

# WORK INCENTIVES IMPROVEMENT ACT OF 1998

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**HEARING**  
BEFORE THE  
SUBCOMMITTEE ON SOCIAL SECURITY  
AND FAMILY POLICY  
OF THE  
COMMITTEE ON FINANCE  
UNITED STATES SENATE  
ONE HUNDRED FIFTH CONGRESS  
SECOND SESSION

ON

**S. 1858**

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JULY 29, 1998

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# WORK INCENTIVES IMPROVEMENT ACT

WEDNESDAY, JULY 29, 1998

U.S. SENATE,  
SUBCOMMITTEE ON SOCIAL SECURITY  
AND FAMILY POLICY,  
COMMITTEE ON FINANCE,  
*Washington, DC.*

The hearing was convened, pursuant to notice, at 2:00 p.m., in room SD-215, Dirksen Senate Office Building, Hon. John H. Chafee, (chairman of the subcommittee) presiding.

Also present: Senator Jeffords.

## OPENING STATEMENT OF HON. JOHN H. CHAFEE, A U.S. SENATOR FROM RHODE ISLAND, CHAIRMAN OF THE SUBCOMMITTEE

Senator CHAFEE. Good afternoon. This is a meeting of the subcommittee of the Finance Committee. It is the Subcommittee on Social Security and Family Policy. The reason we are here this afternoon is to have a hearing on the Work Incentives Improvement Act which was introduced by Senator Jeffords.

We want to welcome everyone here this afternoon. Although I do not see him in the group, I know that Senator Dole is expected shortly. I do not see him here yet, but I know he will be right along. I spoke to him yesterday about this.

Today we are going to explore the health care barriers facing those who are disabled, and yet who wish to work. Senator Jeffords has introduced legislation to address this problem, the Work Incentives Improvement Act, and at today's hearing we will also discuss how this legislation would help disabled people get back to work.

The magnitude of this problem is considerable. At present, there are approximately eight million disabled adults receiving Federal benefits under either the Social Security Disability Insurance, so-called SSDI, and the Supplemental Security Income, SSI, programs.

Federal cash payments to these individuals amounted to over \$60 billion in 1996. This is above and beyond the cost of health benefits provided under Medicare and Medicaid.

Getting disabled individuals back to work is not merely a matter of saving the government money, it is, more importantly, a way to improve their quality of life. A recent survey suggested that about one-third of disabled SSDI recipients are interested in services aimed at helping them get back to work.

A recent GAO study concluded that disabled individuals want to return to work for two major reasons. Both of these are totally un-

derstandable. First, working provides self-esteem. No one will argue with that. And second, work helps to achieve financial independence.

Despite the strong desire to work, only about two percent of SSDI recipients actually return to work—that is an astonishing statistic—and leave the SSDI rolls. It is important for us to identify the disincentives in the present system which discourage disabled people from working, and also to explore new work incentives.

The GAO survey concludes that the number one concern for disabled individuals who return to work, or who are considering returning to work, is availability of health care. Fear of losing health care benefits is a powerful disincentive for a disabled person to return to work.

The Work Incentives Improvement Act is an important first step toward helping the disabled to return to work. I want to congratulate Senator Jeffords and Senator Kennedy, who will be testifying in a few minutes, for their hard work in this area. I look forward to working together to try and resolve this problem.

Before I turn to Senator Jeffords, let me say that Senator Rockefeller spoke to me and asked that I convey his sincere regret that he has a schedule conflict this afternoon and will be unable to attend the hearing.

As we all know, Senator Rockefeller is deeply interested in these matters and has a long-time interest in all health care matters, including those with the disabled, particularly those involving children, and he will be working with us also to find a solution to this problem.

Senator Jeffords?

**OPENING STATEMENT OF HON. JAMES M. JEFFORDS, A U.S.  
SENATOR FROM VERMONT**

Senator JEFFORDS. Thank you, Mr. Chairman. I am so pleased to see my good friend and true advocate of persons with disabilities, Senator Bob Dole, with us here today. This bipartisan issue has brought you here, Senator Dole, and I commend you for your continued leadership with people with disabilities.

I think everyone in this room appreciates your unwavering support in that respect. Your commitment to this issue is not much about health care, it is about giving people back dreams of employment and the dreams that they hold of independence.

Senator Kennedy, we are pleased to have you here testifying. Your advocacy in this area has been long and steadfast in making it a bipartisan piece of legislation that I think is essential.

I believe this is an issue whose time has finally come. Having spent a good part of my career on disability issues, I feel that the ADA, the Individuals With Disabilities Education Act, vocational rehabilitation, and the other Federal programs are missing an essential element: providing health care security for a person with a disability to go to work.

Though we have come a long way since when I came to Congress in the 1970's, so much more needs to be done. I want to briefly discuss changing a broken system, a system that bars a person from

pursuing their dreams, a system that prevents a person from working.

Preventing a person from going to work is unconscionable, but particularly for persons with disabilities. Thousands of persons with disabilities want to work, but are discouraged by a government that penalizes them when they pursue a job.

For months, Senator Kennedy and I have been speaking to countless people here in Congress and in the disability community, telling them that something must be done about these broken programs and broken promises.

Though we have little time left before the end of Congress, we must take action and it must be taken now. In March of this year, we introduced the Work Incentives Improvement Act, S. 1858. We introduced it in an effort to provide health care coverage, which is unavailable in the private sector for disabled Americans.

The bill changes Social Security's 1950's mentality towards a person with disabilities. This bill takes a giant step forward towards a comprehensive reform of the way Social Security treats people with disabilities. This legislation will provide exactly what persons with disabilities desperately need in order to be able to work.

Today I sit before you with the full backing of the grass roots community, many of whom are present here today. You have all worked so hard to ensure that comprehensive work incentives reform becomes a reality in the short time we have left here in Congress, and I know it will.

I have spent a great deal of time with my friends, Senators Kennedy, Dole, and also Senator Harkins, in educating Congress and people out there in the States on the need to provide those who work with continual and affordable access to basic health coverage, prescription drugs, and personal assistance services. Without coverage, a person with a disability will be unable to leave the house, much less leave the Social Security system, to begin working.

People in Washington are now listening. Today, support from the Clinton Administration for our efforts to get legislation to this Congress solves this problem. It helps people recognize that this system is simply broken.

The recognition by Congress, through this hearing, that we cannot stand by while millions are trapped in a system that forces unemployment upon people who want to work has also built momentum for action before the end of this session. We can no longer stand by while the system forces impoverishment upon those who need coverage but cannot get it, lest they are poor.

We can no longer stand by while the dreams of people with disabilities are crushed when their paycheck goes over Social Security earnings limits, depriving them of their health and their ability to live independently.

Congressional inaction this year will perpetuate a system that discourages a person's motivation, stands contrary to the values of which we were raised, and denies a person their dreams. We must move forward in this time that we have left in this Congress. We must pass legislation that gives back these Americans their dreams.

Finally, and succinctly, I cannot understand why it costs more money to continue benefits already being received when a person

with no taxable income starts earning a decent living and paying taxes into the Treasury. The cost estimates related to this provision ignore these savings and ignore the reality that we are extending existing benefits, not starting new ones.

I also want to say I am happy. I heard from the White House this morning, and the President has, by bill number, given his support to this bill today as well.

Thank you, Mr. Chairman. It is good to see Tom Harkin here. I am pleased to have worked with you all these years on issues of this kind, and you have been a steadfast supporter. Thank you.

Senator CHAFEE. Well, thank you very much, Senator Jeffords. I do want to recognize that we have in our audience many, many people, in addition to the witnesses, of course, many who have been long, valiant workers in this cause on behalf of the disabled.

I particularly want to mention Mrs. Eunice Kennedy Shriver, who was kind enough to come up to Rhode Island to help us in an SSI situation. We had an SSI hearing, and Ms. Shriver took the trouble to come there and was very effective, and I express my appreciation to her, as we do to many others in this audience who have been long-time, valiant battlers in this area.

Well, it is a great pleasure to welcome an old friend who has sat in this position many, many hours. So, Senator Dole, we are very, very glad to see you back, and look forward to hearing your testimony. This is an area you have been involved with, I suspect, throughout your entire career in Congress, certainly in the Senate.

So, if you want to proceed, we would be glad to hear your testimony.

**STATEMENT OF HON. ROBERT DOLE, FORMER SENATE  
MAJORITY LEADER, WASHINGTON, DC**

Senator DOLE. Well, since I am unemployed, maybe—[Laughter.]—Ted and Tom may have other things to say.

Senator HARKIN. Boy, would I like to have that unemployment check. [Laughter.]

Senator DOLE. I would be happy to defer to the other Senators.

Senator CHAFEE. It is up to you, gentlemen. All right. How are you fixed for time, Senator Harkin?

Senator HARKIN. We charge by the hour, where I am from. [Laughter.] But, in any event—

Senator CHAFEE. Well, that is why we wanted to get you on and out before the meter ran too high. [Laughter.] Go to it, Senator.

Senator DOLE. All right. Well, I will first ask that my statement be made a part of the record.

Senator CHAFEE. Certainly.

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

Senator DOLE. And I may have some additional information I may want to include in it.

But I appreciate very much this opportunity. I was here the day we had the press conference with Senator Harkin, Senator Kennedy, and Senator Jeffords, and I think the time is right. It seems to me, hopefully you can get something done this session, though I know it is probably going to be difficult. There are not that many days left.



But this is an important issue. It is not very complicated, it is not rocket science, because there are health care barriers faced by people with disabilities when they want to work.

We were just talking here briefly about Casey Martin. Here is a guy that wanted to do something, and he is doing it because certain barriers were lifted.

But now is the time to address these barriers head on. We all recognize the implications of not doing so. I commend you, Senator Chafee, for holding this hearing, and of course; Senator Jeffords, for his long-time interest.

I gave my public support to S. 1858 when it was introduced in March, and I am here today to support, as I indicated, the completion of those efforts.

It has occurred to me over the years that most people with disabilities—in fact, about everyone I have met—would like to work. It is not that they enjoy the disability, enjoy not being able to work because they might lose the benefits somewhere. They would rather be working, but sometimes they do not have that opportunity.

It is precarious, often impossible, for them to work if they do not have access to health care. Over the years, Congress has passed many laws to benefit individuals with disabilities. I initiated and supported most of them, and I am proud of the Americans With Disabilities Act.

I am concerned a little bit about two recent Supreme Court decisions, that we may be losing some side of the common sense combination many of us champion. But, in any event, it has been a good step in the right direction.

Addressing health care for individuals with disabilities, including my own efforts, proved more elusive. Access to health care was a blip on the radar screen in 1990 when we passed the ADA. Unfortunately, it has stayed that way until S. 1858.

Congress must tackle the work disincentives and Federal support for health care to individuals with disabilities. If it does not, the intent and promise of the ADA and other laws will continue to be undermined.

If our laws mandate civil rights and support education, training, and functional independence but do not provide access to health care for people with disabilities, we have not met our goals.

Many individuals with disabilities remain at home today. Last Thursday, the National Organization for Disability released a report that found only 29 percent of people with disabilities are employed. This percentage is worlds away from the 79 percent of the non-disabled employed Americans of working age.

The report also stated that 72 percent of those unemployed persons with disabilities wanted to work. For those in Federal programs supposedly designed to help people with disabilities get to work, less than one percent attempt it every year. Less than 1 percent.

To take an example, a Kansan named John Rowe received SSI benefits every month. John has a disability that requires dialysis treatment three times a week. John has most of his medical care coverage by Medicaid. He had received vocational training and would like to go to work full-time.

The problem is, he would lose his Medicaid eligibility from earnings from a full-time job. It is unlikely his earnings would be enough to replace the medical coverage under Medicaid. So, he also depends on his personal assistance and personal attendant services in his home through Medicaid, and we have a good program in the State of Kansas.

Eight years after the passage of the Americans with Disabilities Act, we have yet to achieve our goals of ensuring the full participation of individuals with disabilities in their communities.

Persons with disabilities could be working if they had access to affordable health care, access to basic care, prescriptions, drugs, or personal assistance services through Medicare or Medicaid.

We say to individuals with disabilities, stay home, do not work, which is not the message that I think, as I have just indicated, most of them want to hear. As a matter of public policy, this is senseless and unjust.

Through the principles of S. 1858, we have the opportunity to set the right policy and change the message to Americans with disabilities, if you work, your government will provide you with access to the health care you need until you can afford to pay for it yourself. It is sort of long for a bumper strip, but it is the message I think we ought to be sending. Now, the power of such a statement is unquestionable. The potential of such a law is unlimited.

I remember the first speech I ever made in the Senate, way back in 1969, was on disabilities, disability issues and people not being able to work. Here we are, almost 1999, 30 years later, and I am not so certain, even though we have tried, that we have made many improvements.

There are still the same people I talked about in 1969, maybe a different generation, that are still not able to work because they have a disability and they cannot give up their benefits, or they give up their benefits and they cannot make enough to pay for benefits or for the things they lost.

So, I want to commend Senator Jeffords and others for their hard work. I might have a couple of suggestions for the committee.

Senator CHAFEE. Well, we would look forward to those suggestions, Senator, because obviously you have been deeply involved and have given this a lot of thought over many years.

Senator CHAFEE. I just am so taken with what Senator Jeffords said in his statement that, if they do not go to work, these individuals get the benefits. So if they go to work, there is income to the Federal Government through taxes. I cannot understand why they should not continue with some kind of medical coverage, Medicare, Medicaid, or some portion of it, and I cannot see how the Federal Government loses money in the deal.

Senator DOLE. Well, in fact, I think the one thing they have not recognized that Senator Jeffords pointed out, is that people are going to make money and they are going to pay taxes. That ought to be offset of whatever the total cost is presumed to be. I think it is a little high, frankly. It ought to be that much deducted from that cost. But it is sort of, follow the money, stay home, do not work, which is not the right attitude.

Senator CHAFEE. Senator Jeffords?

Senator JEFFORDS. Yes. Well, thank you, Senator. I do not know what I would do without your support all these years, and for many things. I deeply appreciate your being here today. It is incredibly important to us.

Just to go back on the question that Senator Chafee asked, the only way you could do that is to say, well, if they had gone to work and were not getting benefits, we would not be paying the benefits and, therefore, we save money. But they forget to ask the question, well, what if they cannot go to work? So it is a bizarre, circular argument.

But I think we can make progress this year, and certainly, with your help and support, I believe that we have a time where the economics of the Nation look pretty good. And if it looks pretty good for the Nation, why do we not make it look good for the disabled who want to work? So, I thank you very much for your statement.

Senator CHAFEE. All right. Senator, I know you have—

Senator DOLE. No. I get paid whether I am here or not, so I will just stay here. [Laughter.]

Senator CHAFEE. All right.

Senator DOLE. I want to hear what Senators Kennedy and Harkin have to say.

Senator CHAFEE. All right. Now we will hear from Senator Kennedy, who has, of course, been so active in this area for many, many years.

Senator, we salute you for the work you have done, and look forward to your testimony.

#### STATEMENT OF HON. EDWARD M. KENNEDY, A U.S. SENATOR FROM MASSACHUSETTS

Senator KENNEDY. Thank you very much, Mr. Chairman. First of all, I want to express appreciation to you for having these hearings today on the eighth anniversary of the Americans With Disabilities Act.

It is a clear indication of your own strong interest on the issues we have before us today, and obviously as a key member on the Finance Committee your support, and help, assistance, and encouragement is invaluable in this effort.

I want to pay tribute to my friend and colleague, Senator Jeffords, who has been tireless in the fashioning and the shaping of this legislation. He was very much involved as we were making the battles for the ADA, and this is really a continuation.

I think, along with Senator Jeffords, there was a recognition that, as we were developing this legislation, that if we were really going to carry through the ideals, the hopes, and the dreams of the ADA, this was really an essential part of it.

For all of the reasons that ADA was important, this is a compelling case as well. When we think of ADA, I think all of us in the Senate take our hat off to Tom Harkin, who was the leader in our committee in the fashioning and the shaping of the legislation, the floor leader, and has been such an important leader in terms of disability issues, going back to Senator Weicker and others.

But this has been a strong, bipartisan tradition in the Senate, and I pay tribute to him here today as we are coming into what

I hope will be really the last thrust of, hopefully, a successful legislative initiative.

I was listening, too, with Senator Dole. I think he would know ways, and perhaps he can counsel us, about how in these final days we can make sure that this legislation is achieved and accomplished.

I believe that it can be, with the kind of broad support that we have from the community, so many of whom who are here today representing families, representing community leaders, representing teachers, representing parents who have been so much a part of this whole kind of effort. We are so glad that so many of them are here.

Just, finally, I want to thank Senator Dole. I think he will remember when we were considering ADA, one of the last meetings we were in his office. It was a rather stormy one, at that. And Senator Harkin was there, and Governor Sununu, representing President Bush.

The basic issue was the scope of ADA, and also the kinds of enforcement and the penalties were there. As we spent a number of hours, that was a really crucial meeting. It was in Senator Dole's office, and his involvement at that time, in particular, is one that I will always remember.

It was really the final important meeting prior to the time that we were able to see this whole legislation on ADA move to the floor. So, I think all of us share your own tribute to the Majority Leader, Senator Dole, for all of his work.

Senator CHAFEE. As I recall, you did not spend that much time in Senator Dole's office, did you? [Laughter.]

Senator KENNEDY. Well, now, wait a minute here.

Senator DOLE. I had to persuade him on many things.

Senator KENNEDY. No. Remember, we got into the Civil Rights Act of 1991, and other kinds of things. [Laughter.]

Let me just take a moment, Mr. Chairman. I think I want to join in commending the President for his strong statement for the efforts that are being made here, the statements that he made today.

So I am very, very hopeful that, with all of this coming together, that we can carry forward the rather important and continuing effort that this Nation has made in terms of freeing ourselves from forms of discrimination.

We have made important progress in many areas, and the area of freeing ourselves from discrimination against the disabled is one of the really most important ones that we have really faced, and we have been making enormous progress in the very recent years.

This, I think, as both you, Mr. Chairman, and Senator Jeffords have pointed out, when we know that more than two-thirds, close to three-quarters, of all of those that have some disability want to work and desire to work, to be part of our whole kind of mainstream in society, to make a contribution on behalf of their families, to their families, and to their communities and the Nation, that the way that this legislation has been fashioned in terms of the maintenance of the health care provisions, the phasing out of the income provisions, and the kind of services that can be so important in terms of pharmaceutical and personal assistance, is really the kind of combination which can give the independence of liv-

ing and the freedom for so many of our fellow citizens, that I think a powerful, important, and generous Nation should be involved in doing so.

You have made the case compellingly about what the real economic implications would be of a successful effort, and it seems to be self-evident, Mr. Chairman, about the savings and what will be contributed by those members of the community.

I am just hopeful, Mr. Chairman, that, as we know, there are many items, as we meet in these final days, that perhaps divide the Senate, that this one here is one that all of us ought to be able to get behind and assure its success and passage.

We are so close to its completion and so close to the realization of the dreams which this legislation can mean, that I would hope that we can leave this meeting here today and find the common ground to make sure that we are going to have this legislation.

It will mean, really, a lifeline of hope and will fulfill the dreams of so many of our fellow citizens if we are able to do it, and I think this is a really central challenge that we should achieve.

I will look forward to working with the Chair, Senator Jeffords, and our other colleagues to make sure that it is done. I thank the Chair very much.

Senator CHAFEE. Well, thank you very much. Thank you very much, Senator Kennedy, for that excellent statement.

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

Senator CHAFEE. Now we will hear from Senator Tom Harkin from Iowa, who, as was mentioned before, was the lead individual in connection with the Americans With Disabilities Act, going back some years ago, and has been so active in these areas for many, many years. And it has been my privilege to have worked with him in connection with children's issues.

So, Senator, we welcome you and look forward to your statement.

#### STATEMENT OF HON. TOM HARKIN, A U.S. SENATOR FROM IOWA

Senator HARKIN. Thank you very much, Mr. Chairman. I would ask that my full statement be made a part of the record also.

Senator CHAFEE. Certainly.

