEHS95–97, Mar. 2, 1995).

Chairman SHAW. Thank you. Do any Members seek recognition?

Mr. MATSUI. Just very briefly, Mr. Chairman, thank you.

[17] See Hillary Williamson Hoynes and Robert Moffitt, "The Effectiveness of Financial Work Incentives in Social Security Disability Insurance and Supplemental Security Income: Lessons From Other Transfer Programs," *Disability, Work, and Cash Benefits*, edited by Jerry L. Mashaw and others (Kalamazoo, Mich.: W. E. Upjohn Institute for Employment Research, 1996), and Hillary Williamson Hoynes and Robert Moffitt, "Tax Rates and Work Incentives in the Social Security Disability Insurance Program: Current Law and Alternative Reforms" (May 1997), unpublished.

Thank you for your testimony.

In terms of the health issue, could you tell me how many people that go off and go into the job market actually end up having health benefits. Do you have that statistic available?

Ms. FAGNONI. We don't.

Mr. FALLAVOLLITA. At least among the sample that we interviewed, it was one-third of the folks while they were on the rolls—this is while they were working—one-third of the folks had employer-based health insurance, and the remaining did not.

Mr. MATSUI. So the remainder, the approximately 65 or 67 percent, did not have health insurance. What happens after the health insurance benefit runs out after 2 years? That's the critical point. One of you can——

Ms. FAGNONI. Well, I think this is where there are concerns, and there is a disincentive for people—you hear a lot from people who say they are afraid to go over that $500—currently DI is at $500 maximum to have their benefits cut off, and then ultimately their health benefits are cut off. They will cut off their work effort or sometimes stop working just to protect those health benefits.

Mr. MATSUI. Right.

Is that what your surveys basically point to? The sample that you took——

Ms. FAGNONI. Well, what the sample really told us—we were interviewing and surveying people who were working—these disabled beneficiaries who were working, so we were really looking at what helped them get to work, and what they said was the health interventions were very important.

Mr. MATSUI. After the benefits run out, I guess they can pick up health insurance, though it is hard to imagine the individual can pick it up himself or herself, since the cost becomes prohibitive because of income levels, right?

Ms. FAGNONI. Clearly, the loss of health coverage is a big concern and barrier to people who are attempting to move from disability into the work force and stay in the work force.

Mr. MATSUI. Would you like to respond?

Mr. FALLAVOLLITA. There is a Medicare buyin for DI workers if they leave the rolls through their earnings. They have the option to purchase the Medicare, but the monthly premium may be prohibitive for folks in lower income wages. For instance, it is about $400 a month to buy in to that, and so that can add up for folks who are not making an income where they can afford that.

Mr. MATSUI. Thank you very much.

Chairman SHAW. Yes, sir.

Mr. HULSHOF. Ms. Fagnoni, under current law, State vocational rehabilitation agencies are really the only game in town as far as providing rehabilitation services for disabled beneficiaries. I am also aware that the Social Security Administration has implemented a program where individuals are referred to alternative providers, but only after 4 months has passed and it is assumed that the vocational rehabilitation is not going to provide services. Is this program working?

Ms. FAGNONI. Well, as you heard the Commissioner say, and Dr. Daniels, that program has not been up and running for very long, and while they have something like 419 providers signed up, very

few people have been run through the system. I think we were told something like 66 beneficiaries had actually been able to take advantage of that alternative-provider system. And I think they said that they are only now looking at the first person to kind of have some outcome from that program. So, there is not yet much to show from that effort.

Mr. HULSHOF. Let me ask you, last year in reauthorizing the Vocational Rehabilitation Act of 1973, Congress directed that disabled beneficiaries would be presumed to be eligible for vocational rehabilitation services unless the State can demonstrate by clear and convincing evidence that the individual is incapable of benefiting in terms of employment outcome due to severity of impairment. And I know that it is too soon to have any data, but will this change in law that we had last year—do you think that will result in more beneficiaries being provided services by State vocational rehabilitation agencies, or is it just too soon to tell?

Ms. FAGNONI. One thing about that provision—if you look at some of the reports we have done that have looked at return-to-work effort, we have put a lot of emphasis on the fact that SSA—when people walk in the door to apply for disability benefits, SSA does not do a good job of informing people of what different services might be available to them, and often people are not in a position to want to focus on efforts to return them to work or talk about vocational rehabilitation because they are focused on trying to prove that they can't work so that they can get disability benefits. So, what our work has shown is that SSA overall only refers about 10 percent of disabled beneficiaries to the State vocational rehabilitation agencies.

So, unless there are other mechanisms for identifying who else could benefit from rehabilitative services, then not many people are getting to the vocational rehabilitation agencies in the first place, so, I think at that front end we probably need more focus coupled with more emphasis by the State vocational rehabilitation agencies in serving disabled beneficiaries coming from SSI and DI.

Mr. HULSHOF. I appreciate that.

I yield back, Mr. Chairman, and I thank you.

Chairman SHAW. Thank you very much. We appreciate your being with us today, and as usual, you have done a tremendous job.

Ms. FAGNONI. Thank you, Mr. Chairman.

Chairman SHAW. Thank you for being with us.

The final panel is made up of Richard Blakley who is the executive director of Services for Independent Living out of Columbia, Missouri—I believe he will be further introduced—Dr. Mary Gennaro, who is the director of Federal and State Relations of the National Association of Developmental Disabilities Councils, on behalf of Consortium of Citizens with Disabilities; Jim McNulty, a member of the board of directors of National Alliance for the Mentally Ill, in Bristol, Rhode Island; and Jeffrey Carlisle, who is president of the National Association of Rehabilitation Professionals in the Private Sector, from Metairi—am I pronouncing that correctly?

Mr. CARLISLE. Metairi.

Chairman SHAW. Metairi, Louisiana.

As with the prior witnesses, we have your full testimony which will be made a part of the record, and we invite you to summarize as you see fit.

We will be having another vote coming up in about 20 to 25 minutes. Hopefully, we can conclude this panel before that vote, but before that I yield to the gentleman from Missouri.

Mr. HULSHOF. Thank you, Mr. Chairman.

It is not often to have a constituent of mine who has traveled from Missouri to come all the way to Washington, DC, and so I am especially honored and proud to have a constituent, Rich Blakley, who we will hear from. Rich is right now the executive director for Services for Independent Living in Columbia, Missouri. He has done a great job managing, I think, 19 members on his staff, but he has also been an activist and a consultant not only in Missouri, but in Illinois. And recently, in fact, just weeks before the election, we had a very successful forum, that Rich put together, talking about these very issues. And so, it is great to have Rich here to give testimony, and it is a special honor and privilege to introduce him to this Subcommittee.

Chairman SHAW. Thank you.

Mr. Blakley.

STATEMENT OF RICHARD BLAKLEY, EXECUTIVE DIRECTOR, SERVICES FOR INDEPENDENT LIVING, COLUMBIA, MISSOURI

Mr. BLAKLEY. Thank you. Thank you for those kind words, Congressman Hulshof.

Mr. Chairman and Members of the Subcommittee, I am honored to be here today.

I would like to talk about Social Security work disincentives from being on the frontlines and dealing with this subject on a day-to-day basis. I would also like to thank Diana Beckley from the University of Missouri for assisting me in preparing this testimony today.

First of all, one of the disincentives that we have seen in Social Security on people with disabilities returning to work is the complexity of the program. People with disabilities coming out of a hospital and the newly injured go to the Social Security Administration and they are asked, "Can you work?" And they have to say, no. to get benefits. The same individuals then return to the vocational rehabilitation agency and are asked, "Can you work?" They are told to say, "Yes, I can," in order to receive benefits. What is the point of that? We don't understand that.

There is a complexity of the issues that should not exist. They need to be streamlined. They need to be taken care of. They need somehow to be put into legislation so that you don't have discrepancies between these two programs.

Vocational rehabilitation agencies do a good job, for the most part. They vary from State to State. It depends from counselor to counselor. The Social Security Administration does a good job for the most part, but again, it depends on who you talk to. It depends on what information they will give you. It depends on what agency you go to and what office you go to.

One of the things that is also a disincentive to people is when you ask them, why don't you get a job? Their answer is, because

I will lose. I will lose benefits. I will lose income. I will lose health insurance. That is not always true, but the information is not always given in a way that they can understand or that they are willing to accept. Also, people with disabilities are a cross section of the population. That is not always a popular thing to say. Some people with disabilities would rather sit home instead of working. That is a fact.

I think that disincentives that exists must be removed and removed in a manner that also encourages people to return to work, if that is a feasible course of action for them.

Let me give you an example. I believe that in my testimony that I mention this. At the age of 17, I became disabled through a diving accident, and I became a quadriplegic. At that point in time I earned enough credits or quarters—it was quite awhile ago—I was able to earn $350 a month because of public SSDI. It was tough going for awhile, many years. As time carried on, I realized that I had to return to college. I couldn't live on this the rest of my life. My parents couldn't support me for the rest of my life. So, I had an incentive to go to work through family encouragement and the knowledge that I must return, if only to fulfill what I must do in the future and that was to become an IRS employee for about 6 months before I discovered another field which I have been in since.

Many people have these opportunities, and they need to be given information which exists that they can return to work and that there are incentives to return to work, as an earlier speaker suggested.

A part of the Medicare system that we think needs to be fixed but is an extremely difficult thing to talk about is the discrepancy between the blind population and people who are not blind. One, people could earn up to $1,000 a month, and not lose benefits, whereas people who are not blind but they have a disability can earn up to $500. It is not a popular issue to talk about, but it is something that must be discussed. I applaud the blind lobby for getting the job done. I think that it is a terrific thing. But people with disabilities also must be given that opportunity.

Let me just conclude by saying that I encourage you to streamline this concept, and streamline the Social Security process and make it much easier for people to access the system, fix the system. Right now, Medicare especially is broken. Medicaid is dying out, but Medicare is a train wreck, and it is wrecking many people's lives. I encourage you to fix it. Make it a ticket program. Millions of people depend on it. Those who want to work get back to work and help part of society as a whole.

Thank you very much for giving me the opportunity to testify.

[The prepared statement follows:]

Statement of Richard Blakley, Executive Director, Services for Independent Living, Columbia, Missouri

I want to thank the Chairman and the Committee members for giving me the opportunity to present my thoughts and ideas regarding the inherent work disincentives that currently exist in the Social Security System for people with disabilities. In addition, I wish to thank Congressman Hulshof for inviting me to Washington to appear before his colleagues in the House of Representatives. I consider it a privilege and an honor to be able to give my comments to the Subcommittee on Social Security in person.

There are a number of items in the Social Security Act that are confusing, irritating, frustrating and incomprehensible to the average individual who obtains a disability. I know this because 23 years ago I was one of those individuals. Trying to get through the bureaucracy and the tangled web of paperwork that involves obtaining benefits is frustrating and sometimes demeaning. My assumption was that after all these years Social Security had changed significantly for people with disabilities. After research for this testimony, it seems that instead of changing, the tangled web of bureaucratic procedure is essentially the same. Hopefully, we can now begin work on changing the system to work for people with disabilities instead of working against people with disabilities. Let me give you an example.

Once a person is eligible for Title II or Title XVI of the Social Security Act, they become dependent on their benefits because of a number of factors. These include fear of losing health insurance, fear of losing income, confusion, and basic dependency. All of these factors prevent people from attempting to enter the work force. In addition, there is a lack of consistency within the various agencies that attempt to get people with disabilities employed as opposed to Social Security, which attempts to keep people unemployed.

If an individual wishes to be employed, the first step is to contact the State Vocational Rehabilitation office. The person with a disability is then hooked up with a Vocational Rehabilitation Counselor. The Vocational Rehabilitation Counselor asks, "Can you work?" If the person with a disability says yes, then they will receive Vocational Rehabilitation services if the individual meets the financial eligibility guidelines. If the individual says no, then they may be denied a college education, hand controls or a lift on a van, any opportunity at some type of significant future employment, or even a wheel chair that is tailored specifically for their needs.

If an individual wishes to be granted benefits under Title II or Title XVI, the person must go to the Social Security office. At the Social Security office, they will be asked the same question "Can you work?" Obviously, the individual with a disability must give a completely different answer than what was given at the Vocational Rehabilitation office. The answer must be "No, I cannot work." Only then will the person with a disability receive benefits under the Social Security Act. In addition, an individual typically waits six months prior to approval due to medical exams, denials, appeals and administrative law hearings.

As you can see, the two agencies are in direct conflict with each other. This causes the number one work disincentive that exists within the Social Security System. This disincentive is confusion. The rules of the Social Security Act are complex and changing all the time. You have Title II, which consists of Social Security Disability Income (SSDI) and Social Security Disabled Adult Child (SSDAC). In addition, Title II contains Medicare, which, in most people's minds, is a program for seniors, not for people with disabilities. More confusion exists under Title XVI of the Social Security Act, which includes Supplemental Security Income (SSI) and Medicaid. I won't even begin to get involved int he different waivers that vary from state to state. This is why I believe people with disabilities often times, choose not to work.

If you ask a person who is on SSDI or SSI what will happen if they work, the first answer you will hear is "I will lose." The answer "I will lose" can mean many things. It may mean I will lose income, I will lose insurance, I will lose attendant care, and I will lose benefits that I will never have the opportunity to obtain once the trial work period is over. Many people with disabilities are terrified of the prospect of losing something as valuable as insurance or income even though it may be a meager living condition in which they exist. Also, there is an 18 month waiting period for pre-existing conditions on most private insurance companies for people with disabilities who have not had the opportunity to be covered by a private carrier in the past.

I remember acquiring my disability at the age of 17. Fortunately, I had worked enough quarters to qualify for SSDI and eventually began paying into the Medicare system. My only income for several years was $350 a month. I was lucky enough to live with my parents who did my personal care and assisted me with the financial ability to purchase a van. I realized I could not live on this amount the rest of my life and only make an additional $500 per month. Therefore, the decision to leave the program was easier for me, however, it was still very frightening being told by the Social Security Administration that after a 9 month trial work period, I would never be able to receive these benefits again. I can only imagine what it must be like for an individual who is capable of working and receiving higher benefits to leave the Social Security Program and begin working. This ties into the confusion and direct conflict that creates a significant work disincentive.

