S. HRG. 106-122

# WORK INCENTIVES IMPROVEMENT ACT OF 1999

## HEARING

BEFORE THE

## COMMITTEE ON FINANCE
## UNITED STATES SENATE

ONE HUNDRED SIXTH CONGRESS

FIRST SESSION

ON

## S. 331

FEBRUARY 4, 1999

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# WORK INCENTIVES IMPROVEMENT ACT OF 1999

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THURSDAY, FEBRUARY 4, 1999

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

The hearing was convened, pursuant to notice, at 9:59 a.m., in room SD–215, Dirksen Senate Office Building, Hon. William V. Roth, Jr. (chairman of the committee) presiding.

Also present: Senators Chafee, Jeffords, Thompson, Moynihan, Kerrey, and Robb.

## OPENING STATEMENT OF HON. WILLIAM V. ROTH, JR., A U.S. SENATOR FROM DELAWARE, CHAIRMAN, COMMITTEE ON FINANCE

The CHAIRMAN. The committee will please be in order.

This is a very special day to have two distinguished colleagues here, Ted Kennedy and—I do not know what to call you, Bob, but I call you a leader or a chairman of a committee or first man or whatever. [Laughter.]

Mr. DOLE. Whatever, I answer to most anything.

The CHAIRMAN. But it is indeed a pleasure to have you here.

I would point out that today our committee is holding, Pat, its first health care hearing in the 106th Congress. And we are here to discuss a very simple goal, helping individuals with disabilities to go to work if they so choose.

In 1990, Congress made a giant step forward, realizing this goal with the passage of the Americans with Disabilities Act. And frankly, it is not a coincidence that our first witnesses today are two of the people most responsible for the enactment of that important piece of legislation. And I thank them.

The Americans with Disabilities Act made an important statement about this Nation's commitment to independence and opportunity for people with disabilities. And since then, barriers that had made even the simplest daily task difficult or even impossible have been lifted.

Millions of Americans now lead more active and integrated lives. But despite the progress that has been made, we all understand that serious obstacles still face people with disabilities, obstacles that stand in the way of getting a job.

So joining with Senators Moynihan, Jeffords, and Kennedy, I have introduced legislation to address some of the remaining impediments to employment for people with disabilities.

Our bill S. 331 promotes access to health insurance and fundamental job assistance. I am pleased that a number of our colleagues have joined us in supporting this legislation.

At a hearing held by our Subcommittee on Social Security and Family Policy last July, lack of health insurance access was identified as a primary barrier to employment for disabled citizens. Hopefully, the Work Incentives Improvement Act will empower States to lift this barrier.

I should point out that rather than continue reading my full statement, I will ask that it be included as if read.

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

The CHAIRMAN. And with that, I would like to make one further statement. We do have here Larry Henderson from Delaware. We are looking forward to his testimony.

And so now, I will be happy to call on you, Senator Moynihan, although my understanding is that you are going to yield to Senator Kennedy because of another engagement.

## OPENING STATEMENT OF HON. DANIEL PATRICK MOYNIHAN, A U.S. SENATOR FROM NEW YORK

Senator MOYNIHAN. I will do exactly that, sir, but may I note that we have 13 members of the Finance Committee have been supporting this measure. And in all, some 41 members of the Senate have already done. And we are on our way and a very important way, too.

By the way, in 1986, Senator Dole, you introduced the Employment Opportunities for Disabled Americans Act. And this follows from there. And I think we are going to make it this year. I have a statement I will place in the record. And thank you, Mr. Chairman.

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

The CHAIRMAN. Thank you, Pat.

Ted, it is pleasure to have you here. And we look forward to your comments.

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

Senator KENNEDY. Thank you very much. Well, I want to thank you, Mr. Chairman, for having these hearings and to my colleagues.

Thanks, Senator Moynihan, for yielding. Both of us was supposed to be at the same place. I do not know how they are going to get along without us, but they will. [Laughter.]

And in any event, this is where it is really at I think. And Senator Moynihan and I would agree.

But I want to thank you, Mr. Chairman, and Senator Moynihan for the really extraordinary leadership which you have provided in bringing us to where we are here today. And it is a real tribute to both of you that we have been able to work, work closely together.

Senator Jeffords is our chair of our Human Resource Committee. We have been trying to work closely with him.

And I think as we look at the start of this session, this is the major piece of legislation that has the strong, bipartisan support and will really affect millions of our fellow citizens not only those that are facing the mental and physical challenges today, but those that may be facing them tomorrow and the next day and the next day. So it is not really a specialized legislation. It really is something for all Americans. And it is really something for the future.

So let me thank both of you so much for your leadership in the hearings that we held last year in the subcommittee and now for giving this the priority. And I thank my good friend and colleague, Senator Jeffords, for his strong and continuing efforts in this area, and Senator Chafee and Senator Thompson, and others.

We are up to 41 co-sponsors. And we hope to be over the 50 mark by the end of this week, by Friday. And this represents a broad range of interests and support across the length and the breadth of the Senate.

I dare say that it is rare that we have that range of support on an issue that is so basic and fundamental and important and significant as this. So we are enormously grateful to you.