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

Senator HARKIN. Let me join with my two colleagues here at the table in, again, thanking you, Mr. Chairman, and also Senator Jeffords, for your long-time leadership and support of issues that are important to all of our citizens with disabilities.

Of course, I have worked with Jim going clear back to the House days on committee work on this for many, many years, and more recently with you, Mr. Chairman. But I know that you have fought very hard for these issues. You have been a tireless advocate for people with disabilities, and I really appreciate it.

Of course, it is a distinct honor and privilege to be here with both Senator Kennedy and Senator Dole. I was just thinking, Senator Dole gave his first speech when he came to the Senate in 1969 on disability policy. It is a great speech; I recommend it to everyone. I was in law school at that time. [Laughter.] I was an older law

school student, if that makes you feel better. [Laughter.] I was older when I was in school. He was my teacher.

But then to be here to serve with both of these individuals who have just led the way on breaking down so many barriers in this country that kept people out of the mainstream of society, whether it was based on race, gender, religion, sexual orientation, or on the basis of disability policy. So, it is a distinct privilege for me to be here with both of them.

In fact, I was just looking at the five of us here. I thought, I am sure that Senator Kennedy would not mind if the five of us could decide disability policy. This is one time I would not mind being in the minority. [Laughter.] If they would just leave it up to us, we could do it.

On this issue, though, this is just so crucial. As Senator Kennedy said, three-fourths of people with severe disabilities are unemployed; eight million people between 18 and 64 are on SSI or SSDI; less than one-half of one percent of these people return to work every year. Less than one-half of 1 percent. It is really unconscionable.

Now, the ADA, as Senator Dole has said, has really worked well. Obviously there have been some bumps in the road, of course, as there is with any major civil rights legislation like that. But it has worked wonderfully well.

My nephew is an architect, and he said to me about a year or so ago, we are finally designing buildings in this country like we should have been designing them. The whole structure of design, for example, has changed just because of ADA.

So, just think, from this point forward, that we will not have those problems with narrow hallways, doors, and bathrooms, and things like that. So that is just one aspect of it.

For those who say, however, that maybe there have been some problems with ADA, and how do you measure some of the success, maybe we have not been as successful in terms of employment, it is very hard to measure hope. But what ADA has done for the young people of this country, young kids with disabilities, families with kids who have disabilities, is it has given them hope.

We now see a whole new generation of younger Americans coming along who are going to school, studying harder, dreaming to be engineers and scientists and things like this that they had never dreamed of being before because they did not see that there was any future for them because they had a disability.

So I think we are going to see the impact of ADA be even larger in the next 10 to 20 years. But if ADA is going to work, it has got to work in all of its aspects. It has worked so far in terms of accommodations and things like that, but if it does not work in terms of getting that person to a job and back, then really it is not working. So this is just the last kind of little thing that has to be done to make sure that the entire ADA works, and works effectively.

Again, I agree with both of you, Mr. Chairman and Senator Jeffords. How can it cost more money? How could this possibly cost more money? You are paying for it anyway. It would seem to me that it just makes not only sense in terms of the civil rights and the aspirations of people with disabilities, but just dollars and

cents to get people to work, have them paying taxes, and then keep up the medical care.

Right now, 80 percent of Medicaid long-term care dollars are spent on institutional services, yet the vast majority of these people would rather live at home, rather be on the job. Most of these people can be served more effectively or more economically in their home or community-based setting.

After the ADA passed, I said at the time that the next big hurdle is going to be personal assistant services. It has got to be something that enables people with disabilities to get out of their homes, get out of their community-based setting, and get to a job.

Speaker Gingrich introduced a bill this year to address this problem. It is called MCASA, the Medicaid Community-Based Attendant Services Act. MCASA's goal is very simple: a person with a disability, not the government, should be able to decide whether that person lives in an institution or at home. Now, Speaker Gingrich and I do not agree too often on many things, but on this issue I could not agree with him more.

MCASA would require States to provide personal assistance services to any individual who, based on functional need, is currently entitled under Medicaid to nursing facility services or intermediate care services for the mentally retarded, but this person requires personal assistance services in order to live at home.

Under MCASA, the money would follow the person. You said, the person is following the money now, because they stay at home. In MCASA, the money would follow the person rather than under this present system.

It recognized that if we are going to stop forcing people into institutions against their will, we need to make changes, real changes, to our Federal laws and it is an excellent starting point.

It has got some problems. It is a complex issue. I know it is going to require further review. But to me, the first step towards implementing that is what you have in front of us here, S. 1858. This is the first step. If we can get this through, then I would be able to lay the pathway for something like MCASA to work, or something perhaps a little bit different, but along those same lines.

It would seem to me that, sitting in this room, we have got some of the best minds in disability policy here, and right here in back of us. I would think, working together, we could develop a bipartisan legislation to address this critical problem of the money following the person, letting the person decide, should I live at home, in a community-based setting, or in an institution, but let the person decide that.

Then, when that person decides that, make sure that that person has, under this bill, S. 1858, all of the medical services that person would otherwise get, living in a nursing home, or at home, or a community-based setting so that person can get to work.

So I see this bill as crucially important to getting to the final step of making sure that we have personal assistance services for all persons with disabilities so that ADA, in all of its aspects, will be a reality.

Thank you very much, Mr. Chairman.

Senator CHAFEE. Well, thank you very much, Senator Harkin. You have given us some good goals to seek to achieve. Like every-

one who has spoken today, I hope we can get this legislation passed this year.

I must say that, with times so prosperous, it is a good time to get a bill like this rolling and where the job opportunities are there for the individuals, should they go to work.

Senator Jeffords?

Senator JEFFORDS. No further comment, but to just thank my good friends, all three, for their tremendous help today. I feel good and I hope all America will feel good when we are done. Thank you.

Senator CHAFEE. Again, thank you all very, very much for coming. We appreciate it, and your testimony.

The next panel will consist of three individuals. Mr. Alan Bergman is the director of State-Federal Relations for the United Cerebral Palsy Association.

Mr. Brian Irish is from Burlington, Vermont. He was injured in an automobile accident 10 years ago and returned to work several years ago, but the impending loss of his Medicare coverage and his SSI cash benefits led to his leaving the job. He is now working only intermittently, and will be able to provide a personal viewpoint on work incentives for the disabled.

Nancy Becker Kennedy is from Los Angeles, California. She suffered a diving accident in 1972. She subsequently received her Master's, was employed as a producer for PBS. She worked as an actor and playwright, and now focuses her energies on disability causes.

All right. Mr. Bergman, why do you not start?

**STATEMENT OF ALAN BERGMAN, DIRECTOR OF STATE-FEDERAL RELATIONS, UNITED CEREBRAL PALSY ASSOCIATION, WASHINGTON, DC**

Mr. BERGMAN. Thank you, Mr. Chairman, Senator Jeffords. My name is Alan Bergman. I have submitted a lengthy statement, which I am sure will be incorporated as part of the record.

I am currently employed as director of State-Federal Relations for United Cerebral Palsy Association here in DC, and I bring the perspective of 31 years of working in this field and the perspective of being the father of a young woman with disabilities who is in the workforce, and a 25-year-old stepdaughter with severe and multiple disabilities who is contributing to her community in a very responsible fashion every day in return for her public benefits.

I am here to endorse S. 1858 as a major step forward to remove barriers for people with disabilities who want to work to be able to work. This issue is bipartisan and, as has been stated earlier, we were pleased to learn this morning and acknowledge the President's support to work with the Senate in crafting this legislation and making it a reality this year.

In my formal testimony, I have walked you through the origins of the SSDI program, the Medicare program, SSI, and Medicaid, and I think there are a couple of salient issues we need to remember.

SSI is not means tested. It is an entitlement program based on paying in or being the son or daughter of someone who has paid in. In Medicare, a couple of the health care benefits that people



with disabilities often need—prescription drug coverage and non-medical personal care, or personal assistant services—are not part of the menu, and many people need those, either singly or in combination.

SSI, on the other hand, is a means-tested program, a poverty program, if you will, and it is different, therefore, from SSDI. Medicaid, in turn, is currently, for the most part, a means-tested program on income assets and resources, and States have lots of choice about what they can give outside of a core benefit package, and some of the optional benefits, like prescription drugs, personal care therapies, et cetera, vary across the 50 States.

Last year in the Balanced Budget Act, you made some effort to change the means testing by allowing States, as an option, to increase up to 250 percent of the Federal poverty level for Medicaid benefits for people who met the SSI disability test and were working, and to impose a sliding scale for cost sharing. I think it is very important that we differentiate cost sharing from means testing.

What this opportunity represents for us, is changing the disability paradigm. SSDI was 1956, SSI was 1972. In those days, the expectations and the notions of severe disabilities were not around gainful employment.

In fact, the definition in the statute around substantial gainful activity implies, basically, that people with severe disabilities are not of the capacity to earn \$500 per month.

Clearly, we know, based on real-world experience, that that is an outmoded notion and we have to now begin to remove the barriers that have created the reinforcement of that perception.

As you will hear from the other two witnesses, people with disabilities want to work. People with disabilities are capable of remunerative employment. With the techniques of job accommodation, job restructuring, job sharing, and the use of assistive technology and devices, people with the most severe disabilities can, and are, working.

We need Federal policy that makes work pay and recrafts this ability from a policy of paternalism and dependency to one which is based on economics, empowerment, contribution, and independence.

You have heard the statistics by Senator Chafee about the eight million folks. You have heard Senator Dole and Senator Kennedy reveal the National Organization on Disability recent poll that only 29 percent of non-institutionalized working-aged adults are working, compared to 79 percent of the regular, typical population. Yet, 72 percent of those folks who are not working say they want to work. What is wrong with the picture?

In the further National Organization study, among those persons with disabilities who are insured, on point of this particular legislation, 32 percent said they have special needs because of their disabilities, such as therapies, equipment, or medicine that are not covered by their health insurance from their employer.

Among adults with disabilities who are not covered by health insurance, 18 percent were still not able to get insurance because of a disability or a preexisting health condition, in spite of the Kassebaum-Kennedy legislation.

These confirm for us that health care and employment are critical for people with disabilities. Then we have further problems if we look into the employer insurance, because most people with disabilities are more likely to become employed by small- or medium-sized businesses who are not having the capacity to spread risk around large employee pools. Yet, that is where the new jobs are being created in the current economy. Or people work part-time or on an intermittent basis. So, looking to the employer insurance as the end-all and the be-all will cause great problems as well.

So, continuous and affordable access to Medicare and Medicaid is absolutely essential if we want to assure equal opportunity for people with disabilities to join the workforce and be contributing.

The linkage, in summary, of SGA—Substantial Gainful Activity—to access to Medicare and Medicaid represents the outmoded policies from the 1960's when severe disability was a synonym for helpless, hopeless, home-bound, and eternal dependency.

We have heard that times are booming. The moral and economic imperatives of 1998 demand that we shift our income support and health insurance public policies for people with disabilities to one that is consistent with the wishes, needs, and increased expectations of people with disabilities and the tenets of the Americans With Disabilities Act.

This foundation, along with other provisions in S. 1858, move us toward a 21st century policy that will begin to make severe disability a new synonym for personal responsibility, choice, empowerment, interdependence, contribution, and economic self-sufficiency. The time is now. Thank you very much. I will be happy to answer questions.

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

Senator CHAFEE. Well, thank you very much, Mr. Bergman. Now, Mr. Bryan Irish from Burlington, Vermont.

#### **STATEMENT OF BRIAN IRISH, CONSUMER, BURLINGTON, VT**

Mr. IRISH. Hi. My name is Brian Irish and I live at 65 South Meadow Drive in Burlington, Vermont. I am a 34-year-old, and I have been disabled with a spinal cord injury since September 21, 1985.

I had worked full-time jobs since 1981, when I was 17. In fact, I worked two full-time jobs from the time I graduated from high school until my injury, which was caused when I fell asleep on the way home.

I have received Social Security Disability benefits for many years. One of my employers kept me on part-time, even after my injury, in order to keep my health coverage. However, they needed a full-time worker for this position and, since I would lose my SSDI and health benefits, I was forced to quit, the first job I had ever quit.

I was disappointed to learn that if I earned over \$500 a month, I would lose my Social Security check of over \$700 a month, plus my medical benefits. After my trial work period ended, I had to choose not to work, although I can work, I want to work, but cannot afford to work. I would be losing money. So, my only choice is

to stay out of the work field to keep my medical benefits and an income I can live on.

To get myself back to work, I have been through many college courses in computer science, have used Social Security Plan for Achieve Self Support, which is called PASS, even though I have been through a lot of occupational and physical therapy and have done everything else to help myself get back to earn a real income and off the public rolls.

To keep busy, I have taken up biking, horseback riding, and serving on the State Attendant Service Program Eligibility Committee, and making candles which I sell to make a few extra dollars without putting benefits at risk.

I therefore think a lot of time and money was wasted on me the way things are standing now. If it changes as the Work Incentives Improvement Act is written, I would be able to pay my fair share of taxes and to return some of my SSDI income to the government, due to the increased opportunity to earn money. It would help a lot of people in my situation be able to work and create a win-win situation for them and the government by making them taxpayers.

Thank you for this opportunity to testify.

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

Senator CHAFEE. Well, that is a very good statement.

Now, Ms. Nancy Becker Kennedy, from Los Angeles, California.

**STATEMENT OF NANCY BECKER KENNEDY, CONSUMER,  
LOS ANGELES, CA**

Ms. KENNEDY. I came to Washington half my life ago to talk about a woman named Lynn Thompson. Lynn had a problem faced by most people with disabilities, a problem we still face now. Lynn was unable to work without losing her health care benefits she needed to live outside of an institution. Lynn Thompson had muscular dystrophy and could only move one finger. She used it to get a job where she earned \$400 a month scheduling nurses for a nurses registry.

There were articles in the newspaper about how happy Lynn was to be employed and how happy her employer was with the job she was doing. Lynn proudly paid her taxes that year, and that is where the happy part of the story ends.

The IRS computer told the Social Security computer, and Lynn received a notice that read like a death sentence to her. The letter from Social Security told her that she would be losing the attendant care and Medicaid that allowed her to live independently in her apartment.

That meant Lynn would only be able to receive these life-support services in an institution. Her apartment and her job would become a thing of the past. The future, without them, was unbearable for her.

Lynn gave her attendant the night off, took a bottle of pills and alcohol, and, while waiting to die, left an audiotaped suicide message. She said, "Tell Social Security I overcame everything, but you were the straw that broke the camel's back."

I was interviewed on 60 Minutes that year, talking about Lynn's death, and came to Washington to join an effort to change the law that threatened all people with disabilities who tried to work.

That law said that, regardless of your true physical disability, if you earned over \$300 for nine non-consecutive months, no matter that that was nowhere near enough money to support a life with a disability, you were no longer considered disabled by Social Security and, therefore, ineligible for attendant services or medical care.

As a 24-year-old just out of college after my injury with a Master's degree, I was terribly thwarted trying to find a job that would pay enough for my extraordinary medical expenses.

Let us look at the math of a life where electric wheelchairs can cost \$11,000. A flat tire on that wheelchair, \$200. Then there is that \$6 pill taken four times a day for chronic bladder infections that come from \$12 indwelling catheters. And if you happen to need a respirator for \$3,000 a month, you had better start pulling down the salary of a corporate CEO if you plan to make enough money to support the expensive habit of being disabled.

Not everyone needs a respirator, but when you do the math you can easily see that, to cover all these needs and pay attendant services as well, one must make a very handsome living to pay for all of this without some assistance.

It was not only hard to find a job that would pay for my disability, but there was the very real fear that the cliff Lynn Thompson rolled over by working for nine months was waiting for me if the job I was lucky enough to get ever ended.

That Sunday night on 60 Minutes when the sound of Lynn's tape recorded suicide message so shocked and saddened the viewing public, our efforts in Washington to change the law accelerated, finally resulting in the addition of Section 1619 to the Social Security Act.

Section 1619 created an elegantly simple and infinitely more sane way to deal with the problem of people with disabilities who wanted to work. It provided a sliding scale of benefit reductions that allowed us to receive attendant and medical services until we made enough money not to need them.

This ushered people gently to independence, and if you lost your job, you were still considered disabled if you were still disabled. Senator Bob Dole, along with others, had a great deal to do with the passage of the 1619 provision to the Social Security Act. And what may sound like a couple of numbers to some sounded like a Liberty Bell to people with disabilities who wanted to work.

Unfortunately, as some of us went on to work for years and to pay into the system, we automatically converted to SSDI eligibility, a program that was supposed to be a superior benefit that rewarded years of work.

But it did not work that way for me, or others like me. There is no 1619 sliding scale on SSDI. It is nine non-consecutive months in 5 years, and you are out, no matter how little money you make or if the work continues.

This year, I was thrown back into the situation I faced as a 24-year-old girl. Once again, it is all or nothing. After 9 months, I will have been miraculously cured of my disability: not in reality, but according to Social Security. I still see a wheelchair. Do you?

I never liked the term "work incentive" because we have never needed an incentive to work. We only needed a way to not to com-

mit a kind of red tape suicide that would remove us from an independent life in the community if we tried to work.

The Jeffords-Kennedy Work Incentives Improvement Act could be the beginning of an end to the dangerous game of "chicken" we play with our freedom when we attempt to work.

The Work Incentives Improvement Act could soon untie us from dependence on cash benefits and welfare. Without this bill, we are trapped in a cycle of poverty and shame. With no chance to participate, we are beached on the sidelines. If we can figure out how to contribute productively without being paid, we still feel handicapped—cap in hand—without the pride of a paycheck or taxes being paid.

Relegated to the fringes, no matter that we are educated, no matter that we are talented, no matter that we are determined, we do not get to participate in contributing. The gulf we have to jump is just too wide.

The Bible says, "Lay not a stumbling block before the blind." Should that not go for people with disabilities as well? Well, this is that stumbling block.

We cannot risk losing the attendant care and health support services that allow us to live in the community, because if we dare to make money and we do not make enough of it for long enough, or if we have to stop, we will be pushed further away from society into nursing homes, those waiting rooms for death, where taxpayers spend several times the cost to take away our freedom.

The current policy makes it seem like benign neglect, but it is, in fact, very cruel, very definite, and effective segregation that divides us from the mainstream of society.

On this even of the eighth anniversary of the Americans With Disabilities Act, our Bill of Rights is not worth the paper it is written on if only one-half of one percent of us a year can take an active part in the life of this community.

I am more weary than I can express of this 26-year struggle, as my disabled brothers, sisters and I pay for our survival with our failure. I want Lynn Thompson's enterprise to be rewarded posthumously. I want her despair to be corrected. I want her life to have mattered. Pass the Work Incentives Improvement Act and let people with disabilities this country the gifts we have to offer. Thank you.

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

Senator CHAFEE. Well, thank you, Ms. Kennedy. That was very moving statement, and we appreciate your coming here all the way from California to testify, and testify so ably as you did.

Mr. Bergman, I would like to just get into the 1619 program, which I am sure you are very familiar with. How has that program been working? Perhaps you could delineate some of the principal inadequacies of it, one of them being, I think, the home care assistance, is it not?

Mr. BERGMAN. Thank you, Senator. I think that is one. But I think, let us start with the 1619 A and B program as they were legislated. To the average person with a disability, they appear to be very complicated, bureaucratic, paper-driven. We still continue to hear reports from the field that folks in the local Social Security

offices do not understand it, do not know how to help people get through the process. Again, I think part of this goes back to this paradigm.

And Nancy said it. I mean, people with disabilities are seen as dependent, are seen as not capable of work. That paradigm exists, in all due deference, in the Social Security Administration culture. It is part of the perception.

So, you work very hard to establish eligibility by saying you are helpless and hopeless and so severely disabled, and then you turn around and come back in a month or two later because you have heard about something called work incentives and you try to fill out papers for 1619 A and B. So, that is sort of the bureaucratic piece.

Then it is, what is the benefit package that you are going to be entitled to continue to receive as you move into the work incentive program? Medicaid, again, varies from State to State, as you well know, with the core benefits, and then the 34 optional benefits.

Thirty-one States—both of the Senators at the table's States—offer personal care. But, again, how the State defines it, is it a medical model, is it a nursing model, the amount, scope and duration still might not be sufficient for that particular individual with a disability to get what they need in order to be able to return to work.