Another problem with Social Security is Title II of the Act, specifically Medicare Insurance. Once again, we are involved with confusion and misinformation. First, Medicare was specifically set up for seniors and people with disabilities were

lumped into the program at a later date. If you ask anybody on the street what Medicare is for, most individuals will say that it is for the senior population. I believe that people with disabilities should be pulled out of the Medicare program and included in a new and innovative health program, specifically set up for individuals with disabilities.

Medicare should be a program that does not drop you if your Substantial Gainful Activity (SGA) exceeds $500. Medicare should be a program that addresses the inequities between disabilities when it comes to the SGA, i.e., people who are blind as opposed to people who have any other type of disability. I applaud people who are blind for having the ability to raise their SGA to $1,100 per month, however, I believe it is important that the SGA is equitable for everyone that is involved. If two able bodied individuals are involved in an automobile accident and one becomes blind, and the other becomes a high level quadriplegic, the blind person will receive a SGA of more than double what the quadriplegic will receive. Therefore, I believe we need a program where the SGA is evened out at $1,100 per month for everyone.

Medicare also is a terrible program in many other ways. First, it has a two-year waiting period before you can acquire benefits. Many individuals in that two year span of time, will have their life savings wiped out, may become deeply involved in debt through medical expenses, may become bankrupt, and may be divorced. This is not an exception to the rule. These things do happen to people who have to wait two years prior to Medicare acceptance. Also, Medicare will not pay for health care supplies or medication. People with disabilities usually need some sort of supply or medication each month. Having a disability is expensive. Medicare does not address this issue. People with disabilities are forced to give up savings and possessions in order to be eligible for the Missouri Medicaid programs.

One major concern regarding Medicare is the payment for durable medical equipment (DME). DME suppliers will not order equipment before they receive prior approval from Medicare. The reason is that they have not received payment upon a Medicare denial if they order the DME prior t pre-approval. This takes a significant amount of time and frustration on both the consumers's part and the part of the DME supplier. In addition, most DME is standardized. Medicare has extreme difficulty purchasing specialized equipment for people with disabilities that require something different from the norm. Finally, the DME has a 20% co-pay. Most people with disabilities, on a fixed income, who have a SGA of $500 per month, cannot afford a 20% co-pay. To most individuals who qualify for Medicare, any co-pay is too expensive.

Assistive technology is something that people with disabilities are acquiring and using more and more frequently. This is the technology age. People with disabilities have discovered new ways to use old devices and are constantly seeing new technological devices on the market that they cannot afford and Medicare will not pay for. Addressing the technology issue for people with disabilities is crucial. Technology is ever changing, is a wave of the future, and definitely enhances the quality of life and reduces medical expenses for people with disabilities.

Medicare does not provide for attendant services unless ordered by a doctor. Ideally, self-directed care would be paid for which will enable people to seek employment. Medicare gives no assistance on any type of attendant care unless prescribed by a physician, therefore causing a tremendous hardship on people who wish to live independently. Studies have shown that people with disabilities must have the ability to live independently before they can be employed. I strongly recommend that self-directed attendant care services be available on the Medicare Program.

There is a significant problem with the Subsidy Work incentive under the Medicare rules. It puts a person with a disability in a position that is demeaning and degrading. The person with a disability must ask their employer to inform the Social Security office that they cannot do the same work as an able bodied employee. This may mean that the individual works slower or needs more supervision. At any rate, forcing an employee into a position of telling the employer that they cannot perform satisfactory work puts the person with a disability in a very precarious position. An employer may find a way to fire the employee, refuse a subsidy, or may ask the employee why they cannot keep up. The whole scenario behind an employee going to their boss and telling them that they cannot do the work expected without more pay is ludicrous. Imagine yourself in this situation. You do the best work you can, cannot make over $500 per month, want to stay employed therefore, you have to tell your boss you cannot do the job. This must be streamlined, re-defined or generally accepted by the Social Security Administration when an applicant applies, based upon information given by the applicant.

The Medicaid Program in Missouri is not as bad as the Medicare Program under Title II. Unfortunately, this program is set up for individuals with disabilities who have virtually no assets. Once again, the rules of the program are confusing and

filled with misinformation. In Missouri, you can own your own home and a vehicle and have less than $1,000 in the bank before you are eligible for Medicaid. Once eligibility is established, you are limited to a certain amount of income unless you enroll in the 1619B Work Incentive Program. The Work Incentive Program income guidelines vary from state to state. In Missouri there is a very liberal income exclusion so that the thresh-hold amount does not apply. However, in other states it varies around $15,000 to $40,000. There is no real consistency between states. This should be rectified in any bill that streamlines the system and eliminates confusion.

Under the Medicaid Program, once again, there is no self-directed attendant care. A person with a disability has an option to a nursing home or has an option for a home health care agency, but they have no option to hire, fire and manage their own attendant. I know an individual who is currently employed, receives Medicaid benefits, is on the 1619B Program and uses a home health care agency. Because of the lack of control over the attendant services that he receives, this individual is continuously late for work, has pressure sore problems which prevent him from being at work 8–5 everyday, and has an overall morale problem because of his lack of control over the attendant services that he receives. Fortunately, this gentleman has an understanding employer who has been in a similar situation and can relate to the everyday life problems that are faced by a lack of self-directed attendant care. National ADAPT is working with Congress on the MiCasa attendant care bill which, if passed, would provide self-directed attendant care services for all eligible participants. MiCasa is an excellent example of self-directed attendant care and would greatly enhance the ability of people with disabilities to be independent and to give them the opportunity to go to work. I have never heard of an individual who is in a nursing home that is also employed. Nursing homes are there for people with chronic or terminal illnesses. People with disabilities are not ill therefore; they do not belong in nursing homes.

Under Title XVI, people with disabilities' SSI is tied directly to a Federal Benefit Rate (FBR) of $500. Exceeding the FBR in a work environment will once again result in the loss of cash benefits. This is a disincentive to work that consistently exists. A person may be able to keep their Medicaid under 1619B, but may lose cash benefits that they have been relying on to survive. This is a frightening and confusing prospect for people with disabilities.

In Missouri, Medicaid in not a bad program. In other states, it is not quite as good. In some states it is better. That is the problem with the lack of consistency. It should not depend on where you live that will determine what services you receive. Let me give you an example, using myself.

Five years ago, I lived in the heartland of Illinois. Because I have a disability, I automatically qualified for public aid, yet I made an annual salary of $35,000 a year. I was on a spend-down program and was able to receive self-directed personal attendant services paid for mostly by Medicaid. My co-pay for the attendant services was $50 a month, while the state of Illinois paid the additional $650 per month for an attendant, morning and night, I lived on my own, without an attendant in my household. When I moved to Missouri, it all changed. I found that I could not qualify for a nonexistent attendant program, due to a lack of a Waiver. I was surprised and shocked to find that in order to live on my own it would cost $700 per month, out of my pocket. This was unaffordable. I had to improvise. I rented a 2-bedroom apartment and gave free room and board to a person to assist me with my daily needs. In addition, I paid, and continued to pay $200 a month for a back-up attendant to relieve the person who works for room and board. This situation is far from ideal. I personally feel penalized for having a disability. I'm not alone in this situation. People with disabilities, in Missouri, who are employed cannot make over $15,000 per year in order to receive self-directed care. This is a huge disincentive in our state. Once again, it goes back to the necessity for a National Self-Directed Care Program.

In closing, let me state that people with disabilities have been subtly discriminated against by a bureaucracy that is demeaning, patronizing, confusing and set up to keep people with disabilities at poverty levels while penalizing them if they work. Sometimes the penalties are genuine and at other times they are perceived. Either way, the indisputable fact is that they exist and keep people with disabilities from seeking gainful, meaningful employment. The work disincentives that are deep-seated within the Social Security Act must be erased. These intrinsic penalties have been in existence for too many years. It is time to change the system. Give it an overhaul, lose the disincentives and allow people with disabilities the dignity that is afforded everyone else in our society. Don't take away the system, but please, I implore you change the system.

Chairman SHAW. Thank you, Mr. Blakley.
Ms. Gennaro.

STATEMENT OF MARY GENNARO, J.D., DIRECTOR, FEDERAL-STATE RELATIONS, NATIONAL ASSOCIATION OF DEVELOPMENTAL DISABILITIES COUNCILS; AND MEMBER, CONSORTIUM FOR CITIZENS WITH DISABILITIES, SOCIAL SECURITY TASK FORCE

Ms. GENNARO. Chairman Shaw, Members of the Subcommittee, thank you for the opportunity to testify.

I am Mary Gennaro, director of Federal-State Relations for the National Association of Development Disabilities Councils. I am also a member of the Social Security Subcommittee of the Consortium for Citizens with Disabilities, and it is as a member of that task force that I testify today. Last, I am also a person with a disability, namely cerebral palsy.

As a person with a disability who is employed, I am one of the fortunate few. This Nation cannot continue to allow human potential to be trapped and wasted. Doing so exacts too high a price.

About 70 percent of adults with severe disabilities are not employed—one of the largest minorities in the Nation without jobs. But people with disabilities want to work, and they want to have that opportunity, especially at a time when our economy is flourishing and unemployment rates are at all time lows.

The question is what is preventing people with disabilities who want to work from working? What major barriers stand in their way? Some of these are: Lack of access to vocational rehabilitation and employment services and choice in those services and providers; lack of access to health care coverage, financial disincentives and complex and confusing rules about what happens to beneficiaries when they work. These are rules that often punish their efforts and success rather than assisting them. These are not all the barriers, but if we address these, we will take a significant step forward in assisting people.

This Subcommittee well knows the benefits of a ticket to work. It is through your dedication on this issue and the bipartisan work of the last Congress that we are here today with strong bipartisan legislation in the Senate and you poised to work on this also, hopefully in a bipartisan way.

The ticket moves us one big step closer to addressing this problem, but there remains a problem. Beneficiaries will not use the ticket if they continue to fear loss of their health care coverage. That is the next disincentive that I would like to discuss.

The problem for DI beneficiaries is that they lose Medicare after working for a period of time and earning a set amount of money. They can lose coverage with earnings of as little as $500 a month. They lose coverage, but their disability remains and their need for health care remains, but if they took a part-time job, or a low-paying job, it is likely that their employer does not offer health care coverage. If coverage is offered, it is likely to be too costly, given the amount of earnings that the person has, or coverage may simply be insufficient.

The Medicare buyin that currently exists is also insufficient, costing $350 some dollars a month, it is out of reach of most people, and currently only 170 people take advantage of enrollment in this program.

Given the choice between work and health care, people choose the only choice possible: preserving their life and health. But this is no choice that anyone should have to make. The results are needless, wasted potential. We need to continue Medicare for people who need it. It must be extended without an arbitrary cutoff after a certain number of years. Doing so is not a matter of adding new people to the program, but of maintaining critical coverage for former beneficiaries who have actually been able to move into work. People will simply have to choose between work and future risk to life and health in 3 years, 5 years, whatever arbitrary limit we set. The choice is unacceptable.

People on SSI also face a problem in regard to health care when their earnings rise, and we must be able to extend health care to them as their needs continue. And we need to let the States extend Medicaid in other ways. To assist people with disabilities, we need it to work. And we should encourage States to develop systems to support the needs of people with disabilities and give them the option to assist them to work. One of these ways is through personal care assistance.

The other disincentive for people is financial, and we have discussed that along with the others today. The SSDI Program does not allow for a gradual reduction of benefits, and it is similar to the SSI Program. In the 105th Congress, you supported a mandated demo to look at the gradual decrease, and we hope you will again include that in any legislation that you put forward.

Finally, as far as barriers are concerned, I wanted to mention the complex, confusing nature of the rules that people who are beneficiaries of the system must comply with. They are confusing; they are complex. People have difficulty getting information, clear information.

Given the risks that people face when they work, it is understandable that they fear using the work incentives. They fear their work will trigger continuing disability reviews. This is not appropriate. We need to protect people so that they can attempt to work and not fear that work will bring an end to the benefits they still need because their disability remains.

Also, people are fearful they will not be able to reenter benefits should they remain disabled, but somehow are now unable to work. We also must address this here so that people can step forward and trust that they will be rewarded for their efforts, not punished.

And we need to give people better access to the information that they need in order to work. Therefore, we need to create a more community-based program of information and assistance so that people can have dependable information and have an understandable way so that they really know the impact. And we need to fund protection and advocacy services for individuals. They will be navigating a new system, and they need help and assistance in doing so.

We have a tremendous opportunity here. I hope we can take it and move forward. We support the bill in the Senate. It does not

do everything, but it has important balances. No bill can address every issue, but it moves us a great deal ahead.

Thank you.

[The prepared statement follows:]

Statement of Mary Gennaro, J.D., Director, Federal-State Relations, National Association of Developmental Disabilities Councils; and Member, Consortium for Citizens with Disabilities, Social Security Task Force

Chairman Shaw, Members of the Subcommittee on Social Security, thank you for the opportunity to testify regarding barriers preventing disability beneficiaries from returning to work. I am Mary Gennaro, Director of Federal-State Relations of the National Association of Developmental Disabilities Councils. I am also a member of the Social Security Task Force of the Consortium for Citizens with Disabilities and I am here testifying on behalf of the Task Force. Lastly, I am a person with a disability, namely cerebral palsy.

The Consortium for Citizens with Disabilities (CCD) is a working coalition of national consumer, advocacy, provider and professional organizations working on behalf of the 54 million children and adults with disabilities and their families living in the United States. The CCD Social Security Task Force focuses its work on disability policy issues and concerns in the Supplemental Security Income (SSI) program and the disability programs in the Social Security Old Age and Survivors programs. The CCD Social Security Task Force appreciates the opportunity to comment regarding the barriers preventing disability beneficiaries from returning to work.

We wish to acknowledge and thank the Social Security Subcommittee for its longtime commitment and leadership in addressing the barriers that prevent disability beneficiaries from returning to work. As the Subcommittee knows, people with disabilities want to work, in spite of the daunting, often impossible barriers in their attempts to do so. Over the past few years these barriers have come into sharper focus and efforts to address them have intensified. In the last Congress, the Social Security Subcommittee focused its efforts on a legislative response to the barriers to employment faced by people with severe disabilities. It is largely because of the Subcommittee's work to fashion an effective legislative response on this critical issue that we are here today, one important step closer to positive change—positive change that will bring economic opportunity, greater freedom and independence, and untold other benefits, to so many people who long to more fully share their talents in their communities and in this great nation.

THE PROBLEM

The Presidential Task Force on Employment of Adults with Disabilities indicates in its first report "Re-charting the Course," that about 70% of adults with severe disabilities are not employed—one of the largest minorities in the nation without jobs.[1] We all know that this is unacceptable, particularly when our nation's economy is flourishing and unemployment rates are at near all time lows. People with disabilities want to work. A 1998 Harris poll found that seven out of ten (72%) of people with disabilities age 16–64 who are not employed say they would prefer to be working.[2] There are 4.8 million individuals receiving Social Security disability benefits and 3.6 million individuals with disabilities, aged 18–64 receiving Supplemental Security Income benefits (SSI). Some Social Security Disability Insurance (SSDI) beneficiaries and SSI beneficiaries are simply unable to work because of their impairments. Some are very seriously ill, others have terminal illness. In fact, SSA has found that 20% of people receiving benefits die within five years. Other people receiving benefits have work potential and want to work to the maximum extent of their physical and mental capabilities. It is for this later group that the CCD Social Security Task Force testifies today.

BARRIERS TO EMPLOYMENT FOR PEOPLE WITH DISABILITIES

If people with disabilities want to work, what is it preventing so many from doing so. The barriers to work are many, yet there are ways we can break down these barriers. We must not be discouraged by the statistics, for if barriers to employment for people with disabilities are seriously addressed these statistics will improve and people with disabilities will work. Some will attain economic self-sufficiency; others

[1] *Re-Charting the Course—A Report of the Presidential Task Force on Employment of Adults with Disabilities*, November 15, 1998.

[2] National Organization on Disability/Louis Harris Survey, conducted April and May of 1998.

will earn enough to move off of benefits, but will require some ongoing support to assist with the extraordinary expense of living and working with disabilities. This support may consist of health care, personal assistance, and housing subsidies, transportation, child care, etc. Still others will work to their maximum potential and continue to require both some cash assistance as well as other supports. In all instances, people with disabilities want to be active members of society, contributing what we can and taking only what we need to survive and prosper.

Some of the barriers that keep SSDI/SSI beneficiaries from working are:

- Lack of access to vocational rehabilitation and employment services and lack of choice in vocational rehabilitation and employment services;
- Lack of access to health care coverage
- Financial Disincentives
- Work Incentives are Complex and Can Hinder Work Attempts

BARRIER: LACK OF CONSUMER ACCESS TO AND CHOICE OF VOCATIONAL REHABILITATION AND EMPLOYMENT SERVICES AND PROVIDERS

Few beneficiaries of SSDI/SSI are referred for vocational rehabilitation, and fewer return to work because of these services. The Congressional Budget Office (CBO) has estimated that about 10 to 15 percent of new SSDI and SSI beneficiaries are referred to State Vocational Rehabilitation (VR) agencies, and about 10 percent of those referred are accepted for services. 1998 data from the Social Security Administration (SSA) indicates that last year 9,950 SSDI or SSI beneficiaries moved off of disability benefits into employment due to SSA funded VR services. During that time about 4.8 million disabled workers received monthly SSDI benefits, and about 3.6 million individuals with disabilities, aged 18–64 received SSI benefits.

In addition to limited access to services, SSDI beneficiaries or SSI recipients have no choice in the providers of their vocational rehabilitation and employment services. Historically, consumers have been assigned to a service provider, which by law had to be a state vocational rehabilitation agency, usually by type of disability, rather than type of services required. Now beneficiaries of SSDI and SSI,, not accepted for services by VR, have access to an Alternate Participant program, but this program is significantly hindered by the current reimbursement system. Consumers who determine that they are not receiving appropriate or high quality services generally have no recourse other than to purchase services themselves from private vendors. Given the cost of private services and the state of most consumer's finances, this is an option very few can afford.[3]

RECOMMENDATIONS TO IMPROVE ACCESS TO AND CHOICE OF SERVICES AND PROVIDERS

Enhance Consumer Choice. The Subcommittee understands the need for consumer choice and knows that benefits will result from increased choice in and access to services. H.R. 3433, the "Ticket to Work and Self-Sufficiency Act," introduced by then Subcommittee Chairman Jim Bunning and Ranking Minority Member Barbara Kennelly, passed the House overwhelmingly by a vote of 410 to 1 in the 105th Congress. The "ticket to work" program contained in H.R. 3433 was incorporated, with only a few refinements, into S. 331, the "Work Incentives Improvement Act of 1999," which was introduced in the Senate and recently, overwhelmingly approved by the Finance Committee. Active participation in the rehabilitation process increases the chances of a successful outcome. The ability to choose one's own services and providers recognizes SSDI and SSI beneficiaries as an adults, capable of making significant life choices. This ownership in the rehabilitation process thereby enhances the individual's self-esteem and confidence. Choice is important for all consumers of rehabilitation and employment services. Some people with disabilities may need assistance in exercising choice and such assistance must be easily available through out the rehabilitation process.

Increase Access. The ticket should be available to all SSDI/SSI beneficiaries enabling those who wish to attempt work to have the opportunity to pursue their goals. Consumers must be able to choose from among the many thousands of public and private rehabilitation, employment service, and related providers in the nation. SSDI/SSI beneficiaries must be able to access the services they need whether provided VR, private providers, or a combination of both.

Reward Outcomes. Payment for services must encourage outcomes. It should encourage work by all SSDI/SSI beneficiaries, regardless of their ultimate work capac-

[3] *SSA Disability Program Redesign Necessary to Encourage Return to Work*, GAO, April, 1996, pp 48–56.

ity. Instead of rewarding providers only for removing people from the rolls, it should reward providers for assisting people to minimize their dependency on cash assistance programs. Paying providers a portion of the savings realized by the federal government will enable many more people to work to their full capacity resulting in greater savings than only paying for those attaining SGA. Payments should be made on a milestone/outcome approach.

Provide for an Advisory Commission. Designing and implementing this program will be a significant challenge to SSA. We recommend that a Commission with equal representation from consumers and their self-selected representatives, providers, and employers be appointed and charged with responsibility to assist SSA in this endeavor. The Commission should have broad authority to research, model, test, and recommend the final structure of the program to SSA and the Congress by a date certain. It is imperative that the missteps that occurred during implementation of the Alternate Participant program be avoided.

BARRIER: ACCESS TO HEALTH CARE COVERAGE

Access to health coverage is increasingly cited as the key obstacle to employment. People fear losing medical benefits that can mean the difference between life and death. A "ticket to work" program will go a long way in addressing some of the major barriers to employment, but if lack of access to health care benefits is not addressed, the success of the "ticket" will be greatly hindered. Until they can be assured that working will not threaten their ability to receive necessary health care services, SSDI beneficiaries and SSI recipients will not take full advantage of what a "ticket" program can offer. In fact, what a ticket program can offer is limited unless the other barriers to employment discussed in our testimony are addressed.

MEDICARE

Currently SSDI beneficiaries are eligible for Medicare benefits 24 months after becoming eligible for cash benefits. They receive Hospital Insurance (Part A) and Supplementary Medical Insurance (Part B). (Part B is voluntary, but virtually all Part A beneficiaries enroll in Part B.) The Part B premium of $45.50 is deducted from the individual's benefit check. SSDI beneficiaries lose cash benefits, after they have completed a nine month trial work period and a 3-month grace period, and earn $500 or more a month. The average monthly cash benefit is $733. (The trial work period consists of nine months within a 5-year period during which a beneficiary is able to test his or her ability to work without losing cash benefits or Medicare coverage. Earnings of as little as $200 a month will be credited toward the trial work period.) After the trial work period and 3-month grace period, Medicare Part A coverage continues for a 36-month extended period of eligibility and cash benefits are suspended for any month in which the individual earns $500 or more in income. After this extended period of eligibility an individual earning $500 or more a month will be found to be able to engage in substantial gainful activity and no longer eligible for benefits. Medicare coverage will cease. If the person is still "medically disabled" he/she can purchase Medicare through payment of monthly premiums, currently $309 a month for Part A and $45.50 per month for Part B at a total cost of $354.50 a month. It is quite hard to imagine how an individual whose earnings may be as low as $500 a month ($6,000/ annually or under $42/day) could afford to continue Medicare. Last year, 170 people nationwide were enrolled under this buy-in program. We believe that the premium cost is prohibitive for many people with disabilities.

What this means in real life terms is that an individual with a disability may be working to their fullest potential at a part-time job, or at a full-time job with limited earnings and lose their cash benefits and health care coverage. Their part-time job doesn't offer health insurance, they find it difficult to qualify for insurance in the private market, or private insurance simply does not provide an adequate benefit package. Yet, their need for health care has not changed. Forced to choose between critical health care and a job, there is only one choice possible; people with disabilities choose to preserve their life and health and remain trapped on benefits as a consequence.

Many SSDI beneficiaries find they need Medicaid to supplement their Medicare coverage and to cover the cost of Medicare premiums, deductibles, and cost sharing requirements. Medicare does not cover prescription drugs, non-medical personal care or personal assistance services. Many people with disabilities need these critical and sometimes commercially unavailable benefits. Clozapine, taken by an individual with schizophrenia, or the personal care received by an individual with a physical disability enabling them to bathe, eat, dress and accomplish other activities of daily

living can be the very things which enable employment. Needing to meet the income and asset limits of Medicaid buy-ins then acts as another disincentive to work.

MEDICAID

Medicaid is a federal-state health insurance and long term care program for certain low-income people. In all but 11 states, individual's who are eligible for SSI are automatically eligible for Medicaid. (The other 11 states link Medicaid eligibility to Section 209(b) disability definitions which may be more restrictive than SSI criteria.) Medicaid mandates coverage of a core set of services for all beneficiaries and gives states the option to cover 34 additional services. Many of these optional services, such as physical therapy, occupational therapy, prescribed drugs, prosthetic devices, rehabilitation services, personal care services, and home and community-based waiver services, are very important for persons with disabilities.

To be eligible for SSI, and thus eligible for Medicaid in most states, an individual must be disabled, according to the SSA definition of disability and meet the income, assets and resource criteria set in the program. Generally, SSA defines disability as the inability to engage in "substantial gainful activity" (SGA) by reason of a physical or mental impairment. The current SGA level is $500 per month for non-blind individuals and $1,110 per month for the blind. Other eligibility criteria requires that an individual's "countable" income fall below the federal maximum monthly SSI benefit, which is currently $500 for an individual, and $751 for couples. The current resource limit is $2,000 for an individual and $3,000 for couples.

Unlike SSDI beneficiaries, SSI recipients can earn more than $500 a month and continue to receive cash benefits if they continue to be disabled, but for their earnings. Section 1619(a) and (b) of the Social Security Act allow cash benefits to be gradually reduced as income increases. Cash assistance is decreased $1 for every $2 in earned income. Eligibility for cash benefits will end when the amount of countable income equals the maximum benefit level for an individual. Currently, this "break even point" is $1,085 per month. When eligibility for cash benefits end, SSI recipients can continue to receive Medicaid if they continue to meet all other requirements for SSI eligibility (disability status, assets and resource limits), they need Medicaid in order to obtain or continue employment, their earnings are not sufficient to provide a reasonable equivalent of the benefits they are receiving from SSI and Medicaid. Each state sets an earned income threshold to measure this last criteria. The thresholds vary by state. For example, in 1998 the threshold in Arizona was $12,636, in Missouri $19,014 and in New York $28,580.

Medicaid covered services often meet the critical everyday needs of people with disabilities. Medicaid may fund residential supports in the community and provide habilitation services which assist people with disabilities in gaining, maintaining and improving the skills necessary for everyday life. It may provide assistive technology to enable an individual to communicate, or a wheelchair to enable his/her mobility. It may also cover prescription drugs that improve or control a person's condition enabling them to function in the workplace.

PRIVATE INSURANCE

For many reasons employer based or private insurance will not adequately meet the needs of people with disabilities. Employers may not offer a group plan, or the cost of the group plan offered may be too expensive given the person's income. This is especially true in part-time or low income jobs in which many SSDI beneficiaries and SSI recipients are likely to be employed. Furthermore, if insurance is offered, the benefit package may be limited, failing to cover many of the items, services and supports needed by many people with disabilities, such as coverage of prescription drugs, mental health services, durable medical equipment, assistive technology, physical, occupational and speech/hearing/language therapies and personal assistance services. Additionally, people with severe disabilities may have difficulty accessing covered services because the insurer uses a narrow definition of medical necessity, limiting services to those which restore health, and not covering services which maintain function and/or prevent deterioration or loss of function. Also of concern is a recent Harris Poll finding that: "Among adults with disabilities who are not covered by health insurance, one in five (18%) were not able to get insurance because of a disability or preexisting health condition.[4]

Private insurance also does not offer personal assistance services, a critical need for many people with disabilities. Personal assistance services refer to a range of services, provided by one or more persons or devices, to assist an individual with

[4] National Organization on Disability/Louis Harris Survey, conducted April and May of 1998.

a disability to perform daily activities on or off the job, which the person would typically perform if they did not have a disability. These services may include assistance with eating, toileting, grooming, dressing, bathing, getting in and out of bed or one's wheelchair, meal planning and preparation, managing finances, cooking, cleaning house, handling money and on-the-job support.

RECOMMENDATIONS CONCERNING ACCESS TO HEALTH CARE COVERAGE—CONTINUE MEDICARE COVERAGE

Continue Medicare Coverage. To address the very real concerns SSDI beneficiaries have regarding loss of Medicare coverage, access to adequate coverage must be assured. The current extended eligibility for Medicare and the Medicare buy-in are simply insufficient to address the needs of beneficiaries. Coverage for Medicare must be extended without an arbitrary cut off after a certain number of years. This is not a matter of adding new people to the program, but of maintaining benefits for beneficiaries. The fear and concern over loss of health care coverage is not addressed if there is an arbitrary time limit on coverage. The barrier will be addressed when beneficiaries can pursue employment secure in the knowledge that doing so will not jeopardizing their life or health. As long as the need for health care continues, access to coverage must be assured.

Extend Medicaid and Allow a Buy-In to Coverage. Medicaid must be available to people with disabilities whose earnings now make them ineligible for coverage. SSI recipients must be able to work to the maximum extent of their ability and have continued access to Medicaid coverage. SSDI beneficiaries must have access to Medicaid, without having to limit their earnings or impoverish themselves, when they need such coverage to supplement Medicare. States should have the option to expand Medicaid to assure such access. States should also be able to raise income and resource levels for Medicaid eligibility, and establish affordable buy-ins for the program.