Ms. KENNEDY. Mr. Chafee, may I add something about 1619?

Senator CHAFEE. Sure.

Ms. KENNEDY. Our primary problem is, it does not apply to SSDI. I benefitted from 1619. You see, what happens is, when you work on SSI for several quarters, you involuntarily convert to SSDI because you have paid so many quarters into the system.

So, instead of being rewarded from all that money being taken out of my paycheck and paying into the system, I was penalized, because once I converted to SSDI, there was no 1619 benefits reduction and there was, again, the nine-month SGA, which meant after I worked for nine non-consecutive months, I was no longer considered disabled and would lose everything. So the main problem with 1619 is, it stops at SSI and does not continue on to SSDI.

Mr. BERGMAN. And if I can add, Senator Chafee, one of the provisions in the bill is to authorize the Social Security Administration to do some demonstrations around the SSDI, what we call, income disregard, the two-for-one slide down. That would be a very important provision to keep in the final legislation, if we cannot make the shift immediately to at least create some data sets to show what Nancy is reflecting here.

Ms. KENNEDY. And then the elder workers, I believe there is already a model there. Elder workers have a three-to-one benefits reduction and their health care, so this would be just a two-to-one benefits reduction for—

Senator CHAFEE. That is under 1619, you are talking, is it not?

Ms. KENNEDY. Under 1619 there is a two-to-one benefits reduction. In this bill, it calls for demonstration projects to show the cost effectiveness of the two-to-one benefits reduction, which I think would be very, very useful.

Senator CHAFEE. I will address this to Mr. Irish, and to you, Ms. Kennedy. Two of the factors that discourage disabled individuals

from going back to work are, one, the potential loss of health benefits, clearly, and that has been touched on. And, under SSDI, the sudden loss of cash benefits when you earn more than \$500 a month.

Ms. KENNEDY. Yes.

Senator CHAFEE. Of those two, which is the most discouraging for disabled workers going back to work?

Ms. KENNEDY. Right. The other extremely important piece is the attendant services. We cannot live without the attendant services and the Medicaid that pays for our pharmaceuticals, and the Medicare that pays for our doctors, and our wheelchairs, and our durable medical equipment.

As far as the cash benefits go, that is also very difficult. The nice thing about a two-to-one benefits reduction, is you get some benefit from working. You might have \$300 more a month to live on than poverty level.

Instead of living on \$640 a month, I might get to live on \$900 a month, which would be a lot easier to make ends meet. So, in the demonstration projects of the two-to-one benefits, that would be extremely useful and I would like to see that picked up nationwide as soon as possible.

The primary problem is that, when you work for nine months, you walk off the cliff. You are not considered disabled anymore. So the scariest provisions are losing our attendant care, losing our medical care, and walking off a cliff after 9 months.

Senator CHAFEE. Let me ask, Mr. Irish, what are your thoughts?

Mr. IRISH. Personally, for me, is I believe the health insurance, and I also believe that getting back into the workforce, you are like everybody else. You can start at the bottom of the scale, like anybody else starting a new job.

I think that if we had health insurance—me, personally, this is my opinion—that right there is enough to keep me into the workforce where I would continue. That was the only thing that stopped me from working before, was they canceled my health insurance.

I can do without the income, because I love the work and I would start at the bottom and work my way up, just like anybody else. But number one is, I could not live without having somebody to help me pay for my wheelchair, or Roho cushion that pops every 6 months, and you are spending \$475 to get a new one. I mean, there is no money in my—

Ms. KENNEDY. Here is a story problem that might be kind of easy to follow. Before I used up my nine-month trial work period, and now I do not dare work, but I was just speaking at the Very Special Arts Conference this weekend.

Before I used that up, I used to make \$2,000 a lecture. I was offered eight lectures this weekend, which I will not be able to take because I will lose my attendant and my medical care. But if this bill passes, I could take that, and eight times, that is \$16,000 I would not be receiving in cash benefits, and paying in taxes.

So, I think in terms of the government, is it more costly to pay my full fare, to pay my cash benefits, or to just pay my attendant and medical care and let me pay my own cash? I can cover my own cash and I can pay taxes. I think that is a savings and it allows me to be productive.

Senator CHAFEE. Makes sense to me, I must say.

Mr. BERGMAN. It is a no-brainer, Senator.

Senator CHAFEE. I do not know where the disconnect is.

Senator Jeffords?

Senator JEFFORDS. Yes. I would just follow up on that. There seems to have been built in here a certain assumption of a large amount of fraud to happen, or something. So we have to, first of all, protect against something we do not even know is going to happen, so we make all these rules to make sure it does not happen, and you cannot go to work.

Ms. KENNEDY. That is what I hate about us being on welfare. The VA has a model of percentage of disability, and then you get your attendant and medical care for life. By being put on welfare, the things that get rid of fakers and the people faking a bad back are the very things, the same detector, that would pick up on a disabled person getting to work. A disabled person who has some ability to work looks like a faker, according to a welfare system. That is our problem.

Senator JEFFORDS. Mr. Irish, I want to thank you for coming down, very much. But it intrigued me that we apparently have all these programs to make you employable, and you can go out, you can learn, and you can do all these things, but then when you go to work, you cannot because you lose the benefits which you need in order to be able to go to work.

Mr. IRISH. That is just it. If you look at what the State has done for me, between paying for college, paying for my equipment to get my van so I could get back and forth to where I go, and all the counseling and stuff, and all the time they spent at my employer's place rearranging their building to make it wheelchair accessible, when they voluntarily did this, this was before the ADA became involved in this, and all the time they spent, that is all the State and government money they spent on me to try to get me back to work.

Then when I finally do get back to work, they say, well, you know, you lose your insurance and you lose your income. I could have dealt with losing my income, because I was \$2 above what they were giving me at the time. But the insurance, I could not afford to do.

Senator JEFFORDS. What was the response of your employer to all this; did they just throw their hands up and say, I cannot believe it?

Mr. IRISH. Yes. They tried all they could. They even cut back my hours and said I was only working some so that I could keep my medical benefits. But then, when it turned out that they had to cut back more, they just said they could not bend over any more.

Ms. KENNEDY. We ask the people who try to help us, employers, we ask them to pay us \$498 a month. That is why maybe the CBO thinks that is all disabled people can make. But people try to help us, and we hobble ourselves. We try not to succeed very much because we will end up in nursing homes at many times the cost of the taxpayer, and with us being deprived of our liberties.

Mr. IRISH. Think about, if I would have kept that job, if they would have just given me my medical benefits right now, I would be on salary, I would have full benefits from the company, which right now I would not be taking any money from the State or the



government at all, period. This is over 12 years ago. So, you figure, for about 11 years they have been paying me that, and they would not have even had to.

Senator JEFFORDS. Now, let me get to the health care eligibility side of it. Obviously what you are saying is, you are in a position where you cannot really get, or the employer cannot insure you because of your disability problems. Or why is that, why could they not insure you?

Mr. IRISH. Well, it is a time period. They have a policy where any new employee that comes into the workforce at their company, they keep them there for—they call it like a trial period. You are there for 12 months, and then you are permanent and you get all of your health benefits.

So for the first 12 months, I would have no insurance. After that, the insurance would kick in. Then you get all the benefits and everything.

Ms. KENNEDY. In my case as a lecturer, there is no health insurance for lecturers. For a lot of disabled people who would be self-employed, who would work as much as they could from home now, because of computers and such—I have a friend who does medical billing for corporations and he gets contracts sometimes. Some months of the year he has contracts, some he does not.

But there is no health insurance in a self-employed situation, which is, a large majority of disabled people would be self-employed from home. So, there would be no insurance policies that they could tap into in a large group where they could be hidden.

Mr. BERGMAN. And, Senator, if I could add to that.

Senator JEFFORDS. Go ahead.

Mr. BERGMAN. I think there are problems, depending on what the employer benefit package is. Sometimes the package that is offered is at total premium cost to the employee and it may be prohibitive. It may be one of those invisible discrimination pieces, where a small group says, oh, my God, I take this person on and they are going to blow my experience rating through the roof, in spite of HIPA, in spite of ADA, and whatever. There are subtle forms of not even wanting to hire people because there is not enough risk pool to spread the cost.

Then I think we step into two other barriers, one of which is, even if there is a group insurance plan, it may be a very modest package and it may not have the benefits of coverage that individuals with disabilities need. And even if we get to that step, there is one more hurdle, and that is the definition of medical necessity.

If medical necessity is tightly defined, as it often is in a small group plan, as restorative health care, then a lot of the things that these two folks and many others need probably will be denied by utilization review folks.

Ms. KENNEDY. And that is not to mention the attendant services that no job gives you.

Mr. BERGMAN. Correct.

Ms. KENNEDY. No job pays for the attendant, the person who gets me up in the morning, helps me shower, helps me with bowel and bladder care. No job pays for that.

Senator JEFFORDS. Mr. Bergman, you have two daughters, I believe. Would you share with us some information there with respect to how your daughters have been affected?

Mr. BERGMAN. Certainly, Senator. First, let me start with Deena. Deena currently works for the Federal Government. She has a variety of disabilities. Probably the most common diagnostic label would be mental retardation, but she has a variety of other issues that she deals with as well. Several people have said to me, how come you want to be sure she works in the Federal Government, do you want her to get a good salary? I said, that is nice.

Frankly, the best thing about Deena working in the Federal Government is she has Blue Cross/Blue Shield, just like every other Federal employee, in a very large pool. For part of her issues, she happens to need access to specialists. She goes where she wants. She has a PPO. She has a point of service option. No big deal.

But she also takes some prescription medications, and Nancy made some reference to the costs of some of the medications. Some of those medications are prohibitive. She gets Blue Cross/Blue Shield to offer her, by the mail, 90-day prescriptions for ongoing medications for \$12. So that is really \$4 a month.

She takes about four medications. If we went to buy them at the cheapest discount store over the counter, it would be about \$465 a month. She would not be working, it is that simple, because she could not afford to pay for her prescription drugs, and rent, food, and utilities and be able to sustain her work.

The other thing is, in terms of her personal assistance, there is some help with her activities of daily living. She is currently on a waiting list in the State of Maryland for home- and community-based services, and hopefully, in a year or two, that may happen. In the meantime, she relies on good old dad and other friends to help her with some of that kind of stuff.

But I think what would have been helpful to Deena, if she ever needed it and if this were to happen, is the whole working incentive and counseling assistance program that is proposed in the legislation to help people figure out how all of this stuff can work, and keep it together.

Let me talk about Mindy, my stepdaughter, in suburban Chicago, who has very severe and profound disabilities. In fact, most people would write her off and put her in a nursing home or an institution and forget about her. We have worked very hard to assist her in having a community living situation and a volunteer community placement. Remunerative work, for Mindy, probably is not in the immediate future, but anything is possible as we continue to raise the ceiling on possibilities for people with disabilities. But I am happy to tell you about her because she is not languishing, she is not rotting, she is not segregated. Five mornings per week, she goes and does volunteer work as a teacher's aide in a YMCA preschool in the neighborhood in which she lives. The experiences that she is getting and that she is contributing back to the community are not quantifiable, but they come back like this: the kids love her, the parents of the typical kids who have never seen anybody like her think she is terrific, and what the staff told us last fall, is she is a role model for the preschool kids. This is someone who has the following diagnostic characteristics: a measured IQ of less

than 10, no expressive language, some cerebral palsy, wears AFOs on both her feet, has a seizure order with medication, somewhat limited because we do not want her zonked, so she occasionally has a petit mal seizure at the preschool, and the kids just roll with it because it is now part of their normal experience, and in addition, she wears diapers because she is not toilet trained.

She is giving back. She is returning on the investment which is, I think, the model we are all proposing here. There are lots of ways to measure it. Certainly, for many people it ought to be employment, be it full-time, part-time, or intermittent. For others, it ought to be other ways to give back. Mindy is on SSI, and on Medicaid, and on Medicaid waiver.

Senator JEFFORDS. Thank you. I asked that because I think it is symbolic of most of the people with disabilities, they want to participate in our society. They do not want to just sit by and watch the world go by, and pick up benefits.

Mr. BERGMAN. Absolutely not.

Senator JEFFORDS. I appreciate that very much.

Senator CHAFEE. Well, thank you all very much for coming. We appreciate it. Some of you have come considerable distances, and we thank you for being here.

Mr. IRISH. Thank you.

Ms. KENNEDY. Thank you.

Mr. BERGMAN. Thank you, Senators.

Senator CHAFEE. Your testimony has been very effective.

Now, if the next panel would come forward, please. Mr. Jeff Bangsberg, who represents the Work Incentive Task Force of the Minnesota Consortium for Citizens with Disabilities; Cynthia Fagnoni, director of Income Security Issues at the GAO; and Paul Van de Water, assistant director of the Budget Analysis Division of the Congressional Budget Office.

All right. We will start with Mr. Bangsberg, who is, as I mentioned, from the Minnesota Consortium for Citizens With Disabilities.

**STATEMENT OF JEFF BANGSBERG, MEMBER, WORK INCENTIVE TASK FORCE, MINNESOTA CONSORTIUM FOR CITIZENS WITH DISABILITIES, NEW HOPE, MN**

Mr. BANGSBERG. Thank you, Mr. Chair. I would also like to introduce my wife, who is assisting me here today, Anita Boucher, who also works at Curry Center, which is a rehabilitation facility, and is also Chair of the Work Incentive Task Force, so we kind of work as a team a lot. So, thank you for allowing both of us to be here today.

Senator CHAFEE. Glad you are here.

Mr. BANGSBERG. Thank you. Again, I am here today representing the Work Incentives Committee of the Minnesota Consortium for Citizens With Disabilities, otherwise known as Minnesota CCD. Minnesota CCD is a broad-based coalition of consumers with disabilities, providers, and advocates as well.

We have identified the loss of Medicaid coverage as the number one policy barrier to employment of people with disabilities. In 1995, the Minnesota CCD initiated State legislation which led to

our State's request for a Section 1115 Earned Income Disregard Waiver.

In 1993, the Minnesota legislature passed a resolution urging Congress to remove Medicaid policy barriers to employment for people with disabilities, and that has been forwarded to Congress as well.

This past spring, the Minnesota CCD and the Minnesota Work Incentives Coalition also conducted an informal survey on health care barriers to employment for people with disabilities.

Almost 1,200 individuals with disabilities completed this survey in Minnesota alone. Of this survey, 52 percent of respondents indicated that they would either seek employment or increase their employment if their health care benefits would not be affected.

Of those respondents, 27 percent reported that they are not working and would consider working; 25 percent are currently working and would either increase their hours or seek higher wages if their health care benefits would not be affected.

Neither employer-based insurance, nor Medicare cover personal assistance services or other ongoing supports commonly needed by persons with disabilities. Because such coverage is only offered by Medicaid, many individuals have no choice to limit or forego employment.

As I mentioned earlier, Minnesota has worked with the Section 1115 Earned Income Disregard Waiver request to HCFA since 1995. If approved, this waiver would allow the working persons on SSDI to continue buying Medicaid on a sliding fee scale to obtain coverage for services not covered by employer-based insurance.

Passage of 1858 is crucial because it requires HCFA to consider potential savings across the entire Federal budget rather than just looking at budget neutrality for the Medicaid program when evaluating these requests. This will make it much easier and quicker for States like Minnesota to develop demonstration projects removing these barriers to improvement. Congress needs to give HCFA and SSA a clear message regarding its intent to make work pay.

On the average, Minnesota Medicaid recipients with disabilities who are ineligible for the SSI 1619 B, like was mentioned earlier, have almost \$3,400 per year in acute and primary care expenses paid by Medicaid.

This cost would be reduced for every individual who gains employer-based insurance. Potential savings to Medicare is even higher, since Medicare pays for much of the acute care expenses with the SSDI program now.

Social Security cash payments to persons with disabilities would also decrease as individuals work their way off of SSDI. According to the 1997 GAO report, the average SSDI payment was over \$1,000 per month in 1994. Thus, Social Security could save an average of over \$12,000 per year for every individual who is able to work their way off of SSDI.

Other Federal expenditures would also go down if people with disabilities move off the program, such as food stamps, subsidized housing, and other types of Federal programs.

In the Twin Cities area, the average of housing subsidy is about \$4,700 per person, per year. Everyone benefits from removing policy barriers to employment. People with disabilities would no

longer be forced into poverty by seeking the long-term care coverage they need.

Employers would also benefit from an expanded pool of employees in the shrinking labor market. In addition, they would not be expected to pick up more health care costs than they do for non-disabled employees.

Finally, taxpayers would benefit as people with disabilities reduce their dependence on the government programs that we have talked about. More people with disabilities could become taxpayers themselves and could begin making FICA contributions to their own retirement.

Many people with disabilities across the country are anxiously awaiting the passage of S. 1858 so they can go to work. Others may quit their jobs if nothing is done to make work pay. Congress cannot afford not to pass 1858 this year. Thank you. I also have attachments submitted with my written testimony as well.

Senator CHAFEE. Well, thank you very much, Mr. Bangsberg, for that testimony.

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

Senator CHAFEE. Now we have Ms. Fagnoni, who is director of Income Security at the GAO. We are glad you are here, Ms. Fagnoni. Will you not go ahead?

**STATEMENT OF CYNTHIA FAGNONI, DIRECTOR, INCOME SECURITY ISSUES, GENERAL ACCOUNTING OFFICE, WASHINGTON, DC**

Ms. FAGNONI. Thank you. Good afternoon, Mr. Chairman and Senator Jeffords. Thank you for inviting me to testify on factors affecting the return to work of beneficiaries in the Social Security Disability Insurance 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 one of every 500 DI beneficiaries has left the rolls to return to work.

There are reforms, such as those being discussed today, that have been proposed to help improve the return to work outcomes. These include allowing beneficiaries who work on the rolls to keep more of their earnings, safeguarding medical coverage, and enhancing vocational rehabilitation.

Today, I would like to focus my remarks on factors that working beneficiaries believe are helpful in becoming and staying employed, and trade-offs and challenges that exist in improving work incentives.

My testimony is based primary on our recent report on factors facilitating work for a group of DI beneficiaries. For that report, we conducted survey interviews with 69 people who are receiving DI benefits and working in one of three metropolitan areas.

First, let me describe the factors that disabled beneficiaries told us helped 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 who 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 bi-polar disorder who was an administrative support worker told us a combination of medications and therapy helped her function in a work environment.

Beneficiaries also told us they received encouragement from family, friends, co-workers, supervisors, health professionals. A beneficiary who was HIV positive told us that his doctor was very supportive, even going so far as to write a letter to his employer explaining his condition and capabilities.

A beneficiary we spoke with who had epilepsy noted that his supervisor checked from time to time to make sure everything was all right and that he was not burning out, even suggesting that he take days off, when necessary.

These beneficiaries less frequently cited factors that were deemed critical, and these included having a flexible work schedule, job-related training and vocational rehabilitation services, the trial work period that we heard of earlier, the nine-month trial work period, and high self-motivation.

And, while our study covered a relatively small number of disabled beneficiaries, our study results are generally consistent with published research regarding factors associated with employment for people with disabilities.

Overall, work incentives that currently exist in the DI program appear to have played a limited role in beneficiaries' efforts to become employed. For instance, the beneficiaries we spoke with indicated the amount signifying a successful month of earnings, \$200, was too low, and the all-or-nothing cut-off that others have mentioned, the cut-off of benefits after 9 months, was too abrupt.

Also, respondents were unaware of the work incentives that are currently in place. For example, three-fifths of the respondents were unaware of the option to purchase Medicare upon leaving the rolls.

Now let me turn to our second point, trade-offs and challenges to improving work incentives. 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.

For example, allowing people to keep more of their earnings would make the program more generous and could cause people who are not currently 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 that 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 those off the rolls.

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

Mr. Chairman, this completes my testimony this afternoon. I would be pleased to answer any questions you might have.

Senator CHAFEE. Well, thank you very much, Ms. Fagnoni.

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

Senator CHAFEE. Now, Mr. Paul van de Water, who is assistant director of the Budget Analysis Division of the Congressional Budget Office. We are glad you are here Mr. Van de Water. Will you not proceed?

**STATEMENT OF PAUL VAN DE WATER, ASSISTANT DIRECTOR,  
BUDGET ANALYSIS DIVISION, CONGRESSIONAL BUDGET OFFICE,  
WASHINGTON, DC**

Mr. VAN DE WATER. Thank you, Mr. Chairman, Mr. Jeffords. I am honored to represent the Congressional Budget Office this afternoon at your hearing on the Work Incentives Improvement Act.

On June 1, CBO staff provided your staff with a preliminary cost analysis of the bill. My oral remarks will touch on the high points of that analysis and identify some of the salient issues in improving work incentives for disabled recipients of Social Security and Supplemental Security Income.

S. 1858 would provide work counseling and assistance services to certain working or work-ready persons with disabilities, and also extended eligibility for Medicare to some former recipients of Social Security Disability Insurance.

The bulk of the bill's costs, however, would stem from the extension of personal assistance services and prescription drug benefits under Medicaid. CBO has estimated that in the first full year of operation, some 200,000 people would receive these so-called Medicaid work incentive services, at an annual Federal cost of over \$1 billion.

Ninety percent of this cost would be attributable to the estimated 150,000 participants who would not otherwise be eligible for Medicaid. Although some observers have suggested that CBO's estimate is too high, there is at least an equal chance that the cost of this bill could be higher, still.

About 8 million people between the ages of 18 and 64 collect Social Security or SSI benefits on account of disability, and 17 million people in that age group report a work disability.

CBO's estimate of 200,000 participants under S. 1858 represents only 2 percent of current DI and SSDI beneficiaries, and just 1 percent of those with a self-reported work disability. Clearly, the potential demand for benefits under S. 1858 could be much greater than CBO has assumed.

The uncertainty over the number of potential recipients is magnified by the fact that the bill would leave it up to the States to

decide whether to participate, and to determine eligibility for benefits if they did.

Not only might CBO have underestimated the number of beneficiaries, the estimated cost per beneficiary of the new Medicaid benefits could also be too low. At present, the combined Federal per capita cost of prescription drugs and personal assistant services for those using such services is \$5,800 a year. Under the enhanced Federal matching rate in the bill, the Federal Government's per capita cost would amount to \$7,000.

Not only are prescription drugs and personal assistant services very expensive, but they are also the fastest-growing components of Medicaid. The per capita costs could further skyrocket if benefits were provided to many users of high-cost prescription drugs, for example, protease inhibitors for patients with HIV.

Another frequently asked question is why CBO's estimate of S. 1858 incorporates no offsetting savings in Social Security Disability Insurance, SSI, or other Federal income maintenance programs.

The historical record indicates that prior efforts to improve work incentives in DI and SSI have had no measurable impact. In 1980, when the programs were modified to provide additional work incentives, 3.3 percent of the relevant age group was receiving Social Security or SSI Disability benefits. Today, that figure has grown to 4.6 percent.

Research by analysts at the Social Security Administration shows that few beneficiaries work, that even fewer beneficiaries leave the benefit rolls, and that many of the factors that lead to work are not likely to be influenced by governmental policies. This result is not surprising, in light of the stringent definition of disability in DI and SSI, and the six-month waiting period for DI.

Even if some beneficiaries were willing to forego other Federal benefits if they were assured of Medicaid work incentive services, there is at least an equal probability that some people would limit their earnings and income in order to qualify for these new benefits.

Moreover, S. 1858 would expand the definition of impairment-related work expenses, thus making it possible for some DI beneficiaries to retain benefits they would otherwise lose.

Finally, both DI and SSI benefits would be costlier if the outreach and counseling efforts required by the bill led to more application for benefits. Because these effects are highly uncertain and work in an opposite direction, CBO's cost estimate of S. 1858 includes no offsetting savings in DI, SSI, or other Federal programs.

In conclusion, Mr. Chairman, S. 1858 focuses on a highly important issue: how to structure the Federal Government's disability programs to provide assistance to those in need, create incentives for productive work, and minimize costs to the taxpayer.

Federal policy makers have been striving to reach these goals for at least 20 years, but achieving them all simultaneously has proved elusive because any across-the-board expansion of benefits raises the possibility of additional Federal costs without any guarantee of offsetting savings.

One alternative would be to provide the Social Security Administration with the authority to try out various work incentives, including those in S. 1858, on an experimental basis.



That concludes my remarks, Mr. Chairman.

[The prepared statement of Mr. Van de Water appears in the appendix.]

Senator CHAFEE. Well, you finished right on schedule.

Mr. Van de Water, when you do your scoring, do you take into account—you have heard the testimony here. I suspect you have been here since we started and you heard the testimony from people like Senator Dole, and the other witnesses here, that if they could, they would go to work.

Mr. IRISH, FOR EXAMPLE, WAS POINTING OUT HOW HE HAD BEEN TO WORK. Do you score the increased contributions to Social Security, for example, if the individual was working as opposed to if he was not working?

Mr. VAN DE WATER. Mr. Chairman, I can answer that question indirectly. As I tried to say in my testimony, as Ms. Fagnoni indicated in hers, we believe there are offsetting effects that are likely to occur if a bill such as this one were enacted.

On the one hand, it is certainly true that certain individuals, such as many of those you have heard here this afternoon, might be induced to work and, therefore, forsake receiving benefits and pay additional Federal taxes.

On the other hand, again, as I and Ms. Fagnoni indicated, there might well also be additional people who, because of the more expansive benefits, were drawn into beneficiary status, and that would work in the opposite direction.

Senator CHAFEE. That is the part that I missed. Why would more people be drawn into it?

Mr. VAN DE WATER. If there is one thing I think that history has shown, it is that there is a clear connection between the generosity of a benefit package and the likelihood that those benefits will be claimed by people.

In the extreme, the prototypical example is, say, to compare this country with some of the European countries, for example, the Netherlands, which have had extremely generous disability benefits and have found a very high rate of people leaving the workforce to claim those benefits.

Senator CHAFEE. But I thought our witnesses were pointing out that, if they do not go to work, they get the benefits. If they do go to work, the demand for the benefits would be decreased. In other words, they could make some contribution toward it, or even if the demand remained constant for the benefits, still they are now, through their job, paying in Federal income taxes.

Mr. VAN DE WATER. Well, I have been trying to focus on S. 1858. I think one of the salient features of S. 1858 that has not been emphasized is that, to a large extent, the personal assistance services and the prescription drug benefits that the bill would provide would go to people who are not currently receiving such benefits. If it were simply a matter of continuing benefits to those already receiving them, as has been indicated at various points, the cost issue would be substantially different.

But, in particular, this bill would provide such benefits to people who are currently receiving only disability insurance, that is, not receiving SSI, and, therefore, not eligible for Medicaid, and also to some people who are not necessarily receiving any Federal insur-

ance or means-tested benefits at all. That is where, as I said in my statement, 90 percent or more of the costs of this bill arise.

Senator CHAFEE. Well, I am missing a point here, I guess. Why would more people suddenly become eligible for these benefits because they were thinking about going to work, for example? Where does the increased demand come from?

Mr. VAN DE WATER. I was talking, in my most recent answer, about the specific benefits that are newly created under S. 1858. Those are new benefits, new Medicaid benefits, that would be provided to people who are not currently eligible for Medicaid. That would represent a new Federal expenditure.

Senator CHAFEE. An increased expenditure.

Mr. VAN DE WATER. Yes.

Senator CHAFEE. I get it. So you are saying that, under the Jeffords legislation, the benefits are more generous than they currently are.

Mr. VAN DE WATER. That is correct, because people who are not receiving SSI would be eligible to receive these personal assistance and prescription drug benefits under Medicaid.

Senator CHAFEE. Mr. Bangsberg, I was interested in what you said in your statement about, the employers would not have to pick up any more in health care costs from the disabled than they would for their regular employees. But I do not know. I am not sure how this works. I am curious.

So, a disabled employee goes to work for Employer A, who has a program of health insurance for his employees and he pays \$300 a month per employee, or whatever he pays. You are saying that that would continue, it would be no different for the disabled employee.

Mr. BANGSBERG. Right.

Senator CHAFEE. Now, what would it do to the employer's insurance rating, if you would? Is it more expensive to have a disabled employee on the insurance rolls, or less; how does that work out?

Mr. BANGSBERG. Well, in Minnesota, we have found it to be the case where an employer who offers health care insurance, they must offer it to all their employees, guaranteed issuance. We have been pretty good about that in our State. There is no particular insurance company that I am aware of that will pick up long-term care supports, like personal assistant services, and some of the specialized medications that are necessary, and also some of the special equipment that is necessary. So that is why people find it difficult.

If they were able to get a job and able to get private employer-based insurance, like I think Mr. Irish is explaining, they would not be able to also receive the long-term care supports like the personal assistant services through an insurance company so it becomes cost prohibitive, although you would save money up front with the acute and the primary care from the employer instead of having the State and the Federal Government pay for that through Medicaid.

If I could respond to what Mr. Van de Water was saying in regards to his earlier question. The State of Minnesota was faced with this problem a few years ago, with people rapidly getting on

the personal assistant services program, and why it did not exist in the first place.

Those people were in institutional facilities, so it was not figured that they would be needing these types of services. We have been able to draw a direct cost-effect linkage to the rise of personal care services that come into States, at the same time as a decrease in institutional care.

People do not like to be on the system. It is very cumbersome. I had a 56-page book that I used to fill out when I was on medical assistance, and I am real proud to say I do not have to fill out that book any more. But it is very difficult to be on the system. People do not want to remain dependent on the system.

Senator CHAFEE. Senator Jeffords?

Senator JEFFORDS. Yes. Would you follow up on Mr. Van de Water's testimony, from your experience. Do you think these large increases in cost to the Federal Government are justified, from your experience?

Mr. BANGSBERG. I tremendously believe that they are justified, and I am hoping that the Congressional Budget Office is taking a look at all of the areas of where savings can be made with regards to the subsidized housing, the food stamps, and the investment that we make with vocational rehabilitation, as well as other types of mechanisms that are put into place.

For example, people who are disabled and receive Medicare, they typically end up becoming healthier when they start to go back to work, thus, you have less acute care costs. I think, also, by allowing people to get out of institutional facilities, you start to save money up front.

Not to mention that they are given the opportunity to work, they are starting to contribute not only to society, but to contribute to their health care needs by paying for insurance with their employer. And also, by allowing this whole system to work, really saves money across the entire board.

I would like to see, if possible, for the Congressional Budget Office to address more of the whole area across the board of saving money to ensure that people can retain their health care services.

Senator JEFFORDS. Mr. Van de Water, when you make presumptions, how does that come about? Do you sit around the room and do you say, what do you think, 10 percent, 5 percent, 20 percent? How do you make those judgments on what is going to happen?

Mr. VAN DE WATER. To the extent possible, we try to rely on whatever research has been available. For example, our staff conducted an exhaustive survey of the work that has been done by the Social Security Administration, all its research and statistics and other researchers on these topics. Obviously, in many cases the literature does not give clear answers, and at that point one just has to make an informed guess.

Senator JEFFORDS. Do you have the wherewithal to know, all these people out there who tell us they want to go to work, and be able to ascertain from interviews, discussions, or whatever of a sample group of what the cost would be for those individuals who are desiring to go to work?

Well, certainly there are the survey results, both those that Mr. Bangsberg cited and Ms. Fagnoni cited, that indicate that there are

a lot of people that express an interest in going to work. Our approach tends to be a bit more empirical.

As I said, when you look at the historical record, that despite periodic changes in these programs to try to increase work incentives, the trend towards increasing prevalence seems to be inexorable. The work incentives, despite these survey results, despite the very impressive testimony we heard here this afternoon, does not seem to produce measurable impact when one looks at the data.

Senator JEFFORDS. Well, if it is not going to induce measurable impact, why would it have additional cost?

Mr. VAN DE WATER. Well, for precisely that reason. One provides additional benefits to people who would otherwise not be getting them, and the offsets that one would hope to achieve do not happen.

Mr. BANGSBERG. Can I speak?

Senator JEFFORDS. Mr. Bangsberg.

Mr. BANGSBERG. Historically, people have stayed in or on the programs in the past. I think the problem is that the incentives that are existing today, and used to exist, are really inadequate.

So, therefore, I can understand why the CBO has not come up with those assumptions, historically, because the people are locked into where they are with not wanting to go back to work, based on what you have heard in the testimony, and it really does not help those individuals on SSDI, just SSI. The people who are on SSDI do have a work history, whereas people in SSI do not, most typically.

Ms. FAGNONI. Well, one thing we have found from other work we have done, and I am sure we have looked at the same studies that suggest that work incentives do not play that large a role in disabled beneficiaries' decisions to go back to work, but what we also found was that there were a lot of other factors that have to be in place for people to be able to go back to work.

As our study shows, they need support from their family and friends, often they need vocational rehabilitation services. So it sometimes needs to be a whole package for people to go back to work, and often that package is not there under the current structure.

Senator JEFFORDS. Ms. Fagnoni, based on what you have heard, would providing access to a work incentive counselor who specializes in explaining return to work benefits and supports for individuals who want to work increase the rate of employment of persons with disabilities?

Ms. FAGNONI. One thing we found in our work is that, currently, people tell us, and from talking to Social Security Administration workers, beneficiaries who are going to the Social Security Administration office for information often either do not receive information about work incentives, or, if they do receive it, it is probably difficult for them to absorb at the time they are applying for benefits because the focus is so much on their inability to work as opposed to helping them being able to work.

So part of the problem with, I think, people understanding the work incentives and taking advantage of them is the way the dis-

ability program is structured, how people enter the system, and how the focus is so much on inability to work.

I know SSA feels that they have some efforts under way, through private vocational rehabilitation counselors, to try to get more information out to people about these work incentives.

Senator CHAFEE. I suspect that is a very important part. Now, unfortunately, we are in the final part of a vote over there.

Do you have any more questions?

Senator JEFFORDS. I just wanted to hear Mr. Bangsberg. He just wanted to speak.

Mr. BANGSBERG. Currently, it does take a rocket scientist to figure this stuff out. It is not just SSA, it is also looking at Medicaid and how the State is administering it, and what the counties are doing, and then how you apply for other benefits.

People are often misinformed by many of these so-called experts, because there are so many different avenues of where all these different benefits come into play.

So, if we were able to have a bill like this and have a work incentives assistance office, I think you would see many more people, as was indicated in our survey, that actually go out and seek gainful employment activity.

Senator JEFFORDS. I assume we can submit written questions to these witnesses?

Senator CHAFEE. Yes, if you wish.

Senator JEFFORDS. I think we have to go, obviously, and vote. I just want to thank everyone today who has been here to help us better understand where we are going, although I have some disagreements with my good friend, Mr. Van de Water. I always do. [Laughter.]

Mr. VAN DE WATER. Not always, I hope.

Senator JEFFORDS. But I do appreciate your efforts.

Senator CHAFEE. Thank you all very, very much for coming. We will study your testimony. There may be written questions. If you receive written questions, I would certainly hope you would respond quickly. Thank you.

Senator JEFFORDS. Thank you.

Senator CHAFEE. That concludes the hearing.

[Whereupon, at 3:46 p.m., the hearing was concluded.]



# APPENDIX

## ADDITIONAL MATERIAL SUBMITTED FOR THE RECORD

### PREPARED STATEMENT OF T. JEFF BANGSBERG

My name is Jeff Bangsberg and I am Director of Consumer Affairs for Becklund Home Health Care in Minneapolis, Minnesota. I am past-chair and a current member of Minnesota's State Rehabilitation Advisory Council which is federally mandated to advise the State on matters pertaining to Vocational Rehabilitation Services. I am here today representing the Work Incentives Committee of the Minnesota Consortium for Citizens with Disabilities (known as Minnesota CCD).

Minnesota CCD is a broad-based coalition of consumers with disabilities, providers and advocates from throughout Minnesota. (A list of member organizations is attached.) For several years, MN CCD has been actively involved in state and national efforts to remove barriers to employment of people with disabilities. We have identified the loss of Medicaid coverage as the number one policy barrier to employment of people with disabilities.

In 1995, Minnesota CCD initiated state legislation which led to our state's request to HCFA for a Section 1115 Earned Income Disregard Waiver. Prompted by Minnesota CCD, the 1998 Minnesota legislature passed the attached resolution, urging Congress to remove Medicaid policy barriers to employment of people with disabilities. At the end of March 1998, this resolution was forwarded by Minnesota's Secretary of State to the Speaker and Clerk of the U.S. House, and the President and Secretary of the U.S. Senate.

This past spring, Minnesota CCD and the Minnesota Work Incentives Coalition also conducted an informal survey on health care barriers to employment of people with disabilities. This informal survey was published in the disability newspaper, Access Press, and distributed by over 200 organizations throughout Minnesota. Almost 1,200 persons with physical, mental health, developmental and multiple disabilities completed the survey. This voluntary response far exceeded original expectations that two to three hundred surveys would be returned.

Significant findings of this survey are:

- 617 or 52% of the survey respondents indicated they would either seek employment or increase their employment if their health care benefits would not be affected.

Of these respondents, 321 (27%) reported that they are not working and would consider getting a job if their health care benefits would not be affected.

296 (25%) are working and would work increased hours or seek higher wages if their health care benefits would not be affected.

- 157 (67%) out of 234 respondents who use personal care assistance services would either seek employment or increase their employment if their health care benefits would not be affected.
- 548 (53%) out of 1,037 respondents who use medications on a regular basis would either seek employment or increase their employment if their health care benefits would not be affected.

(Note: Many individuals need both medications and personal care assistance.)

These results clearly demonstrate that having appropriate, affordable health care is a critical factor in decisions people with disabilities make about working. Many individuals are afraid to work because they can't afford to lose affordable access to continued Medicaid coverage. Neither employer-based insurance, nor Medicare cover personal assistance services, nor do they offer comprehensive coverage of prescription drugs, equipment, supplies and other long term supports commonly needed by persons with disabilities. Because such coverage is only offered by Medicaid, many

individuals have no choice, but to rely on Medicaid, even if they have access to Medicare. To remain eligible for Medicaid under existing policies, they have no choice but to limit or forego employment, even if they are well qualified and highly motivated to work.

For example: My friend, Gary, has received SSDI since he became a quadriplegic over twenty years ago. He has a college degree and stays active doing volunteer work. Gary would like to work, but is afraid to take a job for fear of losing Medicaid coverage for the personal care assistance and other health care services he needs.

Personally, I was only able to discontinue Medicaid because I recently married a woman who is willing and able to provide most of the personal care assistance I need. Not everybody's that fortunate. Paying out of pocket for my caregiving would cost over \$30,000 per year. If my wife hurt her back, we would have to divorce and I would have to once again impoverish myself to qualify for Medicaid.

As I mentioned earlier, Minnesota has been working on a Section 1115, Earned Income Disregard Waiver request to HCFA since 1995. If approved, this waiver would allow working persons on SSDI who require personal care assistance services to continue buying Medicaid on a sliding fee scale to obtain coverage for services not covered by employer-based insurance. Our ultimate goal is to allow such a disregard for all working persons with disabilities on Medicaid who do not qualify for continued Medicaid coverage under the existing SSI 1619(b) program. The proposed waiver request for people who need personal care assistance is at least a step in the right direction.

Passage of S. 1858 is crucial because it gives HCFA a clearer mandate to approve waiver requests like Minnesota's. More importantly, S. 1858 requires HCFA to consider potential savings across the entire federal budget, rather than just looking at budget neutrality within the Medicaid program when evaluating such requests. This will make it much easier and quicker for states like Minnesota to develop demonstration projects removing Medicaid barriers to employment of people with disabilities.

A well-respected fiscal analyst with the Department of Human Services, who is accountable to the Minnesota legislature, now believes that the implementation of Minnesota's earned income disregard waiver will be budget neutral. When potential savings outside of the Medicaid program are taken into consideration, one wonders why Medicaid barriers to employment haven't been removed a long time ago.