Assist Those Who Have Medically Improved. States should also have the option to extend Medicaid coverage to people with disabilities who are employed and become ineligible for benefits due to medical improvement, but continue to have a severe medically determinable impairment. This would enable people to stay employed and retain coverage for the very treatment, services and supports which enabled them to be employed.

Encourage States to Develop Systems of Support. More must be done to assist people with disabilities who work. The federal government must support and encourage States to develop systems to provide the items, services and supports people with disabilities need in order to work. Lack of personal assistance services often is major barrier to employment for people with disabilities. Yet the availability of these services is limited. Currently, only 31 states offer personal assistance services as an optional Medicaid service. All of the states should cover this critical optional service in their Medicaid programs and more needs to be done to encourage States to provide this coverage.

Help to Prevent the Need for Cash Assistance. Finally, Medicaid coverage should be available to workers who have a disability and who without health care and the services and supports covered by Medicaid would likely become eligible for SSDI and/or SSI. By extending Medicaid coverage in this way, people can continue to work and not become dependent on cash assistance in order to have their health care needs met.

BARRIER: FINANCIAL DISINCENTIVES

SSDI beneficiaries who work lose their cash assistance before their earnings are high enough to make up for the loss of benefits. Cash benefits and health care coverage ends at earnings of $500 or more a month, rather than declining gradually as in the SSI program., The Employment Support Institute at Virginia Commonwealth University studied this problem in 1997, using decision-support software, called WorkWorld and found that under current rules, an SSDI beneficiary receiving the then average benefit amount of $704 per month, who attempted to work fell off a net "income cliff" after earning just $600 per month or $7,200 annually. The beneficiary did not recover the same net income level until earnings reached $2,000 per month, or $24,000 annually. On the other hand, because their benefits are reduced $1 for every $2 earned, after allowable income exclusions and disregards, SSI beneficiaries do not reach the same "income cliff" until their income reaches the State Medicaid threshold limit and they may be found ineligible for continue Medicaid coverage. Then they must attempt to purchase medical coverage.

RECOMMENDATIONS TO ADDRESS FINANCIAL DISINCENTIVES

Reduce Cash Assistance Gradually. The SSDI program should allow for a gradual reduction of benefits as earnings increase, similar to the SSI program. This would help alleviate the financial disincentive currently faced by SSDI beneficiaries who want to work. SSDI benefits should be reduced by $50 for every $100 earned beginning at SGA. The $50/$100 sliding scale offset would replace SGA measures only for allowed SSDI beneficiaries who attempt to work. SGA would remain a principal criteria for establishing a work disability at initial eligibility. In the 105th Congress this subcommittee supported a mandate that SSA conduct a demonstration of this gradual decline in benefits. We urge you to include it in this year's bill.

BARRIER: WORK INCENTIVES ARE COMPLEX AND CAN HINDER WORK ATTEMPTS

The effects of disability are not static over time. Sometimes a person with a disability may be able to function quite well and therefore, work to some degree, and at other times the same person's functioning may become quite limited preventing them from working. This fluctuation in ability is not related to desire or willingness to work, but rather to the nature of disability itself. Certain disabilities can be episodic by nature. For instance, people with multiple sclerosis often experience remission of their symptoms, only to have their symptoms reoccur again.

Individuals face two barriers in this regard. First, they may work successfully for a time, but their effects of their disability may change or worsen, at which time they would need to return to benefits. If an SSDI beneficiary attempts to get back on benefits after their extended period of eligibility has expired, or an SSI beneficiary attempts the same after their benefits have been suspended for 12 consecutive months because of work, both individuals will face a lengthy, rigorous process to determine eligibility, as if the person were applying for benefits for the first time. Secondly, work may trigger SSA to perform a continuing disability review (CDR) to determine whether a person remains disabled and eligible for benefits. Even if a person is no longer receiving cash benefits due to work, their health coverage is linked to their disability status. Once again a person with a disability faces the threat that their work will result in a loss of health care coverage.

Work Incentives for SSDI and SSI are very complex and difficult to understand and can hinder work attempts. It can be very difficult to get dependable, accurate information regarding work incentives. Given the risks that an individual with a disability may face (loss of health benefits, lose of cash assistance, loss of other income based assistance) when attempting to return to work, people fear using work incentives. People may fear, with good reason, overpayments by SSA. People can be surprised by overpayments of thousands to tens of thousands of dollars even when they have reported their earnings to SSA. Individuals may forego attempts to work because of lack of or incorrect information regarding work incentives. Within SSA, and in the community at large, there is insufficient knowledge of and outreach regarding work incentives. Individuals need information, advice, advocacy and other supports and services in order to benefit from work incentives and other programs designed to assist them in securing or reentering employment.

RECOMMENDATIONS TO IMPROVE WORK INCENTIVES

Protect Workers Losing Eligibility Solely Due to Work. Work Activity by a person with a disability should not be basis for the scheduling of a continuing disability review. Further, work activity by an individual with a disability should not be used as the evidence that a person no longer has a disability.

Provide for Expedited Redeterminations of Eligibility. A timely process must be available to promote reinstatement of cash and health benefits when a person who continues to meet SSA's standards for disability, finds him or herself unable to work.

Establish a Community-Based Work Incentives Planning and Assistance Program. In order to reduce the fear and risk associated with attempting employment a person with a disability must have access to timely, accurate information on work incentives, and how use of work incentives will impact his/her own life. Community based outreach will help assure that people with disabilities receive the information and assistance they need to make informed choices in regard to preparing for, securing, maintaining and advancing in employment, while at the same time accessing or maintaining access to necessary health care and other supports and services. Work incentives planners using decision-support software can assist beneficiaries in making these informed choices. SSA must also make a greater commitment within its own program to have trained, knowledgeable and accessible work incentive spe-

cialists through which SSDI/SSI beneficiaries as well as community-based planners can obtain reliable information and assistance.

Fund Advocacy and Assistance Services. Beneficiaries of SSDI/SSI must have ready access to protection and advocacy services to assist with a variety of issues and difficulties which can arise as they navigate through a new way of meeting the needs of people with severe disabilities for vocational rehabilitation, employment supports and services, work incentives and other support needs. History has shown us that there will always be some instances in which people need an effective advocate when deal with large complex, service systems. If advocacy and assistance is not available people will not be able to fully take advantage of what programs and services have to offer them.

AN OPPORTUNITY FOR CHANGE

The issues we have discussed are major barriers to the employment of people with disabilities. There are additional obstacles faced by people with disabilities who want to work—lack of adequate transportation and lack of affordable housing are just some examples of these. Nor are the recommendations we have outlined an exhaustive list of actions that can be taken to address this problem. For instance, we also support a tax credit for disability related work expenses as well tax deductions. And we believe asset limitations should be raised to facilitate savings and investment, which can help lessen dependence. We believe that if the barriers and recommendations we have discussed are included in legislation, we would move a great step forward in assisting people with disabilities to move into employment and reduce their dependence on benefits and other assistance. We support S. 331 reported out by the Finance Committee. We believe it represents important balances of the concerns of key stakeholders and would be an important step towards removing barriers. It does not address all issues, no bill could, but it does address critical essential elements necessary to bring positive change.

As we move forward and break down barriers to employment for people with disabilities we will address another, more hidden barrier—attitudes and prejudices regarding the abilities of people with disabilities. We can help to erase prejudice and shatter myths about the ability of people with disabilities to contribute in the workforce and in every area of life. Let's take the tremendous opportunity we have to begin breaking down barriers.

On Behalf Of: Sign-ons submitted for the record - March 25, 1999

American Association on Mental Retardation
American Counseling Assoication
American Network of Community Options and Resources
Council for Exceptional Children
Goodwill Industries International, Inc.
International Association of Psychosocial Rehabilitation Services
Inter-National Association of Business, Industry and Rehabilitation
National Alliance for the Mentally Ill
National Council for Community Behavioral Healthcare
National Association of Developmental Disabilities Councils
National Association of People with AIDS
National Association of Protection and Advocacy Systems
National Association of State Directors of Developmental Disabilities Services
National Mental Health Association
National Multiple Sclerosis Society
National Parent Network on Disabilities
NISH (formerly National Industries for the Severely Handicapped)
Paralyzed Veterans of America
The Arc of the United States
United Cerebral Palsy Associations
World Institute on Disability

Chairman SHAW. Thank you.
Mr. McNulty.

STATEMENT OF JIM MCNULTY, MEMBER, BOARD OF DIRECTORS, NATIONAL ALLIANCE FOR THE MENTALLY ILL, BRISTOL, RHODE ISLAND; AND PRESIDENT, MANIC DEPRESSIVE ASSOCIATION

Mr. MCNULTY. Thank you, Chairman Shaw and Members of the Subcommittee.

I would like to request that my full statement be made a part of the record.

My name is Jim McNulty. I am from Bristol, Rhode Island, and I am here representing the 208,000 members and 1,200 affiliates for the National Alliance for the Mentally Ill, and I would also add that I am president of the Manic Depressive Association in Rhode Island which is an affiliate of the National Depressive and Manic-Depressive Association which is the largest consumer run mental health organization in the country.

I would like to thank you very much for holding this hearing to barriers on employment for people with disabilities.

Rather than read you my prepared testimony, I think I am going to depart from it and tell you a little bit about myself, my own disability which is not necessarily perceptible to most people.

I have been living with manic-depressive illness for about 30 years now. I had my first episode when I was about 19 years old. I was a sophomore in college, and it had a devastating impact on my life, but it did not manifest immediately. It was a lingering onset, if you will, and it wasn't until I was 38 years old that the full impact of it was felt.

So, I, unlike many people, was fortunate. I was able to work from my twenties and into my thirties and buildup a history of work. I graduated from an Ivy League university. I had my own business. I was in town politics in a small town in Massachusetts. I was doing very well. I had two children and a very happy family life. But I had this illness which nobody understood at that time which made things very difficult. As a matter of fact, it ended up destroying my marriage, my job, my career, and it ended up with me being in a hospital for a very long period of time.

I have been extremely fortunate, because I have had the supports that the lady from the GAO spoke about. She said that one of the things they found in their survey is that a supportive environment is the most important thing that most people who went back to work had. I had that. I started from owning a business—it was a pension consulting business. It ended up with my first job as a homeless person delivering bagels for a local bakery to coffee shops in the metropolitan Providence area.

I was happy to have that job. I wanted to go back to work. And I will tell you that I work with mentally ill people every day. I work in a hospital. I go onto the units and deal with seriously mentally ill people. They want to work. There is not one of them that I have run into—I am sure that there must be people who don't, but I haven't run into any personally. They want to work.

As my fellow panelists have said, and as others have said before me, they can't go back to work. They can't risk their benefits. They don't have private insurance. They don't have health insurance. They don't have the cliff that we talk about falling off. And it is a terrible thing to watch because people are torn.

Congresswoman Johnson talked about the Christmas season. People wanted to work, but they couldn't go work the extra hours because, if they did, they would lose all of their benefits. That is a terrible position to put somebody into. That is not the America I grew up in. That is not the America, I think, that any of us wants to see.

As a person with a disability, I want to be accepted as a part of the society. I also want to make my contribution as a contributing member of the society. Believe it or not, I actually like paying taxes—not more than my fair share, however. It is an honor to be able to pay taxes, and I think that many, many people that I work with on a daily basis really, really want that opportunity. It cannot be overemphasized, though, that the ticket to work, which is a critically important part of what you are dealing with, is not going to work without adding the medical insurance portion. Believe me, I have thought about this; I have talked about this for years. I think that this is the key.

I think this is a historic moment and a historic opportunity, and I would urge this Subcommittee to move this legislation forward, and I thank you very much for the opportunity to be here today.

Thank you.

[The prepared statement follows:]

Statement of Jim McNulty, Member, Board of Directors, National Alliance for the Mentally Ill, Bristol, Rhode Island; and President, Manic Depressive Association

Chairman Shaw and members of the Subcommittee, I am Jim McNulty of Bristol, Rhode Island, and I serve on the Board of the National Alliance for the Mentally Ill (NAMI). I am also a president of the Manic Depressive and Depressive Association of Rhode Island. At the outset I would like to thank you for holding this hearing on barriers to employment for people with disabilities in Social Security's programs. This issue is critically important for people with severe mental illnesses—the fastest growing population represented on Social Security's disability programs.

I, myself, have been living with manic depressive illness and for the last nine years have worked with many other Rhode Islanders suffering from severe mental illnesses, including schizophrenia, manic depression, and depression. Over this period I have found an almost universal, visceral desire on the part of people with disabling mental illnesses to return to meaningful, gainful employment. We want to be able to partake as fully as possible in the privileges and responsibilities of being citizens of the United States.

Sadly, for many of us the very system that is designed to help us when we are at an ebb in our health and require the social safety net will not allow us to recover dignity by helping us return to work. As you know, the current "all or nothing" approach to income support and health security operates as a massive barrier to work for millions of Americans with severe disabilities who seek to achieve greater independence and dignity through employment. The dream of the Americans with Disabilities Act (ADA) is full integration of people with disabilities into the mainstream of American society. Reform of the current system is absolutely essential to achieving this important national objective.

NAMI believes that we offer a unique perspective on the critical issues of work incentives, income supports, and employment for people with severe mental illnesses, which are brain disorders. NAMI is the nation's largest organization representing people with severe mental illnesses and their families. Through our nearly 1,200 affiliates and chapters, NAMI represents over 208,000 consumer and family members and works to promote greater public understanding of serious brain disorders such as schizophrenia, major depression, bipolar disorder, obsessive-

compulsive disorder, and panic disorder. Our major activities include research, education, and advocacy aimed at reducing stigma and promoting independence for people with brain disorders.

NAMI has a strong interest in the issue of work incentives, income supports, and employment for people with disabilities. We share your vision of restoring fairness to the Social Security Administration's (SSA) disability programs by enabling those who are truly disabled to receive benefits quickly and stopping payments to persons who have fully recovered. Work is extremely important to people with severe mental illnesses and their families. Yet the supports necessary to achieve employment and independence are simply not in place for most people with these brain disorders who want to leave the Supplemental Security Income (SSI) and Social Security Disability Insurance (SSDI) rolls and join the workforce.