Potential savings from removing Medicaid barriers to employment include:

Reductions in Medicaid and Medicare costs as more people with disabilities access employer or other health coverage. On average, Minnesota Medicaid recipients with disabilities who are ineligible for the SSI 1619(b) program have \$3,379 per year in acute and primary care expenses paid by Medicaid. This cost would be reduced for every individual who gains employer-based insurance. Potential savings to Medicare are even higher since Medicare pays a much greater share of the acute care expenses for individuals on SSDI.

If more Medicaid recipients could work, further reductions in Medicaid and Medicare expenses would result from a decrease in preventable secondary disabling conditions such as situational depression, urinary tract infections, pressure sores, substance abuse and other conditions that result from inactivity.

Social Security cash payments to persons with disabilities will also decrease, as individuals work their way off of SSDI. According to a 1997 GAO report, the average SSDI payment was \$1,050 per month in 1994. Thus, Social Security could save an average of \$12,600 per year for every individual who is able to work their way off of SSDI.

Other federal expenditures would also go down as people with disabilities move off of programs such as Food Stamps and HUD subsidized housing. In the Twin Cities area, the average housing subsidy for the HUD Section 8 certificate program is almost \$4,700 per person per year.

Everyone benefits from removing policy barriers to employment. More people with disabilities could make use of their skills and become self-sufficient. They would no longer be forced into poverty to secure the long term health coverage they need. Employers would also benefit from an expanded pool of qualified, motivated candidates for positions that are difficult to fill in a shrinking labor market. In addition, they would not be expected to pick up any more health care costs than they do for non-disabled employees. Finally, taxpayers would benefit as people with disabilities reduce their dependence on the government programs mentioned above. More people with disabilities could become taxpayers themselves, paying annual income tax and making FICA contributions toward their own retirement. The investment the gov-



ernment is already making in medical and vocational rehabilitation for people with disabilities would also be maximized.

Many people with disabilities across the country are anxiously awaiting the passage of Senate 1858 so they can go to work. Others may quit their jobs if nothing is done to make work pay. Congress can't afford not to pass S. 1858 this year.

Thank you.

Attachments:

### **Minnesota Consortium For Citizens With Disabilities**

**c/o Bob Brick; Arc Minnesota; 3225 Lyndale Avenue, South; Minneapolis, MN 55408; (612) 827-5641**

The Minnesota Consortium for Citizens with Disabilities (MN CCD) is a broad-based coalition of organizations of persons with disabilities, providers and advocates, dedicated to improving the lives of persons with disabilities. We address public policy issues that affect people with disabilities by collaborating with others, advocating, educating, influencing change, and creating awareness for understanding. The Minnesota Consortium for Citizens with Disabilities includes:

Access Press	MN Assn. of Community Mental Health Programs, Inc.
Accessible Space, Inc.	MN Assn. of Community Rehabilitation Organizations (MACRO)
Advocating Change Together	Minnesota Disability Law Center
Alliance for the Mentally Ill of Minnesota	Minnesota Governor's Council on Developmental Disabilities
Alliance Health Care	Minnesota Habilitation Coalition
Arc Minnesota	Minnesota State Council on Disability
Arc of Anoka and Ramsey Counties	National Multiple Sclerosis Society-MN Chapter
Arc of Hennepin County	Parenting Resource Center
Arc Olmsted County	Southeast Minnesota Center for Independent Living-UHHC, Inc.
Association of Residential Resources in Minnesota	Sister Kenny Institute
Becklund Home Health Care, Inc.	Slattery, Jamie, Consumer
Brain Injury Association of Minnesota	Southern Minnesota Independent Living Enterprises and Services
Courage Center	Southwestern Center for Independent Living
Epilepsy Foundation of Minnesota	St. Paul Rehabilitation Center
Executive Assistants	STAR Program
Fairview Multiple Sclerosis Achievement Center	Tasks Unlimited
Flaten, Kris, Consumer	The Disability Institute
Fraser Community Services	Tourette Syndrome Association, MN Chapter
Gillette Children's Specialty Healthcare	United Cerebral Palsy of Central Minnesota
Goodwill/Easter Seal of Minnesota	United Cerebral Palsy of MN
Independence Crossroads	
Johnson, Cindy, Parent/Advocate	
Lutheran Social Service of Minnesota	
Mental Health Association of Minnesota	
Mental Health Consumer/Survivor Network	
Metro Work Center, Inc. Metropolitan Center for Independent Living	

(Please note: This is only a partial listing. MN CCD membership continues to grow.)

**SF2699, as passed by MN Senate on 2/24/98 and by MN House on 3/10/98**

### **A RESOLUTION MEMORIALIZING THE CONGRESS OF THE UNITED STATES TO REMOVE MEDICAID POLICY BARRIERS TO EMPLOYMENT FOR PEOPLE WITH DISABILITIES.**

WHEREAS, seventy-four percent of working-age adults with severe disabilities are unemployed; and

WHEREAS, many people with disabilities are highly dependent on local, state, and federal assistance for support and survival, particularly for necessary health care; and

WHEREAS, a 1995 Lou Harris poll reported that two-thirds of unemployed people with disabilities are eager to work; and

WHEREAS, advances in technology, the civil rights protections of the Americans with Disabilities Act, and the current labor shortage are opening up many new employment opportunities for people with disabilities; and

WHEREAS, current government policies, particularly those relating to Medicaid, discourage people with disabilities from working; and

WHEREAS, existing Medicaid work incentives are flawed and are completely unavailable to people with disabilities who do not qualify for the SSI 1619(b) program; and

WHEREAS, removing policy barriers to employment would enable more people with disabilities to reduce their dependence on Social Security, Medicaid, Medicare, subsidized housing, food stamps, and other state, local, and federal government programs; and

WHEREAS, becoming employed allows individuals with disabilities to contribute to society by becoming taxpayers themselves; and

WHEREAS, employer-based health care and government programs, such as Medicare, Minnesota Comprehensive Health Association, and MinnesotaCare, do not typically cover long-term supports needed by people with disabilities; NOW, THEREFORE,

BE IT RESOLVED by the Legislature of the State of Minnesota that it urges the Congress of the United States to adopt Medicaid buy-in legislation that would allow people with permanent disabilities to retain Medicaid coverage to address unmet health needs when they become employed.

BE IT FURTHER RESOLVED that such Medicaid buy-in legislation should require individuals to take advantage of employer-based health coverage, if available and affordable, and should further require individuals to purchase needed Medicaid coverage on a sliding fee scale, based on their ability to pay.

BE IT FURTHER RESOLVED that the Secretary of State of the State of Minnesota is directed to prepare copies of this memorial and transmit them to the President and the Secretary of the United States Senate, the Speaker and the Clerk of the United States House of Representatives, and Minnesota's Senators and Representatives in Congress.

#### HEALTH CARE BARRIERS TO EMPLOYMENT SURVEY RESULTS

During the spring of 1998, the Minnesota Consortium for Citizens with Disabilities (MN CCD) and the Minnesota Work Incentives Coalition conducted an informal survey on health care barriers to employment of people with disabilities. This survey was developed in relation to several recent initiatives: 1) the "Work Incentives Improvement Act" (S. 1858) and the "Ticket to Work and Self-Sufficiency Act" (H.R. 3433) which are moving through Congress; 2) the creation of the National Task Force on Employment of Adults with Disabilities; and 3) ongoing interest in Minnesota in removing policy barriers to employment, particularly given the State's low unemployment rate of under 3 percent.

The Health Care Barriers to Employment Survey was published in the disability newspaper, Access Press, and distributed by over 200 organizations throughout Minnesota. 1,192 persons with physical, mental health, developmental and multiple disabilities completed the survey. This voluntary response far exceeded original expectations that two to three hundred surveys would be returned.

Significant findings of this survey are:

- 617 (52%) of the survey respondents indicated they would either seek employment or increase their employment if their health care benefits would not be affected.

Of these respondents, 321 (27%) reported that they are not working and would consider getting a job if their health care benefits would not be affected.

296 (25%) are working and would work increased hours or seek higher wages if their health care benefits would not be affected.

- 157 (67%) out of 234 respondents who use personal care assistance services would either seek employment or increase their employment if their health care benefits would not be affected.
- 548 (53%) out of 1,037 respondents who use medications on a regular basis would either seek employment or increase their employment if their health care benefits would not be affected.

(Note: Many individuals need both medications and personal care assistance.)

Based on these results, we recommend that you support the health policy provisions of S. 1858, and the development of other federal and state initiatives to remove health care barriers to employment. Thank you.

**CONTINUED MEDICAID FOR EMPLOYED PERSONS WITH DISABILITIES  
JUSTIFICATION OF BUDGET NEUTRALITY**

**MINNESOTA DATA AS OF JULY 1998**

**SUMMARY**

1. Persons affected (MN Medicaid recipients, ages 18 to 64, who are not already eligible for SSI 1619(b))	19,832 individuals potentially eligible (based on 1996 data).
2. Projected rate of utilization .....	Based on SSI 1619b participation, between 972 and 8,131 individuals (4.9% to 41% of potential eligibles) are expected to participate.
3. Potential reduction in Medicaid costs .....	Average of \$3,379 per person per year decrease in Medicaid acute and primary care costs for each participant who accesses employer health coverage.
4. Potential reduction in Medicare costs .....	Average of over \$11,894 decrease in Medicare costs per year for each participant who accesses employer health coverage. (Note: This figure only includes Medicare expenditures for services where Medicare and Medicaid split the cost. Additional data is needed on acute care costs paid only by Medicare for the potentially eligible individuals. These costs (and thus, the potential reductions) are likely to be considerably higher.
5. Potential reductions in other public expenditures:	
Social Security cash payments .....	Average \$12,600 decrease per person per year
Food Stamps .....	Average of \$120 to \$1,440 decrease per person per year
HUD Section 8 Housing .....	Average of \$4,700 decrease per person per year
Other federal, state & local \$\$ .....	<b>Data needed</b>
6. Potential increases in tax revenues:	Based on 1996 tax rates for individual earning \$20,000/year
Federal tax payments .....	\$3,000 contributed per person per year
State tax payments .....	\$1,278 contributed per person per year
FICA (employer & employee contributions) .....	\$3,060 contributed per person per year
7. Return on public investment in vocational rehabilitation ..	Investment of \$7,000 per person not realized if individuals forego work due to fear of losing health care.
8. Potential increase in public health care expenditures. ....	Woodwork effect unlikely since most people with severe and permanent disabilities already rely on Medicaid and other public programs because they have no other choice.
9. Reductions in health care costs as people become productive.	Specific data needed on studies showing link between productivity and better health.
10. Expanded job possibilities in current market .....	Low unemployment rate in Minnesota, the ADA and technology are opening up new opportunities.
11. Benefits to society (in addition to benefits to taxpayers above).	New labor source to fill job vacancies. Individuals with disabilities able to contribute. Stress on families reduced.

**PREPARED STATEMENT OF ALLAN I. BERGMAN**

**INTRODUCTION**

My name is Allan Bergman. I currently am employed as the Director of State-Federal Relations for United Cerebral Palsy Associations, Inc. in Washington, D.C. I also serve as Director of our newly created Institute on Disability and Managed Care. United Cerebral Palsy Associations is a national non-profit organization dedicated to advancing the independence, productivity and full citizenship of persons with disabilities. United Cerebral Palsy's 149 affiliates nationwide provide direct services to children and adults with cerebral palsy and their families including therapy, early intervention, assistive technology acquisition and training, employment, community living, family support, social and recreational programs, advocacy and information and referral. Everyday more than 30,000 people with cerebral palsy and other disabilities and their families receive assistance from UCP affiliates. United Cerebral Palsy Associations is one of the largest health charities in the country as well as one of the most efficient with 85 cents of every dollar spent directly on programs and services.

I have been a professional in disability for 31 years and have been privileged to help create opportunities which have resulted in great strides in the perception of and actual capacity and contribution of persons with disabilities—intellectual, cognitive, physical, sensory and psychiatric. I also bring the perspective of the father

of a young woman with disabilities in the work force and a 25 year old step-daughter with severe and multiple disabilities who is contributing to her community in a very responsible fashion everyday in return for her public benefits.

On behalf of UCPA, we are pleased to endorse S.1858, The Work Incentives Improvement Act of 1998, and commend its sponsors Senators Jeffords and Kennedy for this very significant piece of legislation that will enable many Americans with disabilities who want to work to be able to do so with incentives, choice and no risk of losing their vital health insurance, prescription drugs and personal assistance services. Senators Jeffords and Kennedy and their staffs have worked very closely with members of the disability community and other stakeholders to reach the consensus we now have on this critically needed legislation.

#### HISTORICAL POLICY CONTEXT

How did we get here and why is this legislation necessary?

##### A. SOCIAL SECURITY DISABILITY INSURANCE (SSDI)

The SSDI benefit was created as an amendment to the Social Security Act in 1956, for workers ages 50-64 who become "disabled" and in 1960 was amended to include workers under the age of 50 who become "disabled" who had paid into the trust fund for 20 of the previous 40 quarters. In 1956, benefits also were extended to children with disabilities over the age of 18 (DAC) of retired, disabled or deceased workers, if the disability of the child occurred prior to age 18. In 1973, consistent with changes in the definition of developmental disabilities in the Developmental Disabilities Assistance and Bill of Rights Act, the definition of the child benefit was changed to age of onset prior to 22.

Generally, disability is defined as the inability to engage in "substantial gainful activity" by reason of a physical or mental impairment. The impairment must be medically determinable and expected to last for not less than 12 months, or to result in death. Applicants may be determined to be disabled only if, due to such an impairment, they are unable to engage in any kind of substantial gainful work, considering their age, education, and work experience.

The first step in the disability determination process for a worker is to determine if the individual is engaging in substantial gainful activity (SGA) which for most people is defined as more than \$500 per month—which is nearly \$2,000 per year less than the federal poverty level. The next step in the process is to determine if the impairment is "not severe" (i.e. it does not significantly limit the individual's capacity to perform work.) If the impairment is "severe", a determination is made as to whether the impairment "meets" or "equals" the medical listings published in regulations by SSA and whether it will last for 12 months. The process continues through numerous steps. SSDI benefits are not paid until the beginning of the sixth full month of disability. As of December 1996, there are 4.386 million persons receiving SSDI with an average monthly benefit of \$704. Unfortunately, the number of SSDI beneficiaries working in September 1997 was only 318,728 (or 6.1% of the SSDI caseload). The percentage of people with disabilities earning over \$500 per month after trial work period and extended eligibility is 0.33%.

The age distribution and medical listing categories are depicted in the charts below from the SSA.

TABLE 1-31.—PERCENT DISTRIBUTION BY AGE, SEX AND EDUCATION OF TITLE II DISABLED WORKER BENEFICIARIES GRANTED BENEFITS IN SELECTED CALENDAR YEARS 1970-96, COMPARED WITH ADULT U.S. POPULATION IN 1990

Characteristics	Year granted benefits													Adult U.S. population <sup>1</sup>	
	1970	1975	1979	1982	1985	1988	1989	1990	1991	1992	1993	1994	1995		1996
<b>Age:</b>															
Under 35 .....	9.0	11.0	13.6	14.4	16.8	15.2	16.2	15.7	15.7	16.8	16.2	14.7	13.3	12.3	45.6
35-44 .....	11.0	10.0	11.5	12.3	15.0	16.5	17.9	18.7	19.6	20.4	20.9	20.7	20.4	20.4	24.4
45-54 .....	26.0	26.0	27.2	26.5	25.7	23.3	24.7	24.7	25.1	25.6	26.8	27.7	28.3	29.7	16.3
55-59 .....	24.0	23.0	27.0	27.2	23.9	20.6	20.4	19.9	19.5	18.5	18.6	19.2	19.9	20.0	6.8
60 and over .....	30.0	30.0	20.6	19.6	18.7	24.4	20.9	21.0	20.1	18.7	17.6	17.8	18.0	17.4	6.9
Median age (years) .....	56.0	55.6	53.4	53.1	51.7	53.3	52.1	51.9	51.4	50.5	50.3	50.8	51.3	51.3	32.9
<b>Sex:</b>															
Male .....	74	68	69	70	67	66	64	64	64	63	62	60	58.4	56.7	49.5
Female .....	26	32	31	30	33	34	36	36	36	37	38	40	41.4	43.2	50.5
<b>Education (years of school completed):</b>															
No schooling <sup>2</sup> .....	2	1	1	1	2	1	1	1	1	1	1	1	NA	1	1
Elementary school (1-8) .....	44	37	29	26	23	18	17	16	16	12	11	12	NA	10	9
Some high school .....	46	52	55	56	59	59	60	62	62	50	45	55	NA	58	45
9-11 .....	23	24	23	22	22	20	19	19	19	15	14	16	NA	16	11
12 .....	23	28	32	34	37	39	41	43	43	35	31	39	NA	42	34
Some college .....	9	10	12	14	14	15	17	17	17	14	12	16	NA	3	45
Unknown .....	0	0	3	3	2	7	5	5	5	23	31	16	NA	28	0

<sup>1</sup> Derived from 1990 census. Figures for age based on population aged 18-64. Figures for education based on persons aged 25 and over.

<sup>2</sup> Also includes special schools for handicapped.

NA—Not available.

Source: Office of Disability, Social Security Administration.

TABLE 1-32.—PERCENT DISTRIBUTION BY DISABLING CONDITION OF TITLE II DISABLED WORKER BENEFICIARIES GRANTED BENEFITS IN SELECTED CALENDAR YEARS, 1970-96

Disabling condition	Year granted benefits													
	1970	1975	1979	1982	1985	1988	1989	1990	1991	1992	1993	1994	1995	1996
Infective and parasitic diseases <sup>1</sup> .....	3	1	1	1	1	0	1	6	6	7	7	6	6	5
Neoplasms .....	10	10	14	17	15	16	18	17	16	13	15	16	16	17
Allergic, endocrine system, metabolic and nutritional diseases .....	4	3	3	4	5	3	3	3	4	5	5	5	5	5
Mental, psychoneurotic and personality disorders .....	11	11	11	11	18	22	22	23	24	25	26	24	22	22
Diseases of the nervous system and sense organs .....	6	7	8	9	8	8	9	9	8	8	7	8	8	8
Circulatory system .....	31	32	28	25	19	18	17	16	15	14	15	14	14	14
Respiratory system .....	7	7	6	7	5	5	5	5	5	4	5	5	5	5
Digestive system .....	3	3	2	2	2	2	2	2	2	2	2	2	2	2
Musculoskeletal .....	15	17	17	16	13	14	11	12	13	13	12	12	12	12
Accidents, poisonings and violence .....	8	6	6	6	4	5	4	4	4	4	3	3	3	4
Other/unknown .....	2	3	3	2	11	7	9	5	5	5	5	6	6	6
Total percent <sup>2</sup> .....	100	100	100	100	100	100	100	100	100	100	100	100	100	100

<sup>1</sup> Beginning in 1990, AIDS/HIV cases are included in this category.

<sup>2</sup> May not add to 100 percent due to rounding.

Source: Office of Disability, Social Security Administration.

## B. MEDICARE LINKAGE

After a two year waiting period, SSDI also entitles beneficiaries to Medicare. In 1996, 4.8 million Americans with disabilities had coverage under Part A and 1.0 million of them actually received reimbursed services. Persons receiving SSDI may elect to enroll in Part B. In 1996, 4.1 million SSDI beneficiaries enrolled in Part B and 3.3 million of them actually received reimbursable services.

If the beneficiary is successful in testing their ability to return to work ("trial work period" of up to nine months and a 36 month "extended period of eligibility"), Medicare coverage continues as long as the individual remains entitled to disability benefits. When Medicare entitlement ends because the person is engaging in SGA, but the person is still "medically disabled", the person may purchase Medicare insurance at a current premium of \$317 per month for Part A and \$43.80 per month for Part B.

Moreover, the Medicare benefit package does not offer prescription drug coverage nor does it offer non-medical personal care or personal assistance services; two critical and often costly benefits necessary either singly or in combination for many people with disabilities to work and to live in the community.

## C. SUPPLEMENTAL SECURITY INCOME (S.S.I.)

The Supplemental Security Income (SSI) program, Title XVI of the Social Security Act, was enacted in 1972 as a means tested, (income and resource limitations) income assistance program. It replaced the former Federal-State Programs of Old-Age Assistance and Aid to the Needy Blind established in 1935 as well as the Program of Aid to the Permanently and Totally Disabled enacted in 1950. All but seven states—Arkansas, Georgia, Kansas, Mississippi, Tennessee, Texas and West Virginia provide some form of state optional supplementary payment.

To qualify for SSI payments, a person must satisfy the program criteria for, blindness or disability. Individuals with 20/200 vision or less with the use of correcting lens in the person's better eye, or those with tunnel vision of 20 degrees or less are defined blind. Disabled individuals are those unable to engage in any substantial gainful activity by reason of a medically determined physical or mental impairment expected to result in death or that has lasted, or can be expected to last, for a continuous period of at least 12 months. The test of "substantial gainful activity" is to earn \$500 monthly in counted income, with impairment-related expenses subtracted from earnings.

At the end of 1996 there were 236,000 SSI recipients between the ages of 18 and 21 and 3,337,000 SSI recipients between the ages of 22 and 64. In addition, there were 958,000 children under the age 18 receiving SSI. The maximum SSI payment in 1997 was \$484 per month for one person and \$726 per month for a couple. Less than two percent of the 18-64 year old recipients are engaged in the section 1619(a) and 1619 (b) work incentive programs. Approximately 40% of the SSI recipients between the ages of 18 and 64 also receive social security benefits.

A BREAKDOWN OF THE SSI POPULATION BY BROAD DIAGNOSIS IS AS FOLLOWS:

TABLE 3-13.—DISABILITY DIAGNOSIS OF SSI AND SECTION 1619 DISABILITY RECIPIENTS, DECEMBER 1996<sup>1</sup>

(Percentage distribution by diagnostic group)

Diagnostic group	Supplemental Security Income (SSI)		
	All SSI disabled 18-64 yrs.	SSI section 1619(a) participants	SSI section 1619(b) participants
Infectious and parasitic diseases .....	1.7	1.1	1.5
Neoplasms .....	1.4	1.3	1.6
Endocrine, nutritional, and metabolic disorders .....	4.3	2.1	2.7
Mental disorders:			
Schizophrenia .....	8.9	9.6	11.6
Other psychiatric .....	21.5	19.3	20.0
Mental retardation .....	28.4	46.6	38.6
Diseases of:			
Nervous system and sense organs <sup>2</sup> .....	10.1	12.1	13.3
Circulatory system .....	4.9	1.5	2.3
Respiratory system .....	2.7	1.0	1.0
Digestive system .....	0.7	0.4	0.6
Genito-urinary system .....	0.9	1.1	1.6
Musculoskeletal system and connective tissues .....	7.3	3.0	4.4
Congenital anomalies .....	1.7	0.9	0.8
Injury and poisoning .....	2.7	2.2	3.3
Other .....	2.7	1.3	1.2
Total percent .....	100.0	100.0	100.0
Total individuals <sup>3</sup> .....	4,375,650	23,101	34,909

<sup>1</sup> Information on diagnosis of SSI disabled recipients under age 65 is from the December 1995 SSI 10-percent disability file. Information on diagnosis for section 1619 recipients is available from SSI source files.

<sup>2</sup> Most of the section 1619(b) participants who are classified as blind individuals are included in this category. A few section 1619(b) blind participants have a primary impairment other than diseases of the eye and are coded in other categories in this table. Also, there are a few participants classified as having diseases of the eye who are not blind, whose impairment does not meet the definition of blindness, and are classified as disabled.

<sup>3</sup> Includes only recipients whose diagnosis information is specifically identified on the source files.

Source: Office of Supplemental Security Income, Social Security Administration.

#### D. MEDICAID

Medicaid, Title XIX of the Social Security Act, was enacted in 1965 as a means tested program (income, assets and resources) of health insurance and long term care. In all but 11 states (the section 209(b) states of Connecticut, Hawaii, Illinois, Indiana, Minnesota, Missouri, New Hampshire, North Dakota, Ohio, Oklahoma and Virginia) a recipient of SSI is federally entitled to Medicaid. In the 11 states, the state determines disability eligibility which may be more restrictive than SSI criteria.

Medicaid is a Federal-State matching funds program that mandates a core set of benefits for all recipients and provides the states the option of 34 additional benefits, many of which are very important to persons with disabilities.

The mandated benefits are:

- Inpatient hospital services
- Outpatient hospital services
- Rural health clinic (including federally-qualified health center) services



- Other laboratory and x-ray services
- Nurse Practitioner's services
- Nursing facility (NF) services and home health services for individuals age 21 and older
- Early and periodic screening, diagnosis, and treatment (EPSDT) for individuals under age 21
- Family planning services and supplies
- Physicians' services and medical and surgical services of a dentist
- Nurse-Midwife services

The optional benefits are: (\*are benefits often needed by persons with disabilities)

- Podiatrists' services
- Optometrists' services
- Chiropractors' services
- Psychologists' services\*
- Medical Social Workers' services
- Nurse Anesthetists' services
- Private Duty Nursing
- Clinic services
- Dental services
- Physical therapy\*
- Occupational therapy\*
- Speech, hearing and language disorders\*
- Prescribed drugs\*
- Dentures
- Prosthetic devices\*
- Eyeglasses\*
- Diagnostic services
- Screening services
- Preventative services
- Rehabilitative services\*
- Age 65 or older in IMDs
- Inpatient psychiatric services for under age 21
- Christian Science nurses
- Christian Science sanatoriums
- NF services for under age 21
- Emergency hospital services
- Personal care services\*
- Home and Community-based waiver services\*
- Transportation services
- Case management services
- Hospice care services
- Respiratory care services\*
- TB-related services

Today all states offer Medicaid beneficiaries the prescription drug benefit.

The following states offer a personal care benefit; however, the states define the amount, duration and scope of the benefit as well as the provider standards and payment methodology and rates.

- |                        |                  |
|------------------------|------------------|
| • Alaska               | • Nevada         |
| • Arkansas             | • New Hampshire  |
| • California           | • New Jersey     |
| • Delaware             | • New York       |
| • District of Columbia | • North Carolina |
| • Idaho                | • Oklahoma       |
| • Iowa                 | • Oregon         |
| • Kansas               | • Rhode Island   |
| • Maine                | • South Dakota   |
| • Maryland             | • Texas          |
| • Massachusetts        | • Utah           |
| • Michigan             | • Vermont        |
| • Minnesota            | • Washington     |
| • Missouri             | • West Virginia  |
| • Montana              | • Wisconsin      |
| • Nebraska             |                  |

The passage of the Home and Community Based Services Waiver Option in 1981 has permitted many persons with disabilities to leave institutions and allowed many persons with disabilities to live in the community. In 1986, amendments to the H-CB waiver authority added supported employment as a habilitation service for per-

sons previously institutionalized. In the Balanced Budget Act (BBA) of 1997 that provision was further amended to allow H-CB waiver supported employment services to anyone reviewing H-CB services.

The BBA also included a provision allowing states to expand eligibility for Medicaid to persons with disabilities who meet the SSI disability "test" and are working, up to 250% of the federal poverty level and to impose a sliding scale for premiums sharing. To the best of my knowledge, no state has submitted a state plan amendment to implement this provision.

#### THE DISABILITY RIGHTS MOVEMENT

The early years of federal disability policy focused almost exclusively on establishing people with disabilities as citizens with cash assistance, health insurance and the full protection of the United States Constitution. As I stated earlier SSDI was enacted in 1956 and SSI in 1972. It was not until 1973 that Section 504 of the Rehabilitation Act was enacted to prevent discrimination against qualified people with disabilities by entities receiving federal funds. In 1975 this country enacted the Education for All Handicapped Children's Act. In 1990 this country enacted landmark, internationally acclaimed civil rights legislation with the Americans with Disabilities Act (ADA). In the ADA we declared that disability is a natural part of the human condition which in no way diminishes the rights of and opportunities for people with disabilities to participate fully in all aspects of American life. We also declared that the barriers to opportunity for persons with disabilities exists outside of the person in the attitudinal, physical, social and economic environments.

As we approach the twenty-first century we have an opportunity to move toward real implementation of the intent of the ADA by beginning to remove some of the major barriers to work for this nation's working age adults with disabilities and the generations to come of children and adolescents benefiting from their right to an education under the Individuals with Disabilities Education Act.

People with disabilities want to work. People with disabilities are capable of remunerative employment. With techniques of job accommodation, job restructuring, job sharing and the use of assistive technology and devices people with the most severe disabilities can and are working. We need federal policy that **MAKES WORK PAY!** And re-crafts disability from a policy of paternalism and dependency to one which is based on economics, empowerment, contribution and independence.

#### TODAY'S CONTEXT: THE NEED FOR CHANGE

Today the United States economy is booming. Unemployment rates for the country are at near all times low and at less than two percent in many states.

Yet with the best of intentions, nearly 8 million working age adults with severe disabilities are not benefiting from this prosperity and seem doomed to a life of dependency and poverty at a cost to the taxpayer of nearly \$74 billion! If they are married and receive SSI and/or Medicaid, we impose on these couples a spousal deeming penalty that makes the marriage penalty under the IRS code look like kindergarten. As a nation we can do better. S.1858 affords us the opportunity to change the disincentives and to disconnect the current link between income support and health insurance. All of the surveys which have been conducted with working age adults with disabilities have reported the loss of health insurance (Medicare and/or Medicaid) as the primary reason why they are financially unable to return to work. The four other principle barriers to work identified by the Consortium for Citizens with Disabilities and the National Council on Disability are:

- the complexity of existing work incentives;
- financial penalties of working;
- lack of choice in employment services and providers; and
- independent work opportunities

New data from a Louis Harris Survey for the National Organization on Disability conducted in April and May of this year reports a continuing part-time or full-time employment rate of only 29% for non-institutionalized working age adults with disabilities compared to 79% for the population. Yet the same survey indicates that 72% of those persons who are unemployed state they would prefer to be working!

In the area of health care the Harris Survey reported the following findings:

- Among those persons with disabilities who are insured, 32% say they have special needs because of their disability (such as particular therapies, equipment, or medicine) that are not covered by their health insurance;
- 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 pre-existing health condition.

These brand new data unfortunately confirm all previous studies and surveys regarding employment and health care for people with disabilities.

Through UCPA's "Choice" Employment Project funded in its 5th year under the demonstration authority of the Rehabilitation Act Amendments of 1992, people with the most severe physical and multiple disabilities are returning to work through an individualized process of personal profiling and choice; however, we also know that in spite of these individuals demonstrated ability, most are choosing to work part-time in order to be sure not to lose their Medicaid. These choices represent flawed national disability policy which S.1858 begins to address.

#### COMMON LIMITATIONS OF EMPLOYER INSURANCE

Most people with disabilities are not likely to end up on the payroll of the federal or state governments or large Fortune 500 corporations which tend to have more comprehensive health care benefits and the capacity to spread risk across a very large employee base. Most people with disabilities are more likely to become employed by small or medium sized businesses where most new jobs are being created in the current economy, or because of the nature of their disability, work on a part-time or intermittent basis.

In the small or medium sized business, persons with severe disabilities tend to encounter the following range of barriers to their health care needs:

- The employer does not offer a group plan;
- The cost of the employer's group plan is very high in relation to the person's income;
- The limited employer benefit package does not meet the needs of the person with a severe disability in areas such as prescription drugs, mental health services, durable medical equipment/assistive technology, physical, occupational and speech/language therapies and none offer personal assistance services; and
- The health care package is constrained by a rigid definition of medical necessity which is limited to services to "restore" health rather than to maintain function and/or prevent deterioration or loss of function which is critical to persons with disabilities accessing the benefit package.

Therefore, continuous and affordable access to Medicare and/or Medicaid is absolutely essential if we want to assure equal opportunity for people with disabilities to join the work force.

We are also beginning to see increased problems in access to health insurance benefits for people with disabilities as a result of the rapid expansion of managed care in the commercial, Medicaid and Medicare markets. The disability community expects this Committee to hold HCFA accountable for providing a study on managed care for people with special health care needs you directed the agency to do in the Balanced Budget Act. Increasing concerns about the impact of managed care on people with disabilities and chronic health care conditions have generated great interest by the disability community in the need for Congress to pass strong, enforceable patient protection legislation this year as well.

#### THE TIME IS NOW

The linkage of SGA to access to Medicare and Medicaid represents an outmoded policy from the 1960's when severe disability was a synonym for helpless, hopeless, homebound and eternal dependency. The moral and economic imperatives of 1998 demand that we shift our income support and health insurance public policies for people with disabilities to one consistent with the wishes, needs and increased expectations of people with disabilities and the tenets of the Americans with Disabilities Act. As a society we cannot afford to wait for the perfect bill that will solve all of the barriers to employment for persons with disabilities. S.1858 begins to lay a new foundation for disability employment policy that provides incentives for people with disabilities to replace some or all of their federal income assistance with a pay check; to pay income taxes and FICA; to maintain their Medicare and/or Medicaid coverage at an affordable premium based on their earnings; and to be able to obtain prescription drugs and personal assistance services at affordable costs. This foundation along with other provisions in S.1858 move us toward a 21st century policy that will begin to make severe disability a synonym for personal responsibility, choice, empowerment, interdependence, contribution and economic self sufficiency. With this first step we can begin to reframe disability policy as a social and economic investment with a valued performance outcome and begin to remedy the 9th finding in the ADA as we celebrate the 8th anniversary of the signing of this historic civil rights law:

"(9) the continuing existence of unfair and unnecessary discrimination and prejudice denies people with disabilities the opportunity to compete on an equal

basis and to pursue those opportunities for which our free society is justifiably famous and costs the United States billions of dollars in unnecessary expenses resulting from dependency and non-productivity."

PREPARED STATEMENT OF HON. ROBERT DOLE

Chairman Chafee, Senator Breaux, Senator Jeffords, thank you for the opportunity to testify on a critically important issue—the health care barriers faced by people with disabilities when they want to work. Now is the time to address these barriers head-on. We all recognize the implications of not doing so and I commend you for holding this hearing. I gave my public support to S. 1858 when it was introduced on March 25 and I am here today to support the completion of your efforts that began in March.

People with disabilities want to work. It is precarious, often impossible, for them to work if they do not have access to health care. Over the years, Congress has passed many laws to benefit individuals with disabilities. I initiated and supported most of them. I am most proud of the Americans with Disabilities Act, I am concerned however, about two recent Supreme Court cases—*Pennsylvania Dept. of Corrections v. Yeskey* and *Bragdon v. Abbot*. I am fearful that the common sense accommodations for Americans with disabilities many of us have championed in 1990 have been overtaken by judicial activism which have been the scope of the ADA.

Addressing health care for individuals with disabilities, including my own efforts, proved more elusive. Access to health care was a blip on the radar screen in 1990 when we passed the ADA. Unfortunately, it has stayed that way, until S. 1858. Congress must tackle the work disincentives in federal supports for health care to individuals with disabilities. If it does not, the intent and promise of the ADA and other laws will continue to be undermined. If our laws mandate civil rights and support education, training, and functional independence, but do not provide access to health care for people with disabilities, we have not met our goals.

Many individuals with disabilities remain at home today. Last Thursday the National Organization on Disability released a report that found only 29 percent of people with disabilities are employed. This percentage is worlds away from the 79 percent of non-disabled employed American of working age. The report also stated that 72 percent of those unemployed persons with disabilities wanted to work. But for those in federal programs supposedly designed to help people with disabilities get to work, less than one percent attempt it every year.

To take an example, a Kansan named John Roe received SSI benefits every month. John has a disability that requires dialysis treatment three time a week. John has most of his medical care coverage by Medicaid. He had received vocational training and would like to go to work full-time. The problem ins that John would loose his Medicaid eligibility from earnings of a full-time job. It is unlikely that Mr. Roe's earnings would be enough to replace the medical coverage under Medicaid. John also depends on personal assistance services in his home through Medicaid. He could not afford the price tag on his own and John is frustrated with this because he must stay poor and on SSI to access these critical services.

Eight years after passage of the Americans With Disabilities Act we have yet to achieve our goals of ensuring the full participation of individuals with disabilities in their communities. Persons with disabilities could be working if they had access to affordable health care. To access basic care, prescription drugs or personal assistance services through Medicare or Medicaid, we say to individuals with disabilities, "stay home, don't work." As a matter of public policy this is senseless and unjust.

Through the principles in S. 1858 you have the opportunity to set the right policy and change the message to Americans with disabilities—"If you work, your government will provide you with access to the health care you need until you can afford to pay for it yourself" The power of such a statement is unquestionable. The potential of such a law is unlimited,

I made my first statement on the Senate Floor on April 14, 1969. It was about individuals with disabilities America's untapped resource. You have a choice in the next few legislative days of the 105th Congress to remove the final barrier to true independence for the individuals with disabilities. What's it going to be? You know where I stand and I encourage you to take the appropriate action now.

Thank you, Mr. Chairman.

## PREPARED STATEMENT OF CYNTHIA M. FAGNONI

Mr. Chairman and Members of the Subcommittee:

Thank you for inviting me to testify on factors affecting the return to work of beneficiaries in the Social Security Disability Insurance (DI) program. DI is one of the largest federal programs providing cash assistance to people with disabilities. In 1996, about 4.4 million working-age people (aged 18 to 64) received DI cash benefits. The average monthly cash benefit in 1995 was \$704, and the overall amount of cash benefits paid was about \$40 billion.

Over the years, the Congress has enacted various work incentive provisions designed to safeguard beneficiaries' cash and medical benefits and encourage them to test their ability to engage in work. For example, for ongoing eligibility determinations, beneficiaries are allowed to deduct from their gross earnings the costs of certain impairment-related items and services needed to work. The Social Security Administration (SSA), which determines beneficiary eligibility, is also responsible for encouraging DI beneficiaries to return to work whenever possible. Despite statutory provisions and SSA efforts—as well as medical and technological interventions that have afforded greater potential for some beneficiaries to work—not more than 1 of every 500 DI beneficiaries has left the rolls by returning to work.

Yet relatively small improvements in return-to-work outcomes offer the potential for significant savings in cash benefit outlays. For example, if an additional 1 percent of the 4.4 million DI beneficiaries were to leave SSA's disability rolls by returning to work, lifetime cash benefits would be reduced by an estimated \$2.4 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) factors that working beneficiaries believe are helpful in becoming and staying employed and (2) trade-offs 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 our more recent report on factors facilitating work for a group of DI beneficiaries.[2] (A list of related GAO products appears at the end of this statement.) In our recent work, we conducted survey interviews with 69 people who were receiving DI benefits and working in one of three metropolitan areas.

In summary, the group of DI beneficiaries we interviewed identified a range of factors that enabled them to return to work. Factors most prominently cited were an improved ability to function in the workplace as a result of successful health care and encouragement from family, friends, health care providers, and coworkers. On the other hand, DI work incentives—such as purchasing Medicare upon exit from the rolls—and assistance from SSA staff appeared to play a limited role in helping beneficiaries become employed. A number of respondents said, however, that the provisions that allow them to work for a period of time without losing cash and medical benefits and to retain health care coverage for a limited time period after cash assistance ends were helpful.

Availability of worksite-based health insurance appears to differentiate respondents who plan to leave the rolls in the future from respondents who plan to stay. In addition, 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 the work incentives. 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.

## BACKGROUND

Established in 1956, DI is an insurance program funded by Social Security payroll taxes. There are a number of criteria an individual must meet to be eligible for DI benefits, including a sufficient work history and a lost capacity to work due to a disability. Medicare coverage is provided to DI beneficiaries after they have received cash benefits for 24 months (individuals do not have the option to purchase Medicare during this waiting period).

To be considered disabled for DI benefits, an adult must be unable to engage in any substantial gainful activity because of any medically determinable physical or mental impairment that can be expected to result in death or that has lasted or can be expected to last at least 1 year. Moreover, the impairment must be of such severity that a person not only is unable to do his or her previous work but—considering

age, education, and work experience—is unable to do any other kind of substantial work that exists in the national economy.