As I noted above, people with severe mental illnesses are the fastest growing population within both the SSI and SSDI programs. More importantly, SSA data reveal that people with mental illnesses are coming on to the disability rolls at an earlier age than their counterparts with other disabilities. Given how difficult it is to get off the rolls through employment—less than one percent successfully do so—it becomes imperative to enact reforms that end the severe penalties for those who are willing to take the tremendous risks inherent in entering the workforce.

However, as important as promoting work is to so many adults with severe mental illnesses, NAMI also believes that we should not lose sight of how important Social Security's disability programs are as fundamental safety net protections. We should bear in mind that both SSI and SSDI have the highest standard of eligibility for any public disability programs in the world—that an individual be totally disabled and unable to attain substantial gainful activity (SGA) in any job in the American economy. Because of this strict definition, most of the adults on these programs have severe disabilities and are some of the most vulnerable citizens in our society.

For the vast majority of SSI and SSDI beneficiaries, the cash assistance they receive meets basic everyday needs on a week-to-week basis. Most have no savings, and depend on cash benefits for food, clothing and shelter. For them, SSI and SSDI are programs that are successful in preventing complete destitution and keeping them out of a state hospital or an institution (and considerably higher cost to taxpayers). Thus, while NAMI strongly supports the goal of promoting work and independence, we believe that these reforms should keep the basic structure of SSI and SSDI in place in order to protect the most disabled and vulnerable beneficiaries.

WHAT ARE THE MAJOR BARRIERS TO EMPLOYMENT FOR PEOPLE WITH DISABILITIES?

Recent studies (including those from the General Accounting Office, the National Council on Disability, and the National Academy of Social Insurance) point to five principal barriers to the employment of individuals with severe mental illnesses who are SSDI or SSI beneficiaries. These barriers are: 1) the loss of health benefits; 2) the complexity of the existing work-incentives system; 3) financial penalties of working; 4) lack of choice in employment services and providers; and, 5) inadequate work opportunities. NAMI believes that all of these barriers must be resolved to empower beneficiaries to go to work.

The current SSI and SSDI programs themselves too often serve as barriers to work. While the existing work incentives in the Social Security Act do make it easier for some people receiving SSI or SSDI payments to go to work, most people with severe mental illness either do not know about, or do not understand, the provisions and therefore do not utilize these work incentives. This is true, both for the so-called SSDI trial-work-period provisions and the SSI 1619(a) and 1619(b) programs. For too many people with mental illness there is a pervasive fear that employment will result in the immediate cut-off of cash benefits and the concurrent loss of critically important medical benefits. NAMI believes strongly that the episodic nature of mental illnesses justifies the need to maintain a basic safety net of assistance for people experiencing acute occurrence of severe symptoms.

Mr. Chairman, as you well know, after certain income disregards, some SSI beneficiaries lose 50 cents in benefits for every $1 in labor earnings, or a 50-percent implicit tax rate on earned income. By contrast, SSDI beneficiaries lose access to cash assistance after reaching substantial gainful activity (SGA) for nine months (not necessarily consecutively), plus a three-consecutive-month grace period. (After losing cash benefits, beneficiaries may have their SSDI benefits restored for any month they don't work at the SGA level for an additional 36 month period). However, even in cases where people with mental illness decide to use existing Social Security work incentives, they still face the loss of medical coverage even if they are able to retain limited cash benefits after reaching SGA.

The issue of access to medical coverage is absolutely critical to people with serious brain disorders, especially coverage for prescription drugs. This issue generates a high level of concern among NAMI members. Without coverage for the newest and most effective medications and other treatments for disorders such as schizophrenia and major depression, many people find it hard to maintain a stable life in the community, let alone achieve complete independence through employment. Moreover, for many people with severe mental illnesses, the first step in the process toward competitive employment is supported employment or low-wage, service-sector jobs. Few of these opportunities offer employer-provided health insurance, especially insurance that adequately covers someone with a serious brain disorder. And, even when people have access to private health insurance through employment, most of these policies do not provide adequate coverage for treatment of severe mental illnesses.

Some of the proposals now before Congress would begin the process of eradicating these disincentives by addressing head-on the loss of health insurance coverage for people who want to move away from dependence on public programs through work. NAMI strongly supports the goal of making the SSI and SSDI programs more responsive to needs of people with serious brain disorders who want to leave the benefit rolls for employment.

Why kind of reform does NAMI support?

1) It should expand individual choice through enactment of a "ticket to independence" program for beneficiaries who need employment and rehabilitation services.

2) It should address head-on the issue of extended health coverage in a way that recognizes the unique treatments of people with severe disabilities, including people with severe mental illnesses.

3) It should begin the process of reforming the severe penalties in the SSDI program that wipe out cash benefits just as beneficiaries begin moving toward independence.

4) It should address the overly complicated and often conflicting rules involved in each of these public programs.

5) It should do no harm to those beneficiaries who are either not ready to go to work or who try to work and fail.

6) It must benefit all Americans—taxpayers, employers, and families—yet furthering the goals of the ADA by promoting empowerment and independence.

I would like to address these issues individually:

1) Promoting consumer choice through implementation of a "ticket to independence" program. The "ticket to independence" program was the linchpin of last year's House bill (HR 3433). As members of the Subcommittee know, this legislation passed the House on June 4, 1998, by a margin of 410 to 1. NAMI strongly supports the policy underlying the "ticket" program. Giving individuals a return-to-work ticket and placing them in control of their own return-to-work plan will be putting consumers in the driver's seat for the first time. Providers will be forced to compete for business on the basis of how well they meet the individual needs of consumers. State vocational rehabilitation (VR) agencies will no longer be in control of the resources directed towards helping people with disabilities achieve work and independence.

NAMI believes that the current public VR system is failing people with severe mental illnesses. How? The problems associated with VR result of the basic structure of VR being inconsistent with the employment and training needs of people with severe mental illnesses. VR is directed almost exclusively toward a single goal: case closure. For VR agencies and counselors, the process ends once a client is placed in a job for the required time period and a file can be marked closed. This inflexible goal fails to take into account the fact that illnesses such as schizophrenia and manic depression are episodic and intermittent. Moreover, for many people with severe disabilities, this "closure" is only the beginning of the process.

Ongoing supports and services are oftentimes critical to one's ability to stay in a job over the long-term. The current VR system spends too much time testing and assessing clients prior to employment instead of actually placing people in jobs and providing the ongoing supports and services that will help them stay employed, get of the rolls, and (eventually) reach full independence. People with severe mental illnesses typically need assistance that is both flexible and ongoing to help them live with their disability in a way that will promote, rather than inhibit, work.

By giving individuals a return-to-work ticket and placing them in control of their own return to-work plan, you will be putting consumers in the driver's seat for the first time. Providers will be forced to compete for business on the basis of how well they meet the individual needs of consumers. State VR agencies will no longer be in control of the resources that are directed towards helping people with disabilities achieve work and independence.

With a "ticket" program, individuals will be able to skip the laborious testing and assessment process within state VR programs. By receiving a ticket directly, consumers will be able to select a provider on the basis of their relative experience in serving people with severe mental illnesses and their record in placing them in jobs. Moreover, extending payments to providers for up to 60 months, based upon whether a consumer stays in the workforce, will result in increased access to support and follow-up services in the workplace.

By contrast, the current public VR system abandons clients after a few short months on the job. NAMI urges that Congress resist any effort to remove from last year's bill the provisions repealing a) priority referral by Social Security to state VR agencies and b) benefit deductions for persons refusing to accept VR services. While the ticket program will not fix every problem in the current system, when coupled with extended health coverage it offers a very positive step forward.

2) Extended health coverage. Health security is central to the lives of people diagnosed with a severe mental illness. Without access to coverage for treatment, any attempt to enter the workforce is doomed to failure. Despite all the progress made in scientific research on the brain, we still have no "cure" for diseases such as schizophrenia and manic-depressive illness. Most treatments are palliative in nature; i.e., directed toward the control of symptoms that allows an individual to lead a normal life. The most advanced treatments for severe mental illnesses involve medications such as new atypical anti-psychotics and selective serotonin reuptake inhibitors (SSRIs) that can be very expensive.

Even in cases where consumers and their families have access to private health insurance coverage, such coverage typically falls short of meeting the real needs of someone diagnosed with a severe and episodic illness such as schizophrenia or bipolar disorder. Many policies still have discriminatory copayments and deductibles or lower treatment limits that can exhaust coverage and resources as a result of a single hospitalization. While we are making real progress in rooting out this discrimination—through the federal Mental Health Parity Act of 1996 and the 19 state parity laws across the country—more work needs to be done. The reality is that too many people with severe mental illnesses have been forced onto public disability programs as a result of insurance discrimination. Despite efforts to stay in the workforce, too many consumers are pushed out of their jobs once their health coverage has been exhausted or simply becomes unaffordable. Once coverage for essential treatment is gone, consumers are faced with no alternative but to go into poverty to qualify for Medicaid.

The need to spend down resources to qualify for Medicaid results not only from the disability and poverty, but also because Medicare (available to SSDI beneficiaries after 24 months) does not include an outpatient prescription drug benefit. This gaping hole in the Medicare program is a major concern for NAMI in trying to reform these programs. Consumers and their families should no longer be forced to go into poverty to ensure continued access to treatment and some measure of income security. The problems associated with the mental illness benefit within Medicare are also the reason that so many adults with severe mental illnesses are now "dual eligible" for both SSI and SSDI.

Mr. Chairman, NAMI recognizes that this Subcommittee does not have jurisdiction over the Medicare program. Further, we also understand that the Ways and Means Committee's shares jurisdiction over Medicare with the Commerce Committee, which also has exclusive jurisdiction over the Medicaid program. NAMI respects the need for standing committees in the House to respect jurisdictional boundaries when developing major legislation such as this. Nevertheless, NAMI believes that any attempt to reform Social Security's disability programs to promote work must forcefully address the issue of access to health care coverage.

Addressing disincentives relative to cash benefits and increasing access to employment and rehabilitation services will not achieve the goal of getting more beneficiaries into the workforce. More importantly, any system that creates a new inducement to move toward employment is likely to fall short if healthcare coverage is left out. Put simply, few consumers will be willing to place their health coverage at risk, no matter how effective a reformed system is in meeting their unique employment and rehabilitation needs. Thus, inclusion of meaningful extended health coverage will ensure that your efforts to reform these programs meets both your expectations and the aspirations of the disability community. NAMI therefore urges you to work with your colleagues on the full Ways and Means Committee and the Commerce Committee to ensure that extended health coverage is made available to SSI and SSDI beneficiaries willing to take the risks inherent in moving off of cash assistance and into employment.

What kind of health coverage is needed? For SSDI beneficiaries, Medicare coverage needs to extended far beyond the 39 months (under Social Security's existing

trial-work period and extended period of eligibility programs). The legislation approved last week by the Senate Finance Committee (S 331) extends Medicare for 10 years for SSDI beneficiaries going to work. Such an approach appears generous, but it is needed to ensure that people stay in the workforce over an extended period.

NAMI also believes that states should be allowed the option of expanding Medicaid eligibility to outpatient prescription drug coverage available to individuals who can and want to work, but need coverage for medications to get into (and stay in) a job. This coverage would be made available to individuals who meet Medicaid eligibility standards on the basis of their disability, but who would likely fall above Medicaid income standards. Such a policy would "catch people on the way down" by filling the gaps in both private plans and Medicare so that they will not have to permanently leave employment and go into poverty to ensure health security. This is a critical protection needed for individuals living with an episodic illness of the brain that too often fails to follow a predictable course.

Critics may charge that extending subsidized Medicare to people in the workforce and extending Medicaid eligibility beyond current income restrictions is either fiscally irresponsible or unfair to current and future beneficiaries who elect not to enter the workforce. At the same time, we have to recognize that without a change in policy, every disabled beneficiary who might take advantage of these options for extended coverage would be receiving the same health benefits if current law is kept in place. In other words, leaving the status quo in place will, in all likelihood, result in the same individuals staying on public assistance.

Moreover, the empowerment and increased self-esteem that can result from being gainfully employed rather than dependent on cash benefits is likely to have the added effect of actually limiting future health care costs. Such a beneficial impact may not be readily assessed as part of a Congressional Budget Office "score," but it something tangible that many people with severe disabilities (including serious mental illness) and their families experience everyday.

3) Reforming the SSDI "cash cliff." Last year's House-passed legislation HR 3433 required Social Security to conduct a demonstration of a sliding-scale reduction in SSDI cash benefits. This study is critically important for moving us toward an income-security system that meets the needs of SSDI beneficiaries in the 21st century. NAMI believes that the ultimate solution to the problem of the "cash cliff" in the SSDI program is a "2 for 1" cash offset for earnings above SGA. Under current law, SSDI beneficiaries earning above the artificially low SGA level can lose eligibility for cash benefits all at once. This barrier to work strikes consumers just at the point when they are beginning to achieve the rewards of work and independence. It sends a terrible message to consumers and their families when case managers and Social Security field office staff tell consumers that they are better off quitting their part-time job or severely cutting back their hours.

The time is now to put in place a sliding-scale "2 for 1" offset that gradually reduces benefits as earnings rise. Such a system would reward, rather than penalize, work. NAMI is deeply troubled that Congress has been prevented from enacting this fundamental reform because of concerns about the budgetary impact of such a change in federal policy. It is important to note that these estimates, in NAMI's opinion, are based not on a careful evaluation of data generated from actual experience of declining cash assistance on a sliding-scale basis. Rather, these estimates appear to be based on untested assumptions regarding "induced entry" or "woodworking" among persons not currently in the SSDI program. NAMI believes that such assumptions about the behavior of workers under a reformed SSDI work-incentive program are simply invalid.

The experience of NAMI's consumer and family membership is clear: there is no way that otherwise eligible consumers would leave the workforce for a period as long as 36 months (the duration of the disability determination process for many consumers) to eventually take advantage of sliding-scale cash benefits. The experience of the 1619(a) and 1619(b) programs bears this out. NAMI is confident that a properly designed "2 for 1" offset demonstration program will reveal that the fiscal burden is minimal and probably a benefit to taxpayers in the long run.