The Social Security Act states that people applying for disability benefits should be promptly referred to state vocational rehabilitation agencies for services in order to maximize the number of such individuals who can return to productive activity.[3] To reduce the risk a beneficiary faces in trading guaranteed monthly income and subsidized health coverage for the uncertainties of employment, the Congress established various work incentives—including a trial work period, an extended period of eligibility, and Medicare coverage buy-in. These incentives are intended to safeguard cash and health benefits while a beneficiary tries to return to work.

The trial work period allows DI beneficiaries to work for a limited time without their earnings affecting their disability benefits. Each month in which earnings are more than \$200 is counted as a month of the trial work period. When the beneficiary has accumulated 9 such months (not necessarily consecutive) within a 60-month rolling period, the trial work period is completed. The extended period of eligibility begins the month following the end of the trial work period. The extended period is defined as a consecutive 36-month period during which cash benefits will be reinstated for any month the beneficiary's earnings are less than substantial gainful activity level (in 1997, \$500 for people with disabilities; \$1,000 for people who are blind). Cash benefits may be paid for an even longer period of time if a person is unable to perform any substantial gainful activity.

Another work incentive allows for continued Medicare coverage for at least 39 months following a trial work period, as long as the individual continues to be medically disabled. When this premium-free period ends, medically disabled individuals may elect to purchase Medicare coverage at the same monthly premium—over \$300 for full coverage in 1996—paid by individuals age 65 or older who are not insured for Social Security retirement benefits.

#### FACTORS THAT AFFECT BENEFICIARIES' MOVEMENT INTO THE WORKFORCE

Most working DI beneficiaries we interviewed reported that financial need and enhancing self-esteem were the main reasons for attempting work. They reported a number of factors as helpful to becoming employed (see table 1). The two most frequently reported factors—health interventions and encouragement—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, but they were also seen as important to maintaining ongoing work attempts. Encouragement to work was also critical. Respondents told us they received encouragement from family, friends, health professionals, and co-workers.

**Table 1: Factors That Facilitated Working DI Beneficiaries' Employment, by Frequency of Reporting<sup>a</sup>**

Factor	Description	Significance
<b>Primary</b>		
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
<b>Secondary</b>		
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.	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 ease transition to work force.	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
<b>Tertiary</b>		
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.	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/leg braces, canes/crutches, adapted computers/keyboards, and wheelchairs	Usefulness of assistive devices and equipment is largely limited to people with physical impairments.
Provisions provided by Americans With Disabilities Act (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

A number of beneficiaries described the factors that helped 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 . . . encourag[ed] 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 [allow] 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 Medication[s] for [my] epilepsy help keep [my] condition under control, which minimizes seizures and the risk of getting fired. . . . [My supervisor] check[s] 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 capabilities. [My] parents are very supportive [and my] medications have made me physically able to work. [Coworkers are] providing emotional support. In addition to medical intervention, Louis—a financial counselor in his twenties who has cancer—credited the ADA for providing him rights to continue working:

All my treatments—chemo, radiation, and my eye surgery—helped me to get well and become physically able to work. If I did not have treatments, I would be dead. [The ADA] keeps employers aware that employees cannot be dismissed because of . . . disabilities.

Yvonne, a cashier in her forties with an anxiety disorder, also 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 they would not have hired me because of my problems.

Other, less frequently reported factors also enabled beneficiaries to work. Although these factors were less prominent overall, any single factor may 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.

Our study results are generally consistent with published research regarding factors associated with employment for people with disabilities. For instance, many of the respondents we talked to reported a high motivation to work, were educated beyond high school, or were in their thirties or forties. For many, work seemed to be economically advantageous because they were earning at least moderate-level wages and receiving very few program benefits—such as housing assistance and food stamps—that are contingent upon low earnings. Consistent with other research, medical interventions, technology, accommodations, and social support were found to facilitate return to work. Unlike other studies, transportation appears to be neither a strong facilitator nor an impediment to employment. However, this may be due to the fact that our respondents were selected from major metropolitan areas.

#### *Role of SSA Work Incentives and Staff Involvement*

Based on our discussions with beneficiaries, 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, several indicated it had shortcomings. For instance, they 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. 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.

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.<sup>[5]</sup> 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 decide to limit their employment for fear of losing health care coverage, while others, planning to leave the rolls, may think they are putting themselves at risk of foregoing health care coverage entirely upon program termination.

Generally, respondents told us SSA staff with whom they interacted provided neither much help in nor 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 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. Also, 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 gainful activity level (and therefore no longer eligible for benefits) is set too low.

When examining respondents' comments indirectly related to our questions, we found that about one-third indicated frustration or dissatisfaction with some aspect of SSA or the DI program. For example, some respondents told us they felt that the program was humiliating and lost sight of people's needs. Moreover, some respondents indicated that SSA suddenly informed them that they needed to repay cash benefits mistakenly paid to them in the past.

We previously reported that DI beneficiaries were confused by program provisions and recommended that SSA better implement existing return-to-work mechanisms.[6] Recently, SSA told us that its strategy to better promote return to work is evolving and that it envisions a partnership between field office staff and the private sector. SSA noted it continues to train field office staff about work incentives and to disseminate multimedia publications about work incentives. In addition, SSA said it has been using the private sector to help inform beneficiaries and encourage them to work and expects to do so more in the future. Also, SSA has funded (in conjunction with the Department of Education's Rehabilitation Service Agency) a research project that developed models for training private sector disability case managers about Social Security DI provisions and work incentives. Moreover, SSA expects that private vocational rehabilitation providers, participating under its experimental Alternate Provider Program and other proposed initiatives, will provide beneficiaries information and encourage them to work.

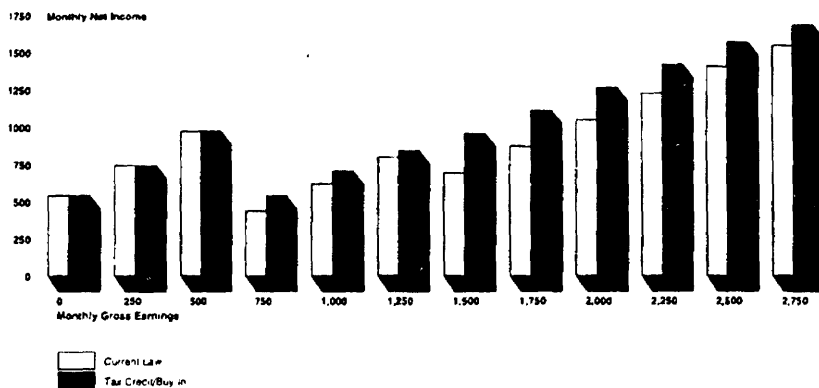
#### *Longer Term Work Decisions Were Also Affected by Health Concerns*

Not surprisingly, personal health appears to be an overriding issue as beneficiaries consider their future status in the DI program and at the worksite. 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. Again, we found little difference in future work and program plans between people with physical and psychiatric impairments.

#### WORK INCENTIVES ILLUSTRATE DIFFICULT TRADE-OFFS IN DISABILITY REFORM

As noted earlier, some work incentives were perceived to be more helpful than others. However, changes to work incentive may help some individual beneficiaries or groups of beneficiaries more than others. Data from Virginia Commonwealth University's Employment Support Institute illustrate this point.[7] 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. A second income cliff may occur if Medicare is purchased when premium-free Medicare benefits are exhausted.

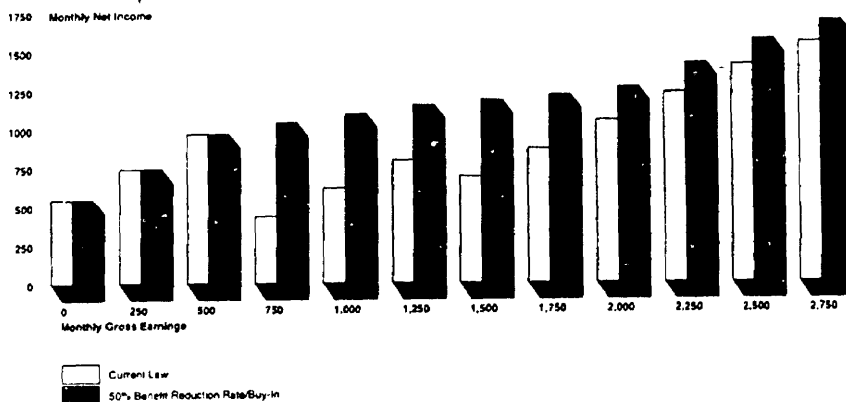
**Figure 1: Comparison of Net Income for DI Beneficiaries Under Current Law and Under Proposed Tax Credit and Sliding-Scale Medicare Buy-In**



Source: Employment Support Training Institute, Virginia Commonwealth University.

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.[8] 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 entire drop. However, as figure 2 shows, this income cliff is eliminated when benefits are reduced \$1 for every \$2 of earnings above substantial gainful activity level.

**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 Training Institute, Virginia Commonwealth University.

These illustrations underscore the complex interactions between earnings and benefits. 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 the changes in work incentives 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.[9] 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 the work incentives could also keep some in the program who might otherwise have left. Allowing people to keep more of their earnings would also mean that 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 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. 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.

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

#### ENDNOTES

- [1]: The estimated reductions are based on fiscal year 1995 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]: *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); *Social Security: Disability Programs Lag in Promoting Return to Work* (GAO/HEHS-97-46, Mar. 17, 1997); and *Social Security Disability Insurance: Multiple Factors Affect Beneficiaries' Ability to Return to Work* (GAO/HEHS-98-39, Jan. 12, 1998).
- [3]: State vocational rehabilitation agencies also provide rehabilitation services to people not involved with the DI program.
- [4]: 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.
- [5]: 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.
- [6]: See GAO/HEHS-96-62, Apr. 24, 1996.
- [7]: 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.
- [8]: The tax credit used in this example assumes that the credit is refundable and supplements the existing Earned Income Tax Credit.
- [9]: 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," in *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.

#### RELATED GAO PRODUCTS

- 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-HEHS-95-97, Mar. 2, 1995).
- Social Security: Disability Rolls Keep Growing, While Explanations Remain Elusive* (GAO/HEHS-94-34, Feb. 8, 1994).
- Vocational Rehabilitation: Evidence for Federal Program's Effectiveness Is Mixed* (GAO/PEMD-93-19, Aug. 27, 1993).

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PREPARED STATEMENT OF BRIAN IRISH

My name is Brian Irish. I live at 65 Meadow Drive in Burlington, Vermont. I am 34 years old and have been disabled with a spinal cord injury since September 21, 1985. I had worked full-time jobs since 1981 when I was 17. In fact, I worked two full-time jobs from the time I graduated from high school until my injury which was caused when I fell asleep on my way home from work.

I have received Social Security Disability benefits for many years. One of my employers kept me on part-time even after my injury in order to keep health coverage. However, they needed a full-time worker for this position and since I would lose my SSDI and health benefits, I was forced to quit—the first job I ever had to quit. After lots of efforts, I was disappointed to learn that, if I earned over \$500/month, I'd lose my Social Security check of over \$700/month plus my medical benefits. After my trial work period ended, I had to choose not to work although I can work, want to work, but can't afford to work. I'd be losing money so my only choice is to stay out of the working field to keep my medical benefits and an income I can live on.

To get myself back to work I have been through many college courses in computer science, have used Social Security's Plan for Achieving Self Support (PASS), been through a lot of occupational/physical therapies, and have done everything else to help myself get back to earn a real income and off from public benefit rolls. To keep busy, I have taken up bike riding, horseback riding, serving on the State's "Attendant Services Program" Eligibility Committee, and making candles which I try to sell to make a few dollars without putting benefits at risk.

I therefore think a lot of time and money was wasted on me the way things are standing now. If it changes, as the "Work Incentives Improvement Act" is written, I'd be able to pay my fair share of taxes and to return some of my SSDI income to the government due to my increased opportunity to earn money. It would help a lot of people in my situation to be able to work and create a win-win situation for them and the government by making them taxpayers.

Thank you for the opportunity to testify.

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PREPARED STATEMENT OF HON. EDWARD M. KENNEDY

Mr. Chairman, Senator Breaux, Senator Jeffords and other members of the Subcommittee, thank you for holding this hearing today to consider the serious health care barriers that prevent citizens with disabilities in this country from working and becoming contributing members of their communities.

One of the most significant of these barriers is the lack of appropriate and affordable health care, which continues to rob persons with disabilities and their families of their right to fulfill the American dream of working and living independently.

The Nation is now enjoying an extraordinary period of unparalleled prosperity and continuing economic growth. Three quarters of the 54 million persons with disabilities across the country say they want to work, and large numbers of them have the capacity to work. But they are unable to do so because of the insurmountable barriers they face.

A number of these men and women are here today. They are consumers, family members, citizens, and advocates. And they will tell us that the current work incentive programs for persons with disabilities are failing them and forcing them into poverty.

Too often, persons with disabilities fear that if they take jobs, they will lose the health care that can mean the difference between living and dying. They fear they will lose their current cash benefits, even if they earn only modest amounts from work.

We need to do more to make the opportunities of our prosperous economy available to citizens with disabilities. That is the promise of the Americans with Disabilities Act, and it is time for Congress to do more to redeem that promise.

Senator Jeffords, Senator Harkin, and I continue to work to fulfill that obligation, so that children and adults with disabilities will have access to the health care they need to achieve their full potential.

Our goal is to improve the current disability programs, so that they do more to encourage the disabled to work and live independently. That goal should be the birthright of all Americans—and when we say all, we mean all. Since our Work Incentive Bill was introduced in March, we have been working together to refine the legislation and have made significant progress. We are working closely with the Administration, the House of Representatives, and the disability community.

This bipartisan legislation is designed to remove the unfair barriers facing persons with disabilities who want to work. It will make health insurance coverage more available through to those who work. It will gradually phase out the loss of cash benefits as income rises—instead of the unfair sudden cut-off that so many workers with disabilities face today. It will provide increased assistance to give persons with disabilities greater access to the services they need to become successfully employed.

This legislation is the right thing to do. It is the cost effective thing to do. And now is the time to do it. For too long, citizens with disabilities have been left out or left behind—both in employment and health care coverage. Now is the time to right these wrongs.

I commend Senator Jeffords and Senator Harkin for their leadership on this legislation. We have an excellent opportunity this year to enact legislation that will enable every American to contribute and be part of their community.

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Testimony by Nancy Becker Kennedy to the Senate Finance Committee on  
The Work Incentives Improvement Act of 1998

I CAME TO WASHINGTON HALF MY LIFE AGO TO TALK ABOUT A WOMAN NAMED LYNN THOMPSON. LYNN HAD A PROBLEM FACED BY MOST PEOPLE WITH DISABILITIES--A PROBLEM WE STILL FACE NOW. LYNN WAS UNABLE TO WORK WITHOUT LOSING THE HEALTHCARE BENEFITS SHE NEEDED TO LIVE OUTSIDE OF AN INSTITUTION. LYNN THOMPSON HAD MUSCULAR DYSTROPHY AND COULD ONLY MOVE ONE FINGER. SHE USED IT TO GET A JOB WHERE SHE EARNED 400 DOLLARS A MONTH SCHEDULING NURSES FOR A NURSES REGISTRY. THERE WERE ARTICLES IN THE NEWSPAPER ABOUT HOW HAPPY LYNN WAS TO BE WORKING AND HOW HAPPY HER EMPLOYER WAS WITH THE JOB SHE WAS DOING. LYNN PROUDLY PAID HER TAXES AND THAT'S WHERE THE HAPPY PART OF THE STORY ENDED.

THE IRS COMPUTER TOLD THE SOCIAL SECURITY COMPUTER AND LYNN RECEIVED A NOTICE THAT READ LIKE A DEATH SENTENCE TO HER. THE LETTER FROM SOCIAL SECURITY TOLD HER THAT SHE WOULD BE LOSING THE ATTENDANT CARE AND MEDICAID THAT ALLOWED LYNN TO LIVE INDEPENDENTLY IN HER APARTMENT. THAT MEANT LYNN WOULD ONLY BE ABLE TO RECEIVE THESE LIFE SUPPORT SERVICES IN AN INSTITUTION. HER APARTMENT AND HER JOB WOULD BECOME A THING OF THE PAST. THE FUTURE WITHOUT THEM WAS UNBEARABLE TO HER. LYNN GAVE HER ATTENDANT THE NIGHT OFF, TOOK A BOTTLE OF PILLS AND ALCOHOL AND WHILE WAITING TO DIE, LEFT AN AUDIO TAPED SUICIDE MESSAGE. SHE SAID "SOCIAL SECURITY, I OVERCAME EVERYTHING, BUT YOU WERE THE STRAW THAT BROKE THE CAMEL'S BACK."

I WAS INTERVIEWED ON "SIXTY MINUTES" THAT YEAR TALKING ABOUT LYNN'S DEATH AND CAME TO WASHINGTON TO JOIN AN EFFORT TO CHANGE THE LAW THAT THREATENED ALL PEOPLE WITH DISABILITIES WHO TRIED TO WORK. THAT LAW SAID THAT REGARDLESS OF YOUR TRUE PHYSICAL DISABILITY, IF YOU EARNED OVER 300 DOLLARS FOR NINE NON CONSECUTIVE MONTHS, NO MATTER THAT 300 DOLLARS WAS NOWHERE NEAR ENOUGH MONEY TO SUPPORT A LIFE WITH A DISABILITY, THAT YOU WERE NO LONGER CONSIDERED DISABLED BY SOCIAL SECURITY AND THEREFORE INELIGIBLE FOR ATTENDANT SERVICES OR MEDICAL CARE.

AS A 24 YEAR OLD, JUST OUT OF COLLEGE AFTER MY INJURY WITH A MASTER'S DEGREE, I WAS TERRIBLY THWARTED TRYING TO FIND A JOB THAT WOULD PAY ENOUGH FOR MY EXTRAORDINARY MEDICAL EXPENSES.

LET'S LOOK AT THE MATH OF A LIFE WHERE ELECTRIC WHEELCHAIRS CAN COST 11 THOUSAND DOLLARS, A FLAT TIRE ON THAT WHEELCHAIR CAN COST 200 DOLLARS AND THEN THERE'S THAT 6 DOLLAR PILL TAKEN FOUR TIMES

A DAY FOR CHRONIC BLADDER INFECTION FROM 12 DOLLAR INDWELLING CATHETERS AND IF YOU HAPPEN TO NEED A RESPIRATOR FOR THREE THOUSAND DOLLARS A MONTH, YOU BETTER START PULLING DOWN THE SALARY OF A CORPORATE CEO IF YOU PLAN TO MAKE ENOUGH MONEY TO SUPPORT THE EXPENSIVE HABIT OF BEING DISABLED. NOT EVERYONE NEEDS A RESPIRATOR, BUT WHEN YOU DO THE MATH, ONE CAN SEE THAT TO COVER ALL THE NEEDS AND PAY ATTENDANT SERVICES AS WELL, ONE MUST MAKE A VERY HANDSOME LIVING TO PAY FOR ALL OF THIS WITHOUT SOME ASSISTANCE.

IT WAS NOT ONLY HARD TO FIND A JOB THAT WOULD PAY FOR MY DISABILITY BUT THERE WAS THE REAL FEAR THAT THE CLIFF LYNN THOMPSON ROLLED OVER FOR WORKING FOR NINE MONTHS WAS WAITING FOR ME IF THE JOB I WAS LUCKY ENOUGH TO GET EVER ENDED.