4) Simplifying the process for consumers and families. One of the most common complaints among NAMI members about the current work-incentive structure is the Social Security bureaucracy. When trying to get straight answers about one's own benefits and possible opportunities for work incentives (including PASS), consumers often find that SSA field offices and headquarters staff give conflicting and confusing answers. No doubt, this flows from the complexity of the programs, especially in the case of PASS and 1619(a) and (b) for SSI beneficiaries. However, this complexity does not excuse wrong or misleading answers to basic questions and the (too often) complete lack of effective counseling about what the real options are. Making work incentive specialists available to beneficiaries will go a long way toward help-

ing consumers cope with this new program. More importantly, these work-incentive specialists should not be employees of SSA so that the advice they give consumers is independent and free of the biases that we often see in SSA field staff.

5) Beneficiary protections. NAMI feels strongly that any legislation designed to reform the current SSA work-incentive programs should first ensure that it does no harm to vulnerable beneficiaries with severe mental illnesses and other severe disabilities. No individual with a severe mental illness who is receiving SSDI or SSI should have his or her benefits jeopardized by enactment of these badly needed reforms. Several proposals in Congress in recent years have contained important protections ensuring that persons who take the risk and go to work will not be subject to an unscheduled continuing disability review (CDR).

The reality is that there are many people with mental illnesses who are currently part of the SSI and SSDI programs who are experiencing symptoms that are so severe that they cannot be reasonably expected to enter the workforce over the short-term. They should not be forced to participate in a work-incentive program until they are ready. Likewise, participation in this program should not be used as evidence that an individual no longer meets the standards of eligibility for SSI or SSDI. Participation in this program should operate independently of the current CDR requirement for beneficiaries, both in terms of timing and the evidentiary standard for future eligibility.

Finally, NAMI urges that serious consideration be given to adding protections for both the ticket and healthcare coverage elements of a reform package so that consumers can seamlessly move on and off of these programs. The episodic nature of serious brain disorders such as schizophrenia, manic-depressive illness, and major depression requires that these programs be flexible enough to accommodate consumers who may experience severe, though brief, episodes of acute illness.

6) *Benefits for all Americans.* Congress is poised make important improvements in Social Security's disability programs that will enable SSDI and SSI beneficiaries to work to the greatest extent of their abilities. It is important for SSA disability programs to begin the process of evolving from their original purpose of serving as early retirement programs for injured workers. They must start moving toward including a new purpose of supporting individuals with disabilities in the workforce. In this way SSA's disability programs can be transformed from a safety net into a trampoline so that they not only catch people with disabilities as they fall out of work, but also give them a boost back into work when they are ready.

These reforms have the potential to be a win-win situation for all Americans. It can help beneficiaries by enabling them to return to or enter the workforce as wage earners. It can help employers by adding skilled workers to the labor pool. It can help employment service providers by enabling them to serve more participants. Finally, reform offers tremendous long-term potential benefit for taxpayers by assisting workers with disabilities to begin, or continue, paying taxes.

CONCLUSION

Mr. Chairman, millions of people like me who live with a serious brain disorder are able to work and be productive. We are taxpaying members of our communities. With access to effective treatment through healthcare coverage, people with severe mental illnesses who are on the SSI and SSDI rolls can move toward greater independence. Unfortunately, the current structure of the system, including both the pervasive work disincentives in the SSDI program and the unresponsive nature of the state-federal VR program, make work a frequently unachievable goal. Put simply, the current system is hostile toward work for people who can and want to work, but whose disability prevents them from moving rapidly and permanently to full employment. More important, the system has the perverse effect of trapping people in poverty. The status quo cannot remain in place if we are to achieve the important national goal of full participation and integration into the mainstream of American society for all people with disabilities.

Finally, work and independence are also vital to our ongoing efforts to eradicate the stigma that is so closely associated with severe mental illnesses. Reform of these outdated and unfair programs will continue the path of progress Congress established with the ADA and the MHPA. Thank you for this opportunity to share NAMI's views on this important legislation.

Chairman SHAW. Thank you for being here.

Mr. Carlisle.

STATEMENT OF JEFFREY E. CARLISLE, PRESIDENT, NATIONAL ASSOCIATION OF REHABILITATION PROFESSIONALS IN THE PRIVATE SECTOR

Mr. CARLISLE. Chairman Shaw, Ranking Member Matsui, and Members of the Subcommittee, on behalf of the National Association of Rehabilitation Professionals in the Private Sector, NARPPS, I thank you for allowing me to testify.

I am here as the current president of NARPPS to provide our analysis and comments on Social Security reform and barriers which prevent disability beneficiaries from returning to work. My education is in rehabilitation counseling, and I am a certified rehabilitation counselor, case manager, and disability analyst. I have worked in the field of rehabilitation for approximately 25 years with 19 of those as a private practitioner. As such, I am often called upon by the Social Security Administration to serve as a vocational rehabilitation expert in SSI and SSDI determination hearings.

Representatives of NARPPS have had the honor of testifying before this Subcommittee in the past, and I would like to thank the former Chairman of this Subcommittee, now-Senator Jim Bunning, for all of his work on this issue.

Our primary goals are to limit the impact of disability, to restore the individual to the maximum level of functioning possible, and to return individuals with disabilities to suitable and gainful employment.

NARPPS believes that there are three main barriers from preventing Social Security beneficiaries from returning to work: The cash cliff, the fear of losing health care, and the inability to choose a private-sector or public-sector vocational rehabilitation provider.

We believe the consumer is the expert on the cash cliff and about what health care he or she needs in order to make it easier to return to work. However, we also strongly believe that continuation of health care significantly enhances an individual's chance for successful and long-term employment. As for choice, we believe any legislation to remove these barriers must contain a means by which a consumer can utilize the services of the private sector, or specifically, a ticket to work.

A ticket program would provide the consumer with a choice over who their service provider is, and it will motivate providers to deliver cost-effective, timely, and results-oriented services to that consumer. However, for the ticket program to be successful, we also believe that it must contain certain safeguards.

We recommend the inclusion of milestone payments at two significant levels of progress achieved prior to actual placement of the individual. Such payments will make it possible for more qualified providers to participate in the program. Without milestone payments, smaller providers could not participate because of the tremendous burden of having to be capitalized until the recipient has been placed and employed for a number of months.

NARPPS agrees with SSA and believes there is a need for the program to be open ended without being reauthorized. To include a reauthorization date may prevent a significant number of beneficiaries and providers from getting involved, if they have reason to

believe that such a program could be eliminated, or, at the very least, interrupted for a period of time.

We believe that any phase-in sites for the ticket program should be chosen by the SSA Commissioner with special consideration given to past demonstration projects and in consultation with providers and consumers who have participated in these programs.

Finally, we support the creation of an advisory panel made up of all the sectors impacted by and participating within this program which can assist the Social Security Administration with the evaluation of project effectiveness and with recommendations to the President and Congress. We welcome the inclusion of State vocational rehabilitation agency participation, and we believe the public and private-sector rehabilitation professional can form an effective partnership to deliver this much needed service to the disability beneficiary. Already in many parts of the country, State vocational rehabilitation agencies contract with the private-sector rehabilitation provider to provide the initial evaluation of an applicant, and, likewise, the Social Security Administration contracts with private-sector rehabilitation counselors to serve as vocational experts at SSI and SSDI hearings.

Now, it will be critical for the service provider to have substantial expertise and experience within the field of vocational rehabilitation, employment, case management, and other support services. NARPPS actively enforces standards and ethics which meets this criteria.

In conclusion, before us is a significant and exciting opportunity to help the disability beneficiary return to work, resume truly productive lives, and enhance one's self-sufficiency. We welcome the opportunity to provide these return-to-work services to Social Security disability beneficiaries and to work further with the Subcommittee to help make this a reality.

On behalf of NARPPS and myself, I thank you for the opportunity to meet with you and to provide this testimony today.

Thank you very much.

[The prepared statement follows:]

Statement of Jeffrey E. Carlisle, President, National Association of Rehabilitation Professionals in the Private Sector

Chairman Shaw, Ranking Minority Member Matsui and members of the Subcommittee, on behalf of the National Association of Rehabilitation Professionals in the Private Sector, NARPPS, I thank you for allowing me to testify before you today. I am here as the current President of NARPPS to provide our analysis and comments on Social Security reform and barriers which prevent disability beneficiaries from returning to work. I will focus my remarks primarily on how the private sector can play a significant role in the effort to return Social Security recipients with disabilities back to meaningful employment.

My education is in rehabilitation counseling and I am a certified rehabilitation counselor, case manager, and disability analyst. I have worked in the field of rehabilitation for approximately twenty-five years, with nineteen of those as a private practitioner. For the past five years, I have been a partner in my current place of employment which is located in the New Orleans, Louisiana area. As such, I am often called upon by the Social Security Administration (SSA) to serve as a vocational rehabilitation expert in SSI and SSDI disability determination hearings.

Representatives of NARPPS have had the honor to testify before this Subcommittee in the past, and I would like to thank the former chairman of this Subcommittee, now Senator Jim Bunning, for all his work on this issue. Our membership, approximately 3,200 in number, includes vocational rehabilitation counselors, nurse case managers and allied health professionals. Our membership consists of individuals who are private practitioners, business owners, and employees of regional or

national organizations. Our primary goals are to limit the impact of disability, restore the individual to the maximum level of functioning possible, and return individuals with disabilities to suitable and gainful employment.

NARPPS believes that there are three main barriers preventing Social Security beneficiaries from returning to work; the cash cliff, the fear of losing health care, and the inability to choose a private sector, or public sector, vocational rehabilitation provider. NARPPS believes that consumers are the experts on the cash cliff and on what health care he or she needs in order to make it easier to return to work. However, we do believe that the continuation of health care significantly enhances an individual's chance for successful and long-term employment. As for choice, we believe that any legislation to remove these barriers must contain a means by which a consumer can utilize the services of the private sector, or specifically, a "ticket to work."

A ticket program would provide the consumer with a choice over who their service provider is, and it will motivate providers to deliver cost-effective, timely, and results-oriented services to that consumer. The ticket will create a natural weeding-out process of those providers who fail to deliver a high standard of service to the consumer. However, for the ticket program to be successful, it must contain certain safeguards.

- We recommend the inclusion of milestone payments at two significant levels of progress achieved prior to actual placement of the individual. Such payments will make it possible for more qualified providers to participate in this program. Without milestone payments, smaller providers could not participate because of the tremendous burden of having to be capitalized until the recipient has been placed and employed for a number of months.
- NARPPS believes that there is a need for the program to be open ended without being reauthorized. To include a reauthorization date may prevent a significant number of beneficiaries and providers from getting involved if they have reason to believe that such a program could be eliminated, or at the very least, interrupted for a period of time.
- We believe that any phase-in sites for the ticket program should be chosen by the SSA Commissioner with special consideration given to past demonstration projects and in consultation with providers and consumers who have participated in these programs. Together with providers and consumers, the Social Security Administration will be in a good position pick such sites.
- Finally, we support the creation of an advisory panel made up of all of the sectors impacted by and participating within this program, which can assist the Social Security Administration with evaluation of project effectiveness and with recommendations to the President and Congress.

We welcome the inclusion of state Vocational Rehabilitation (VR) agency participation. These agencies have developed over the years an effective model for evaluation and service delivery. Individual counselors who work in that setting are extremely dedicated. Many private sector individuals got their start with a state VR agency. The private sector likewise has developed an effective model for evaluation and service delivery which also has the added component of bottom-line results and payment from our referral sources. We believe that the public and private sector rehabilitation professional can form an effective partnership to deliver this much needed service to the disability beneficiary.

Already, in many parts of the country, state VR agencies contract with the private sector rehabilitation provider to provide the initial evaluation of an applicant. Likewise, the Social Security Administration contracts with private sector rehabilitation counselors to serve as vocational experts at SSI and SSDI hearings. In addition, the Department of Veterans Affairs, Vocational Rehabilitation Agency, contracts with private sector rehabilitation providers to conduct the initial evaluation of veterans and to recommend a vocational rehabilitation plan for those who have applied for rehabilitation benefits. As I stated earlier, I am fortunate to be one who provides these services to the Social Security Administration and also the Department of Veterans Affairs.

It will be important for the service provider to have substantial expertise and experience within the fields of vocational rehabilitation, employment, case management, and other support services. NARPPS has published Standards and Ethics by which each member is required to abide. They are subject to peer review and are a condition of membership. NARPPS has a Standards Compliance Review Board for peer review functions. In addition, the typical NARPPS member has board certification in one or more areas on a national level, and because of certain state requirements, must be licensed to practice vocational rehabilitation in certain areas of the country.

Before us is a significant exciting opportunity to help disability beneficiaries return to work, resume truly productive lives, and enhance one's self sufficiency. The private sector rehabilitation professional has enjoyed this opportunity in many other arenas which deal with disability. We welcome the opportunity to provide these return to work services to Social Security disability beneficiaries and to work further with the Subcommittee to help make this a reality.

On behalf of NARPPS and myself, I thank you for the opportunity to meet with you and to provide this testimony today. I would be happy to answer questions at the appropriate time.

Chairman SHAW. Thank you.

Mr. Hulshof.

Mr. HULSHOF. Thank you, Mr. Chairman.

First of all, I thank each one of you for being here with your very powerful testimony about what you each have encountered, so thank you for being here and helping to enlighten us.

Rich, a couple of things—you talked about—and I wasn't aware, really, to the significant degree of the confusion that is caused by having to give different answers to the very simple question, Can you work? What recommendations, if any, do you have to correct that anomaly, if you will?

Mr. BLAKLEY. First of all, I think the Social Security Administration and local State vocational rehabilitation agencies need to work closer together. There needs to be some sort of way for them to connect and to stop making people give different answers. What that would be precisely is something that I can't answer right now. I would like to give some thought on it, but I think it is something that can be fixed. At this point in time, I am not exactly sure what it would be.

Mr. HULSHOF. The other question I would have of you, Rich, and really anybody on the panel that wishes to answer, feel free, but I know especially because of your background having been both in Missouri and in Illinois—and as your written testimony pointed out, there are differences between State policies that affect people with disabilities. You talk about a necessity for a national self-directed care program. Do you have any suggestions or recommendations on implementation of this or other policies we might want to pursue on a nation-wide basis?

Mr. BLAKLEY. Very much so.

I like the mi casa bill which is a policy which is being promoted by the national ADAPT. Mi casa would be a national attendant-care program.