— THAT SUNDAY NIGHT ON "SIXTY MINUTES, WHEN THE SOUND OF LYNN'S TAPE RECORDED SUICIDE MESSAGE SO SHOCKED AND SADDENED THE VIEWING PUBLIC, OUR EFFORTS IN WASHINGTON TO CHANGE THE LAW ACCELERATED. FINALLY RESULTING IN THE ADDITION OF SECTION 1619 TO THE SOCIAL SECURITY ACT. 1619 CREATED AN ELEGANTLY SIMPLE AND INFINITELY MORE SANE WAY TO DEAL WITH PEOPLE WITH DISABILITIES WHO WANTED TO WORK. IT PROVIDED A SLIDING SCALE OF BENEFIT REDUCTIONS THAT ALLOWED PEOPLE WITH DISABILITIES TO RECEIVE ATTENDANT AND MEDICAL SERVICES UNTIL THEY MADE ENOUGH MONEY NOT TO NEED IT. THIS USHERED PEOPLE GENTLY TO INDEPENDENCE. AND IF YOU LOST YOUR JOB, YOU WERE STILL CONSIDERED DISABLED IF YOU WERE STILL DISABLED. SENATOR BOB DOLE ALONG WITH OTHERS HAD A GREAT DEAL TO DO WITH THE PASSAGE OF THE 1619 PROVISION TO THE SOCIAL SECURITY ACT AND WHAT MAY SOUND LIKE A COUPLE OF NUMBERS TO SOME SOUNDED LIKE A LIBERTY BELL TO PEOPLE WITH DISABILITIES WHO WANTED TO WORK.

UNFORTUNATELY, LIKE THE LAW THAT COULD HAVE SAVED LYNN THOMPSON'S LIFE, 1619 IS STILL LITTLE KNOWN BY MOST PEOPLE WITH DISABILITIES AND MANY PEOPLE IN SOCIAL SECURITY AS WELL. ANOTHER PROBLEM WAS THAT AS SOME OF US WENT ON TO WORK FOR YEARS AND PAY INTO THE SYSTEM. WE AUTOMATICALLY CONVERTED TO SSDI ELIGIBILITY. A PROGRAM THAT WAS SUPPOSED TO BE A SUPERIOR BENEFIT THAT REWARDED YEARS OF WORK. UNFORTUNATELY, IT DIDN'T WORK THAT WAY AND FOR ME AND OTHERS LIKE ME. THERE IS NO SLIDING SCALE OR 1619 PROVISION ON SSDI. IT'S NINE NON CONSECUTIVE MONTHS IN FIVE YEARS AND YOU'RE OUT. NO MATTER HOW LITTLE MONEY YOU MAKE OR IF THE WORK CONTINUES. THIS YEAR I WAS THROWN BACK INTO THE SAME SITUATION I FACED AS A 24 YEAR OLD GIRL. ONCE AGAIN IT'S ALL OR NOTHING. AFTER 9 MONTHS, CONGRATULATE ME, I WILL HAVE BEEN MIRACULOUSLY CURED OF MY DISABILITY, NOT IN REALITY BUT ACCORDING TO SOCIAL SECURITY.

I NEVER LIKED THE TERM "WORK INCENTIVE" BECAUSE WE HAVE NEVER NEEDED AN INCENTIVE TO WORK. WE ONLY NEEDED A WAY NOT TO COMMIT A KIND OF "RED TAPE SUICIDE" THAT WOULD REMOVE US FROM AN INDEPENDENT LIFE IN THE COMMUNITY IF WE TRIED TO WORK. THE JEFFORDS/KENNEDY

"WORK INCENTIVES IMPROVEMENT ACT" COULD BE THE BEGINNING OF AN END TO THE DANGEROUS GAME OF "CHICKEN" WE PLAY WITH OUR FREEDOM WHEN WE ATTEMPT TO WORK. "THE WORK INCENTIVES IMPROVEMENT ACT" COULD SOON UNTIE US FROM DEPENDENCE ON CASH BENEFITS AND WELFARE.

WITHOUT THIS BILL, WE ARE TRAPPED IN A CYCLE OF POVERTY AND SHAME. WITH NO CHANCE TO PARTICIPATE. WE ARE BEACHED ON THE SIDELINES. IF WE CAN FIGURE OUT HOW TO CONTRIBUTE PRODUCTIVELY WITHOUT BEING PAID WE STILL FEEL HANDICAPPED--CAP IN HAND. TRAPPED IN POVERTY. NO PRIDE IN A PAYCHECK OR TAXES PAID. RELEGATED TO THE FRINGES, NO MATTER THAT WE'RE EDUCATED. NO MATTER THAT WE'RE TALENTED, NO MATTER THAT WE'RE DETERMINED--WE DON'T GET TO PARTICIPATE IN CONTRIBUTING. THE GULF WE HAVE TO JUMP IS JUST TOO WIDE. THE BIBLE SAYS, LAY NOT A STUMBLING BLOCK BEFORE THE BLIND. SHOULDN'T THAT GO FOR ALL PEOPLE WITH DISABILITIES AS WELL. THIS IS THAT STUMBLING BLOCK.

WE CAN'T RISK LOSING THE ATTENDANT CARE AND LIFE AND HEALTH SUPPORT SERVICES THAT ALLOW US TO LIVE IN THE COMMUNITY. BECAUSE IF WE DARE TO MAKE MONEY BUT DON'T MAKE ENOUGH OF IT FOR LONG ENOUGH OR HAVE TO STOP, WE WILL BE PUSHED FURTHER AWAY FROM SOCIETY--INTO NURSING HOMES-- THOSE WAITING ROOMS FOR DEATH--WHERE TAX PAYERS SPEND SEVERAL TIMES THE COST TO TAKE AWAY OUR FREEDOM.

THE CURRENT POLICY MAY SEEM LIKE BENIGN NEGLECT BUT IT IS IN FACT CRUEL--VERY DEFINITE AND EFFECTIVE SEGREGATION THAT DIVIDES US FROM THE MAINSTREAM OF SOCIETY. ON THE EVE OF THE 8TH ANNIVERSARY OF THE AMERICAN'S WITH DISABILITIES ACT, OUR BILL OF RIGHTS ISN'T WORTH THE PAPER IT IS WRITTEN ON IF ONLY 2 PERCENT OF US CAN TAKE PART IN THE WORKING LIFE OF THIS COUNTRY. DON'T MAKE US RISK OUR SURVIVAL TO TAKE PART IN THE LIFE OF THE COMMUNITY THAT OTHERS TAKE FOR GRANTED. I AM MORE WEARY THAN I CAN EXPRESS OF THIS 26 YEAR STRUGGLE AS MY DISABLED BROTHERS AND SISTERS AND I PAY FOR OUR SURVIVAL WITH OUR FAILURE. I WANT LYNN THOMPSON'S ENTERPRISE TO BE REWARDED POSTHUMOUSLY. I WANT HER DESPAIR TO BE CORRECTED. I WANT HER LIFE TO HAVE MATTERED. PASS THE "WORK INCENTIVES IMPROVEMENT ACT" AND LET PEOPLE WITH DISABILITIES GIVE THIS COUNTRY THE GIFTS WE HAVE TO OFFER.



## PREPARED STATEMENT OF PAUL VAN DE WATER

Mr. Chairman and Members of the Subcommittee, I am honored to represent the Congressional Budget Office (CBO) this afternoon at your hearing on the Work Incentives Improvement Act. On June 1, CBO staff provided you with a preliminary cost analysis of the bill. My oral remarks will touch on the high points of that analysis and identify some of the salient issues in improving work incentives for disabled recipients of Social Security and Supplemental Security Income (SSI).

S. 1858 would provide work counseling and assistance services to certain working or work-ready persons with disabilities and extended eligibility for Medicare to some former recipients of Social Security Disability Insurance (DI). The bulk of the bill's costs, however, would stem from the extension of personal assistance services and prescription drug benefits under Medicaid. CBO has estimated that, in its first full year of operation, some 200,000 people would receive these so-called Medicaid work incentive services at an annual federal cost of over \$1 billion. Ninety percent of this cost would be attributable to the 150,000 participants who would not otherwise be eligible for Medicaid.

Although some observers have suggested that CBO's estimate is too high, there is at least an equal chance that the costs of the bill could be higher still. About 8 million people between the ages of 18 and 64 collect Social Security or SSI benefits on account of disability, and 17 million people in that age group report a work disability. CBO's estimate of 2200,000 participants under S. 1858 represents only 2 percent of current DI and SSI disability beneficiaries and just 1 percent of those with a self-reported work disability. Clearly, the potential demand for benefits under S. 1858 could be much greater than CBO has assumed. The uncertainty regarding the number of potential recipients is magnified by the fact that the bill would leave it up to the states to decide whether to participate and to determine eligibility for benefits if they did.

Not only may CBO have underestimated the number of beneficiaries, the estimated cost per beneficiary of the new Medicaid benefits could also be too low. At present, the combined federal per capita cost of prescription drugs and personal assistance services—for those using such services—is \$5,800 a year. Under the enhanced federal matching rate in the bill, the federal government's per capita cost would amount to about \$7,000. Not only are prescription drugs and personal assistance services very expensive, but they are also the fastest growing components of Medicaid. The per capita costs could further skyrocket if benefits were provided to many users of high-cost prescription drugs, for example, protease inhibitors for patients with HIV.

Another frequently asked question is why CBO's estimate of S. 1858 incorporates no offsetting savings in Social Security Disability Insurance, SSI, or other federal income maintenance programs. The sad fact is that prior efforts to improve work incentives in DI and SSI have had no measurable impact. In 1980, when the programs were modified to provide additional work incentives, 3.3 percent of the relevant age group was receiving Social Security or SSI disability benefits. Research by analysts at the Social Security Administration shows that few beneficiaries work, that even fewer leave the benefit rolls, and that many of the factors that lead to work are not likely to be influenced by governmental policies. This result is not surprising in light of the stringent definition of disability DI and SSI and the six-month waiting period for DI. Even if some beneficiaries were willing to forgo other federal benefits if they were assured of Medicaid work incentive services, there is at least an equal probability that some people would limit their earnings and income in order to qualify for those new benefits. Moreover, S. 1858 would expand the definition of impairment-related work expenses, thus making it possible for some DI beneficiaries to retain benefits they would otherwise lose. Finally, both DI and SSI benefits would be costlier if the outreach and counseling efforts required by the bill led to more applications for benefits. Because these effects are highly uncertain and work in opposite directions, CBO's cost estimate of S. 1858 includes no offsetting savings in DI, SSI, or other federal programs.

In conclusion, Mr. Chairman, S. 1858 focuses on a highly important issue—how to structure the federal government's disability programs to provide assistance to those in need, create incentives for productive work, and minimize costs to the taxpayer. Federal policymakers have been striving to reach these goals for at least 20 years, but achieving them all simultaneously has proved elusive. Because any across-the-board expansion of benefits raises the possibility of additional federal costs without any guarantee of offsetting savings, one alternative would be to provide the Social Security Administration with authority to try out various work incentives, including those in S. 1858, on an experimental basis.



## COMMUNICATIONS

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### STATEMENT OF THE NATIONAL ALLIANCE FOR THE MENTALLY ILL

(SUBMITTED BY JIM MCNULTY)

Chairman Chafee 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 this very important legislation for people with severe mental illnesses.

I, myself, suffer from 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 assisting us to 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. S. 1858 is 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 its 1,140 affiliates and chapters, NAMI represents 185,000 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.

We know that 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 1% 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.

Recent studies all demonstrate that there are 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 work incentives; 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 Work Incentive Provisions of 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, 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 high-cost medication 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 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.

S. 1858 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 does NAMI support S. 1858?

- (1) It addresses 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,
- (2) It begins the process of reforming the severe penalties in the SSDI program that wipe out cash benefits just as beneficiaries begin moving toward independence,
- (3) It expands individual choice for beneficiaries who need employment and rehabilitation services,
- (4) It addresses the overly complicated and often conflicting rules involved in each of these public programs,
- (5) It does no harm to those beneficiaries who are either not ready to go to work or who try to work and fail,
- (6) It benefits all Americans—taxpayers, employers, and families—by furthering the goals of the Americans With Disabilities Act (ADA) by promoting empowerment and independence.

### *1. 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 control of symptoms that allows an individual to lead a normal life. The most advanced treatment for severe mental illnesses involve medications such as new atypical antipsychotics and selective serotonin reuptake inhibitors (SSRIs) that are very expensive.

Even in cases where consumers and their families have access to private health insurance coverage, such coverage often 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.

S. 1858 addresses these issues head-on by extending Medicare coverage and allowing states the option to make outpatient prescription drug coverage available to SSDI recipients who are ready to enter the workforce. More importantly, it will “catch people on the way down” by filling the gaps in both private plans and Medicare so that people will not have to permanently leave employment and go into poverty to ensure health security. This is a critical protection for persons living with an episodic illness of the brain that too often fails to follow a predictable course.

## *2. Reforming the SSDI “cash cliff”*

S. 1858 requires 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 “wood-working” among persons not currently in the SSDI program. NAMI believes that 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.

## *3. Promoting consumer choice through the “ticket to independence”*

It is NAMI’s understanding that the sponsors of S. 1858 intend to add the “ticket to independence” contained in HR 3433 to the bill that passed the House on June 4 by a margin of 410 to 1. NAMI applauds this decision. 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 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 the 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 positive step forward.

#### *4. Simplifying the process for consumers and families*

One of the most common complaints among NAMI members regarding 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. Putting work incentive specialists in SSA field offices will go a long way toward helping 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 the passage of this bill. The current bill contains 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 protections be added to both the ticket and healthcare pieces of this legislation to ensure 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 dictates that these programs be flexible enough to accommodate consumers who may experience severe, though brief, episodes of acute illness.

#### *6. Benefits all Americans*

S. 1858 sets the stage for important improvements in SSA'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, not only catching people with disabilities as they fall out of work, but also giving them a boost back into work when they are ready.

This legislation has the potential to be a win-win situation for all Americans. It benefits beneficiaries by enabling them to return to or enter the workforce as wage earners. It benefits employers by adding skilled workers to the labor pool. It benefits employment service providers by enabling them to serve more participants. Finally,

it benefits taxpayers by assisting workers with disabilities to begin, or continue, paying taxes.

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 importantly, 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. Passage of S 1858 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.

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#### STATEMENT OF THE PARALYZED VETERANS OF AMERICA

Paralyzed Veterans of America commends Senators James Jeffords and Edward Kennedy for introducing the Work Incentives Improvement Act of 1998. This legislation represents a laudable, bipartisan effort to refashion the Social Security disability insurance system by removing significant barriers to work that now confront beneficiaries of disability insurance [SSDI] and supplemental security income [SSI].

Because 78 percent of PVA members receive either SSDI or SSI, PVA has identified certain principles to which we believe any reform legislation should conform. Foremost is the need to assure that individuals who leave the SSDI or SSI rolls to attempt working should retain access to health care coverage. Right now, SSDI and SSI recipients who return to work can remain covered by Medicare for free for up to 39 months, with an expensive buy-in provision beyond that. However, if their job carries no health insurance coverage, they risk becoming uninsured when that time expires. This is one of the greatest impediments to SSI and SSDI beneficiaries' ability to return to productive employment.

The Jeffords/Kennedy bill offers an OPTIONS program to long-term SSDI beneficiaries which provides free Medicare Part A coverage for beneficiaries earning up to 250% of poverty with a sliding scale buy-in beyond that. A Part B buy-in at the standard premium would also be available. Beneficiaries would use the employer-provided health coverage, if such coverage is provided. However, if no employer insurance is offered, or is inadequate for their needs, these beneficiaries would have the security of knowing that Medicare would be there as a backup for as long as they needed it. In addition, states would be encouraged to adopt a program through their Medicaid system whereby these individuals could obtain personal assistance services (PAS) and prescription drugs through a buy-in to that program. This latter provision is especially important to beneficiaries who need PAS and certain high cost prescription drugs to enable them to return to work.

PVA also believes that SSDI and SSI recipients should have the freedom and opportunity to select the services they need to attain career and employment goals. HR 3433, approved by the House in May, contains significant provisions that would broaden peoples' choice of vocational and employment providers. Augmenting the Work Incentive Counseling and Assistance Program within S. 1858 with a system of "tickets" like that proposed in HR 3433 should help beneficiaries identify services that are available to meet their needs.

Third, PVA believes that people should not be financially penalized for returning to work. Too many SSDI beneficiaries feel compelled to keep their earnings below the level of substantial gainful activity [SGA], which is currently set at \$500 per month in earnings for the non-visually impaired, in order to preserve their limited cash support and access to Medicare. This is a tragic waste of human potential. The Jeffords/Kennedy bill retains the existing SGA level but does require the SSA Commissioner to conduct demonstration projects to test the idea of phasing out benefits. PVA believes that cash benefits should be phased out as earnings rise but recognizes that concerns over costs make demonstration projects the approach most likely to succeed in finding an answer to this difficult question. If the SGA concept must

be retained, PVA would prefer that the limit, which has not been increased since 1990, be made consistent for all people with disabilities and indexed for inflation.

Another helpful aspect to this measure is the expanded Impairment Related Work Expenses deduction it provides to long term SSDI recipients for costs associated with traveling to and from a job. This provision may help keep recipients' income below SGA and thus avoid the "income cliff" while they are attempting a return to work.

The bill also offers some protection to individuals who had been in the 24-month waiting period for Medicare, who enter the work incentives program, and who then must drop out. The bill would return them to their same status but they would receive credit toward Medicare eligibility for the time they were in the OPTIONS program. In addition, the bill stipulates that entrance into the work incentives program should not result in a continuing disability review [other than those already scheduled] and that participation in the work incentives program cannot be used as evidence that the disability has ceased. Many beneficiaries live in fear that any attempt to work will prompt a disability review with the prospect that their benefits may be terminated. Provisions such as these ensure that beneficiaries who enter the OPTIONS program but are unsuccessful in their efforts to leave the rolls will be no worse off than if they had not attempted a return to work.

The Work Incentives Improvement Act of 1998 is a solid step in the right direction. We look forward to working with the authors of this measure to move this initiative forward during this Congress. We offer to Senators Kennedy and Jeffords PVA's commitment to transforming federal disability programs from barriers to work to bridges to opportunity.

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#### STATEMENT OF THE SOCIETY FOR HUMAN RESOURCE MANAGEMENT

Chairman Chafee and Members of the Subcommittee:

We commend the Subcommittee for holding a hearing to examine S. 1858, the Work Incentives Improvement Act. Thank you for the opportunity to express the views of the Society for Human Resource Management. The Society for Human Resource Management (SHRM) is the leading voice of the human resource profession. SHRM, which celebrates its 50th anniversary in 1998, provides education and information services, conferences and seminars, government and media representation, online services and publications to more than 100,000 professional and student members through out the world. The Society, the world's largest human resource management association, is a founding member of the North American Human Resource Management Association and a founding member and Secretariat of the World Federation of Personnel Management Associations (WFPMA).

We are strong supporters of initiatives that aim to break down barriers to those seeking employment. Earlier this year we sent a letter to the Senate supporting the Work Incentives Improvement Act, H.R. 3433. Our support is based on the SHRM Board approved Fair Employment Principles which state that: "SHRM is committed to promoting workplace diversity and fair employment practices because they contribute significantly to the success of our members and our member's organizations. Recognizing that this country's competitive advantage will be derived from individual contributions, SHRM encourages employers to take proactive steps to eliminate the physical, attitudinal and organizational obstacles that may prevent individuals from reaching their full potential in the workplace."

We need to examine the barriers that the disabled face in their efforts to find employment. Health insurance coverage for individuals with disabilities who want to work is a critical issue. We should not force the disabled to choose between work and healthcare and there should be incentives for them to join the workforce, not disincentives. As you may know, one critical barrier to those who are disabled is their inability to obtain affordable health insurance through Medicare. Out of more than 3.5 million beneficiaries, only 114 have chosen to buy in to Medicare because of the cost of the \$370 premium per month.

This legislation will help many more individuals to reach their full potential as they join the workforce. We have seen a dramatic transformation in the ability of the disabled to contribute to the economy. Until recently, we could not even imagine the advances in technology and medicine and the changes toward attitudes towards the disabled that have helped them more fully participate in the workforce. This type of legislation will continue the positive trend.

A recent Louis Harris survey for the National Organization on Disability reported a part-time or full-time employment rate of only 29% for non-institutionalized working age adults with disabilities compared to 79% for the population. The same survey indicates that 72% of those persons who are unemployed said they would prefer



to work. The survey also found that 32% of those disabled individuals who have health insurance have special needs, such as equipment or medicine that aren't covered by their health insurance. One in five or 18% of those that don't have health insurance were unable to get it because of a disability or a pre-existing condition.

Numerous tangible and intangible benefits will result by increasingly employing disabled individuals. We strongly urge Congress to enact this critical legislation.