Right now, depending on what State you live in, either you get attendant care or you don't. When I moved from Illinois to Missouri, it was sticker shock. In Illinois, I made approximately the same as I made in Missouri monetarily, and the State paid $650 in attendant care. I paid a $50 copayment. I moved to Missouri, and there was nothing. I had to get a roommate and offer free room and board for an attendant. It was not an ideal situation. It was very, very difficult, and it still is. Missouri is lagging behind Illinois and Kansas in that respect, and we have told people that live along the border, when they call our office and ask, What should we do? we have actually said that they may want to move across the river or across the border to receive attendant care, and that is a shame.

Mr. HULSHOF. Anybody else have a comment on that question?

Mr. MCNULTY. I would just like to make one brief point analogous to the personal care attendant situation. For people with mental illness, very often our lifeline to being able to work is medication, and, unfortunately, most of the medications that are effective are very new, and they are very expensive, and Medicare currently has no provision to pay for those, but it does under Medicaid.

Different States do have different policies, but people run into sticker shock if they move from one State to another even within New England. They find that if you move from Rhode Island to one of the other States—I don't want to name any—you might find that a medication that is paid for in Rhode Island is not paid for in another State which means that you would have to go to one of the old-style, antipsychotic medications which are inexpensive, but they also have such terrible side effects which is why people very often stop taking them.

So, it is one of those penny-wise, pound-foolish kind of things that does mandate, I think, a more rational policy.

Mr. CARLISLE. On a related matter, I have found that there are differences from State to State just in terms of eligibility for vocational rehabilitation services on the State level.

For example, in a State like Louisiana, because of some funding issues, they are only accepting the most severely disabled individual for vocational rehabilitation services, whereas, the State of Mississippi allows them to accept a wider population of individuals.

Mr. HULSHOF. I appreciate that—I'm sorry?

Ms. GENNARO. I also just wanted to chime in that they might possibly do a great deal in the area of attendant services and supports. We are hoping that another bill similar to the mi casa bill will be introduced that more clearly indicates what it will cover and it will really help the situation out tremendously.

Mr. HULSHOF. Again, thanks very much, each of you, for being here.

Mr. Chairman, my time has expired, and thank you again.

Chairman SHAW. Surely.

Mr. Matsui.

Mr. MATSUI. Thank you, Mr. Chairman.

I would just like to thank the panel. I think their testimony was very revealing and helpful to me, and I hope to others as well. I thank all four of you.

Chairman SHAW. Mr. Doggett.

Mr. DOGGETT. Ms. Gennaro, I think you addressed this critical health insurance matter in your testimony. Is it your belief that unless we address the health insurance issue in the manner that the bipartisan Senate bill has done, that, for most individuals with disabilities who are out there and who would like to go back into the work force, we really will have essentially just given them a ticket to no where?

Ms. GENNARO. Yes, that is true.

The Senate bill recognizes the need to let people trust that the Medicare coverage is going to be there when they need it—not a limited coverage that will go a few years more for you because the risk still is there for them in terms of what exactly they will need down the line, I have been successful with my employment but my

disability is still there and I have critical needs. Yes, we will have false expectations for people.

And also we will have said that we will have made tremendous improvement in employment, and that really won't happen because people won't be able to use the ticket as they could. It will be a lost opportunity.

Mr. DOGGETT. Or to put my same question another way, if all this House does in this session of Congress is the little that it did last time in approving—and I voted for it along with, I think, all but one Member of the House who voted that day—but if all we do is this very limited, narrow type of ticket to work bill that was considered last session, we may create the illusion of progress, but in terms of really making a difference in the real-life struggle of most people with disabilities, we will have done very little.

Ms. GENNARO. That is true, unfortunately.

Mr. DOGGETT. Mr. McNulty, do you agree with that?

Mr. MCNULTY. Absolutely, Mr. Doggett, I do. It is unfortunate, but without health insurance people can't work. Our lives are dependent on our health, everyone's is, but we are just more aware of it than most people because we are confronted with it every day.

Mr. DOGGETT. Mr. Blakley do you agree with that?

Mr. BLAKLEY. Yes, I do, and one thing I am really concerned about is the Medicare Program. You say Medicare to people and what you think about is senior citizens you don't think about people with disabilities. Ask anybody on the street, and they will say that Medicare equates seniors. Maybe it should be pulled out of the Medicare's purview and a new innovative program set up for people with disabilities to receive health insurance.

Mr. DOGGETT. Mr. Carlisle, I know that your focus has been on the very important issue of vocational rehabilitation, but you see these health insurance issues come up also. Do you agree with that?

Mr. CARLISLE. Oh, yes, sir, absolutely. When we are working with an individual and placing them back into employment, a primary consideration is benefits, bottom line and most importantly the issue of health care. And there are any number of times when we have been working with individuals that have all the qualifications necessary for the job, are extremely interested in it, but because of the virtual lack of health care available to them, they simply can't take the job.

Mr. DOGGETT. Well, thank you very much. Yes, ma'am?

Ms. GENNARO. If I could just chime in for a moment.

I wanted to say that it is really not necessary to remove the disability Medicare Program from the Medicare Program. That would be a mistake. We need to just educate people to understand that Medicare covers a range of needs amongst all peoples.

Mr. DOGGETT. Thank you very much, and I hope we can do more than just pass a bill with a nice sounding name but really make some progress that will make a difference to you and to the many people that you represent. Thank you for what you are doing for people with disabilities.

Mr. CARLISLE. Thank you.

Ms. GENNARO. Thank you.

Mr. BLAKLEY. Thank you.

Mr. MCNULTY. Thank you.

Chairman SHAW. I have one question for Mr. Carlisle. One of your recommendations for the ticket-to-work program was the inclusion of milestone payments for significant levels of progress achieved in given cases. Why are milestone payments so important, and what would be the impact on the number of providers participating if milestone payments were not a part of any program?

Mr. CARLISLE. To me, sir, the milestone payments are critically important because, more so than not in our country these days, private-sector rehabilitation providers are smaller companies. They may be one or two individuals, or perhaps a handful of individuals, but we are seeing the days of the large corporate entities which provide rehabilitation services going away, and, for a company to be able to really provide this type of service in our opinion, there needs to be some milestone payments along the way in the overall administration of the vocational rehabilitation plan. And I think that it is important to add for the record, we in no way see the level of milestone payments as being really profitable for the company, but basically helping to just cover their expenses, or perhaps a little less than that, and there are any number of companies in our country today that simply could not afford to spend thousands upon thousands of dollars with the only opportunity for payoff coming once the person is gainfully employed for 9 months. It is just clear to me, as the current president of NARPPS from comments that I have received from our members around the country and those outside our organization, that, if a milestone payment is only occurring at the time of placement or after 9 months of employment, people are simply not going to choose to get involved in the program.

Chairman SHAW. Thank you.

I want to thank, again, all the witnesses, as the other Members have. You have contributed, particularly, with your personal testimony as to what you have encountered and what you have overcome. It is particularly important to this Subcommittee in the drafting of legislation. We thank each and every one of you.

This does conclude the hearing. We were fortunate that we weren't interrupted by another vote. I appreciate all of you being here, and I appreciate the participation of the Members up here on the dais.

Thank you.

The hearing is adjourned.

[Whereupon, at 12:52 p.m., the hearing was adjourned.]

[Submissions for the record follow:]

Statement of John Rio, Corporation for Supportive Housing, New York, New York

Chairperson Shaw, members of the Subcommittee on Social Security, my name is John Rio and I am a Project Coordinator with the Corporation for Supportive Housing's employment initiative. The Corporation for Supportive Housing, or CSH, is a nonprofit national intermediary founded by 3 of Americas leading private foundations—the Pew Charitable Trust, the Robert Wood Johnson Foundation and the Ford Foundation to increase the supply and quality of supportive housing in the United States. Supportive housing is a solution to homelessness offering people affordable housing with on-site supportive services including social services and employment services. An array of supportive services voluntarily accessed by tenants is a first-line strategy in helping people pursue self-determined goals in our housing projects.

CSH believes that supportive housing provides not only the opportunity to decrease homelessness but offers tenants a stable platform for developing self-sufficiency. Since our founding in 1991, CSH has created partnerships in 9 locations around the country with 184 nonprofit agencies who have developed more than 8,000 supportive housing apartments across the U.S. CSH has raised over $80 million in philanthropic and public funding sources to help our partners build supportive housing and have also placed $144 million in gross equity in supportive housing projects totaling 2,864 units through syndication of Low Income Housing Tax Credits in partnership with the National Equity Fund.

The tenants of supportive housing are individuals with histories of homelessness frequently complicated by severe disabilities including mental illness, substance abuse, HIV/AIDS and other medical conditions as well as chronic poverty or histories of incarceration. Although of late the need for supportive housing among families has become apparent, most of the supportive housing population is single adults or non-custodial parents. More than 50% of the supportive housing population are beneficiaries of the Social Security disability programs.

I am sure that each of you has heard what people with disabilities want. It should come as no surprise that they want what most citizens in America wanta safe affordable place to live and a job that you like and that pays and, of course, health care.

Within supportive housing the majority of those tenants receiving Social Security disability benefits are individuals with mental illness who face multiple barriers to employment including poorly integrated employment services in our communities across America. People with mental illness have a greater chance of being re-hospitalized for their illness than landing a living wage job! Tenants of supportive housing want to work and we have the technology to help them but, the losses people fear and experience substantially challenge our efforts in the Social Security disability and the Vocational Rehabilitation systems. Individuals with psychiatric disabilities should not be left out of workforce development systems. But they will be, if your leadership does not reform existing law and make good on a federal policy that helps all Americans work, even those with severe disabilities.

While there are significant barriers in the employment and entitlement systems serving formerly homeless tenants of supportive housing, we think you should hear about things that work and show potential. In 1995 the Rockefeller Foundation funded an employment initiative at CSH called *Next Step: Jobs."* In this project 21 non-profit supportive housing agencies partnered with CSH to increase the rates of employment among individuals in supportive housing with multiple barriers to employment. Our research[1] shows that supportive housing offers the basic critical ingredients for positive vocational outcomes, that is continuous case management, permanent housing and a culture supportive of working tenants. In the first two years of this project more than 1,000 tenants went to work. We invite you, Chairman Shaw, and members of the Committee to look more closely at this strategy during your inquiry.

Despite the creativity and flexibility in our demonstration, the disincentives in our nation's entitlement systems pose significant barriers to people with disabilities who want to work. I would like to take this opportunity to tell you some of what we have heard though our national employment initiative. I would also like to note our observations regarding the Work Incentives Improvement Act.

Two dominant themes persist in the experience of both providers of employment services and for the tenants they help. First, the very nature of the Social Security work incentives are too complex and second, the rules do not support a safety net for people with long term episodic illnesses in which an "easy on; easy off" access mechanism would encourage work.

People make rational choices and, in general, people will prefer to work, if it is to their financial benefit and if the health risks of going to work are minimized. The chronic and intermittent nature of mental illness or HIV/AIDS mean that people living with these illnesses may be well enough to work for months or even years at a time with needed supports. At other times, an acute episode of illness makes it impossible for individuals to meet the demands of work. People with these illnesses (who want to work and can work) do not fit into an entitlement system based upon a case-open/case-closed design. In the system we have in place today, tenants of supportive housing are making the rational decision to minimize their health care risks and maximize their income by staying on the SSA rolls by either deliberately limit-

[1] Proscio, T. (1998). Work in Progress 2; An Interim Report on next Step: Jobs. A report to the Corporation for Supportive Housing and Rog. D., Holupka, S.C., Brito, C.m., Storm, A., Hopper, K., Roy, K., Davidson, C. and Lester, R. (1998). Next step: Jobs Second Evaluation/Documentation Report. June.

ing their earned income or by not working at all. Any reform of the SSA disability program should make flexibility paramount in the design to promote employment. Such flexibility would support work when people with disabilities can work and provide sustenance when disabling conditions impair work ability.

TICKET TO INDEPENDENCE

The Ticket has been heralded as a key feature of Social Security Disability reform and we concur that it has the potential to offer people with disabilities new opportunities. People with disabilities believe that the Ticket will give them a choice of vocational rehabilitation providers whereas in the current system, the State vocational rehabilitation agency is the only provider. We support the concept of increasing choices and your efforts to give people with disabilities a choice in whom they go to for help.

However, we foresee limitations in the Ticket program as it is currently constructed which are likely to dash the hopes of so many of us. The Ticket program is likely to only serve those with fewer, less severe barriers to employment and we will, yet again, leave behind those who need us most. The Ticket encourages providers to help only those who are likely to be able to sustain employment with the least amount of service. There are no provisions to direct or encourage providers to help those with severe and episodic impairments such as individuals with mental illness. This is not a program to help Social Security beneficiaries who are formerly homeless individuals with mental illness, HIV/AIDS or other chronic medical conditions.

Nor does the Ticket fairly share the cost savings and program expenses when a vocational service provider helps a beneficiary work and leave the SSA rolls. Under the best of circumstances in which a person with an SSDI benefit of $700 a month leaves the Social Security cash benefits program due to earnings and works continuously for five years, a provider would receive a total of $16,800. This amounts to an annual payment claim of $3,360 to a provider. In FY 1997 the SSA reimbursed the State vocational rehabilitation agencies for their costs that averaged $10,700 per claim to help individuals with disabilities sustain work for 9 months!

Both the milestone and outcome payment systems perpetuate the all or nothing feature of the SSA disability program that has kept people from jobs. Some beneficiaries will give up their cash benefits and leave the rolls but more are able to work with a reduced reliance on SSA cash benefits. There is no structure in the Ticket for beneficiaries to access their choice of vocational rehabilitation providers when their ability to work is less than what is needed to leave the rolls. In other words the ticket does not pay for those who through earned income can reduce their reliance on cash benefits but who cannot work at the level needed to leave the rolls entirely.

The Work Incentives Improvement Act should provide the Commissioner of Social Security the authority to maximize the participation of community based vocational rehabilitation agencies in the Ticket program for our population.

WORK INCENTIVES AND ENTITLEMENT COUNSELING

The current system of work incentives have become an entangled web that holds people back from working rather that acting as a safety net of support should a work attempt not succeed. The complexities of Social Security work incentives has become so confusing that it is very common to request information from that agency and receive different answers to the same questions. Such confusion has resulted in the fact that beneficiaries do not take advantage of such programs as the Plan for Achieving Self-Support. Two years ago there were some 10,000 PASS plans in effect. Today there is only 3,000 PASS plans. We need simpler incentives and benefits counselors that can help people with disabilities access these incentives to maximize their employment potential.

Current entitlement counseling in supportive housing focuses on helping tenants get on and maintain Supplemental Security Income and/or Social Security Disability Insurance benefits. Most service staff is unfamiliar with the current work incentive provisions and is not aware of proposed changes. Legislation that improves the availability of experts in work incentives and entitlement counseling is much needed legislation. From our point of view, we need to build upon the talents of supportive housing case managers and employment staff to upgrade their capabilities to help tenants manage the entitlement system, work more and rely less upon the Social Security disability program. Work incentives and entitlement counseling are core services needed by beneficiaries and best provided directly by community based organizations rather that the SSA.

HEALTH CARE

When you ask people with disabilities the question "Why aren't more people with disabilities working?" they will tell you it is about health care and about losing our benefits. The Deputy Commissioner of SSA[2] asked this question and was told "when we get cash benefits, we also get access to Medicare and Medicaid and we can't replace that no matter what we make. We are uninsured and uninsurable in the private market. And we are afraid that if we give up our cash benefits, we might have to give up our health care, as well. And if we give up health care, we might give up our lives. Even though many of us can give up the cash and earn our way, we will never be able to earn the kinds of services and supports we need that we get in Medicare and Medicaid." Tenants of supportive housing have echoed these concerns.

Any Social Security work incentive reform must also address the critical problem of health care for working disabled individuals. The Balanced Budget Act of 1997 included a provision in section 4733 that gave States the option to offer a Medicaid buy-in for a new category of working disabled participants. But, so far only the State of Oregon accessed this option. Why is that? There are no incentives for the States to step up to the plate. Local advocates will do their job to bring attention to the needs of people with disabilities who work but they will need your support to entice States to establish health care coverage through a Medicaid buy-in. In the great State of New York, Governor George Pataki expressed his point of view saying, "The challenge is clear: disabled individuals in New York State want and deserve to work, and we intend to see that they succeed in doing so. We want to enhance access to employment for persons with disabilities, but for this to happen, we need to build assurances into the system so that persons with disabilities who collect SSI or SSDI can work without fear of losing their health insurance and other critical benefits."[3]

This Committee should include in their recommendations a provision for health care so that people with disabilities who want go to work but cannot get health care insurance coverage (or coverage that will help them pay for treatment of their impairments) can participate in the workforce of America. If we expect States to adopt such options as Section 4733 in the Balanced Budget Act of 1997, your recommendations must also include help for the States finance their system of health care for working disabled individuals. Allowing States to limit their fiscal exposure while ramping up a Medicaid buy-in option that sunsets after an implementation period should carefully be considered. The Committee should consider limiting the number of persons in the State's Medicaid buy-in program or limit its application to certain areas of the State for a period of 3 years before making the option available Statewide. Your influence will also be required to encourage the Health Care Financing Administration to work proactively with the States to efficiently and swiftly establish this health care provision.

HOUSING

Nowhere in the work incentives discussions has there been a focus on the housing needs of individuals with disabilities. We are concerned that if we do create Social Security and tax based work incentives, many people with disabilities may run up against disincentives in the housing programs. Many individuals with disabilities rely on housing subsidies such as section 8 certificates through which individuals pay up to 30% of their total income up to certain limits. When people with disabilities in special needs housing go to work not only do their rents go up; they also jeopardize the stability of their housing.

We would like this Committee to direct the appropriate federal agencies to investigate what housing-based or rent-based work incentives can be made available to working disabled individuals. The Quality Housing and Work Responsibility Act of 1998 made certain work incentive provisions available to tenants of public housing. We would like these incentives to be available to individuals in homeless housing and disability housing programs.

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[2] Susan M. Daniels, Ph.D., Deputy Commissioner for Disability and Income Security Programs Social Security Administration, Opening Session, Tapping Worker Potential through Technology Conference, President's Committee on Employment of People with Disabilities, New Orleans, Louisiana, May 6, 1998.

[3] Press Release, Governor George Pataki, September 14, 1998, Governor Seeks To Eliminate Employment Barriers For Disabled.

CONCLUSION

People with disabilities want and can work, but they will not do so if working means having less that they do now. The provisions you include in the Work Incentives Improvement Act can be the first steps toward encouraging more people to choose and sustain employment. S.331 and HR 1180 offers such promise and hope to thousands of Americans with disabilities.

[An attachment is being retained in the Committee files.]

March 11, 1999

Mr. A.L. Singleton, Chief of Staff
Committee on Ways and Means
U.S. House of Representatives
1102 Longworth House Office Building
Washington, D.C. 20515

Att: Congressman E. Clay Shaw, Jr., Chair, Subcommittee on Social Security

Subj: Barriers Preventing Disability Beneficiaries From Returning to Work

Dear Chairman Shaw and Members of the Social Security Subcommittee

Members of the San Francisco Bay Area Network on Disability (SF BAND) wish to add our voices to the many asking for change in the requirements of the Social Security Administration which prevent us, and others across the country, from gainful employment. We are encouraged by the strong support in the Senate of S. 331, the Work Incentives Improvement Act of 1999, and ask that you pass similar legislation in the House such that persons with disabilities may actually see a positive change before the end of this century!

We are a group of over 100 persons with disabilities and their friends in the San Francisco Bay Area who communicate daily over the internet. We represent persons with disabilities who have many skills, who contribute much to the lives of each other and of others. We are fortunate in that we have computers and the requisite skills to use the internet to support each other, to lobby for legislation that improves our lives, to inform and educate ourselves about events that are of concern to persons with disabilities, and to inform and educate the nondisabled populace of our abilities and our humanity.

Clearly among us are many who would be able to refocus such skills in productive, paying employment. Indeed, many business could use the special skills which have been honed by the exigencies of life with a disability and by the ability to problem-solve in ways that we have so clearly demonstrated. Medical science and engineering have enabled us, but without legislation such as you have supported with your action last week, we must forgo all thoughts of becoming part of the work force, and remain tax burdens rather than tax payers.

We encourage you now to take the courageous actions which will help mainstream us as valuable and valued members of society as we move into the new century.

Very Sincerely,

JEAN NANDI, CHAIR,
San Francisco Network on Disability (SF BAND)
1529 Josephine St.
Berkeley, CA 94703–1168

U.S. HOUSE OF REPRESENTATIVES
COMMITTEE ON WAYS AND MEANS
SUBCOMMITTEE ON HEALTH
March 11, 1999

The Honorable Clay Shaw
The Honorable Robert Matsui
Subcommittee on Social Security
Committee on Ways and Means
Washington, DC 20515

Dear Chair and Ranking Member:

Congratulations on holding today's hearing on barriers preventing the disabled from returning to work.

I would like to request that my Statement of February—to the Senate Finance Committee on "Return to Work" legislation be included in your hearing record.

Specifically, the key barrier is lack of health insurance for those returning to work, and improvements in Medicare and Medicaid can play a key role in encouraging the disabled to return to work.

As my testimony indicates, we should give some special attention to those with End Stage Renal Disease. There is tremendous potential to help many of these patients to return to a more productive, satisfying life.

Since my testimony to the Senate, I've had the chance to read an article from the January, 1999 *Journal of the American Society of Nephrology* entitled, "Can Renal Replacement be Deferred by a Supplemental Very Low Protein Diet?" The answer is yes-by as much as a year among motivated patients! We should amend this Return to Work legislation to give Medicare the flexibility to cover such therapies to delay the onset of dialysis, which would make it much easier for kidney disease patients to maintain employment while saving Medicare money.

I look forward to working with you on this legislation to ensure it achieves the maximum impact on improving the opportunities of the disabled community.

Sincerely,

PETE STARK
Member of Congress

Attachments
Statement to Senate Finance Committee
Article entitled, "Catch-22 for a Transplant"
Article entitled, "Can Renal Replacement be Deferred by a Supplemental Very Low Protein Diet?"

cc: Members of the Subcommittee on Social Security

Statement of Hon. Fortney Pete Stark, a Representative in Congress from the State of California

PLEASE GIVE SOME SPECIAL ATTENTION TO E.S.R.D. PATIENTS IN THE "WORK INCENTIVES IMPROVEMENT ACT OF 1999"

Mr. Chairman:

I urge the Committee to give some special consideration to helping End Stage Renal Disease patients return to work.

As you know, there are about 260,000 Americans on dialysis and another 80,000 who are dependent on a kidney transplant (with about 11,500 kidney transplants performed annually). About 120,000 dialysis patients are of working age (between 20 and 64), yet, extrapolating from recent data, fewer than 28,000 are working—roughly 100,000 are not in the workforce. The USRDS Abstract of Medical Evidence Reports, June 1, 1996 to June 1, 1997, reports that 38.1% of all dialysis patients 18–60 years of age were employed full time, part time or were students *before* onset of ESRD. 22.9% of ESRD patients in the same age group were employed full time or part time or were students *after* the start of dialysis. It is the 15% (38.1% minus 22.9%) differential that is the prime hope for return to work efforts.

Of the transplant patients, most (88%) are of working age, and about half of these are working.

ESRD patients are extraordinarily expensive. They constitute about 0.5% of all Medicare patients, yet use about 5%—about $11 billion—of the Medicare budget.

The promise of ESRD, and especially of transplantation, was that it would enable people to live mainstream lives—and the problem of rehab/return to work has long been a theme in Congressional review of this program.[1]

Yet for many reasons, return to work has not been very successful in this patient population. The 1991 landmark Institute of Medicine study entitled *Kidney Failure and the Federal Government* explains some of the reasons (see attached).

Section 102 of your bill provides Medicare coverage for working individuals with disabilities—but ESRD dialysis patients already have this protection. For transplant patients, Medicare does not cover their major health need—coverage of $8,000-$10,000 per year for immuno-suppressive drugs—after 36 months.

Clearly, we should tailor some special provisions to this population.

I would like to suggest a series of ESRD return-to-work amendments that would save total government revenues in the long run. While these proposals may increase Medicare spending, they would reduce Social Security disability and Medicaid spending.

These are just preliminary ideas, and I hope that you and the renal community could refine these ideas prior to mark-up.

1) A huge percentage of ESRD patients qualify for Medicaid. The disease is so expensive ($40-$60,000 per patient per year) and the out-of-pocket costs so high that it impoverishes many. For transplant patients, the cost of life-saving immuno-suppressive drugs alone can be $8,000, $10,000 or more per year. No wonder many are tempted to avoid actions which would disqualify them for help.

As part of general Medicare policy, I have always thought that we should cover pharmaceuticals and, in particular, indefinitely cover immuno-suppressives. It is maddening to hear the stories of $80,000-$100,000 kidney transplants lost, because a patient couldn't afford the $10,000 per year of medicine.

I think a good case can be made to add to this bill coverage of immuno-suppressives indefinitely, to encourage people to leave Medicaid/Disability and return to work.

2) Some ESRD facilities do a good social work job helping patients return to work. Others don't seem to even try. We should honor and reward those centers which, on a risk adjusted basis, are doing the best job of rehab in their renal network area.

The honor could be as simple as a Secretarial award of excellence and public recognition.

The reward could be something more tangible—a cash payment to the facility for each patient of working age who does not have severe co-morbidities which the center is able to help return to work (above a baseline—perhaps 5% of eligible patients). For example, if a center had 100 working age patients, it could receive a $1000 payment for each patient above 5 who had lost employment and is helped to return to work. This would be a phenomenally successful investment and would partially compensate the dialysis center for the cost of vocational rehab and social work.

3) Renal dialysis networks, which are designed to help ensure ESRD center quality, should be able to apply for designation as rehab agencies and for demonstration grants under this legislation.

The law spelling out the duties of Networks has a heavy emphasis on rehabilitation. Indeed, it is the first duty listed:

> "...encouraging, consistent with sound medical practice, the use of those treatment settings most compatible with the successful rehabilitation of the patient and the participation of patients, providers of services, and renal disease facilities in vocational rehabilitation programs;"[2]

I suspect that the 17 Networks vary widely in their emphasis on rehabilitation. Again, the Network(s) that do the best should receive recognition and share their success with the others.

4) Kidney failure remains a medical mystery. It often happens very quickly, with no warning. But for thousands of others, there is a gradual decline of kidney function. I am told by medical experts that in many cases the descent to terminal or

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[1] See testimony of HHS Inspector General Kusserow, in hearings before the House Government Operations Committee, February 23, 1982, p. 20, when it was noted that only about one fourth of those with jobs before the onset of ESRD continued employment, a figure which appears not to have changed much over nearly twenty years. See also Ways and Means Oversight Subcommittee hearing of June 24, 1975. At that time, there were about 20,000 ESRD patients, generally clustered in the more-employable cohort of 20 to 55 years of age, and it was estimated that 50% of the dialysis patients and 75% of the transplant patients were working.

[2] Sec. 1881(c)(2)(A); see also (B) and (H).

end-stage renal disease can be slowed by (1) nutrition counseling, or (2) medical treatment by nephrology specialists.

I hope that you will make it clear that the Medicaid (or Medicare) funds provided in this program to prevent disability could be used to delay the on-set of the devastatingly disruptive and expensive ESRD. Monies spent in this area would return savings many times over.

Also in the 'preventive area,' some of the leaders in the renal community are reporting exciting results from more frequent, almost nightly dialysis. Like frequent testing by diabetics for blood sugar levels, it may be that more frequent dialysis can result in a less disrupted life and a better chance to contribute to the workforce. We should watch these medical developments and if there is a chance that some additional spending on more frequent, but less disruptive dialysis would encourage return to work, we should be supportive.

5) Finally, I urge you to coordinate this bill with another proposal of the Administration—skilled nursing facility employment of aides to help with feeding. As you know, last summer we received a GAO report on the horror of malnutrition and death by starvation in some nursing homes, due to a lack of staffing to take the time to help patients who have trouble eating and swallowing and who take a long, long time to eat (e.g., many stroke patients). A coordinated effort by the nursing home industry and ESRD centers to fill this minimum wage type position would help nursing home patients while starting many long-out-of-work ESRD patients back on the road to work.

Mr. Chairman, these are just a few, quick ideas. I am sure that experts in this field could suggest other steps to ensure that the ESRD program not only saves lives, but helps people have a good and productive life. Thank you for your consideration.

[Attachments are being retained in the Committee files.]