I am honored as well to be with someone, Senator Dole, who I think all of us understand has been for such a long period of time such a leader in the whole disability movement.

I remember going back to the 504 legislation, going back to the measures that Senator Moynihan has mentioned sitting in the room of the majority leader for him taking the time when we were considering the Americans with Disabilities Act and to have his leadership at that time really made all of the difference.

And I think for those of us who know his commitment in this area and are aware of his own foundation that does extraordinarily good work in terms of the disabled in this country, having his involvement and support is enormously important. And when the legislation passes, it certainly will be a major tribute to Senator Dole even though he will not have a vote. We might bring him back for a vote on that particular day. [Laughter.]

We will have him on our side. He will be welcome on yours, but we will be glad to include him.

Senator MOYNIHAN. For that vote anyway. [Laughter.]

Senator KENNEDY. I will be very brief, Mr. Chairman. I do not think that there has been a piece of legislation, I am sure you would agree, that the fashion has really been of the people, by the people, for the people as this legislation.

It has been in the works really for 18 months. And I think for those that have really worked at it, it has been eight-hour days, very long, tough, difficult, challenging kinds of negotiations, but so many of those are sitting behind us here today and deserve such a tribute because they have been the ones who have taken this understandable concept, and that is those that are part of the 54 million Americans today that have some disability, want to work, be part of the mainstream, carry through their hopes and dreams, and because of inhibitors in the whole range of previous policymakers, they are discouraged from doing so with the loss of their health insurance, the cash cliff, and the failure of being able to continue to be able to upgrade their skills through vocational education.

And what we have seen is with the development of this legislation, we really have addressed those in a very important and significant way. As the Social Security Administration would point out, of the 55 million, there are approximately 7.5 million disabled individuals on SSI or SSDI. Social Security reports that less than one-half of 1 percent ever go or return to work. If only 75,000 or 1 percent of these individuals work, you are talking about saving $3.5 billion over the work life of the individuals, and I think only 1 percent is a very low estimate of those wanting to work.

That is an important aspect of this legislation. I think it is not of the importance of the legislation that it has in terms of what it means for individuals to be able to be independent, to live their own lives, to be contributing members of the society. And that is what this legislation is really all about.

I want to say finally, Mr. Chairman, we appreciate the leadership of President Clinton. He had indicated his strong support and the support of the administration in support of this legislation during his State of the Union. And also, he had indicated in his budget the favoring through the tax system, the personal attendants that will look after the disabled and other provisions in the HUD program that have some special significance and importance.

So we welcome the chance, Mr. Chairman, to speak to this issue today. We are hopeful of being able to pass this at an early time to really start off this legislative session in a way that will make such an extraordinary difference to millions of our fellow citizens in a way that really speaks the best of the Senate and the House of Representatives that will make such a difference in the lives of millions of our fellow citizens.

And I would ask consent that my full statement be included in the part of the record.

The CHAIRMAN. Without objection.

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

The CHAIRMAN. And just let me say the reason we are having the hearing this morning is that I agree with you. I think it is important that we move ahead early. And I think it is a good indication of what can be accomplished in a bipartisan fashion. We appreciate your being here today.

Senator MOYNIHAN. Mr. Chairman, may I say that a bipartisan measure would improve the lives of the Senators as well. [Laughter.]

The CHAIRMAN. I would agree with that. Senator Moynihan, we will now turn to you.

Senator MOYNIHAN. Thank you very much. I think Senator Jeffords.

The CHAIRMAN. Senator Jeffords.

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

Senator JEFFORDS. Thank you, Mr. Chairman. This is an exciting moment for all of us that have worked so long. Myself, when I came in back in 1975, we started with the kids. And here we are now today finally getting an opening in that final door for those who have disabilities to really have a meaningful life. And I think that this is an incredible moment. And I deeply appreciate all your support.

I would like to make my full statement a part of the record.

But I want to also especially thank Senator Dole for his support over the years and his inspiration in this particular piece of legislation, recognizing that this was the most important final step for reality for people with disabilities to have a real chance to participate in our society.

So I ask to submit my statement.

The CHAIRMAN. Sure.

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

The CHAIRMAN. We are pleased to have here John Chafee.

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

Senator CHAFEE. Thank you very much, Mr. Chairman. I want to join in thanking you. And I particularly want to join in welcoming Senator Dole back. He certainly spent a lot of time in this room, right in that chair and this chair, too.

And I just want to join enthusiastically in the support of this legislation. I want to thank Senator Kennedy for all the leadership that he has given to it.

And what we are trying to do is just make it possible for those with disabilities to, as has been pointed out here, enjoy the full fruits of our society and be able to work. And that is what this is all about.

So I want to enthusiastically support it. And I am so pleased that we are making some progress on this bipartisan effort. Thank you, Mr. Chairman.

The CHAIRMAN. Thank you, Senator Chafee.

I do not know that I have ever officially welcomed Fred Thompson to the committee. We are delighted to have him. It is another example of another chairman joining this committee, but I know he will contribute mightily.

Senator MOYNIHAN. He is most welcome on our side too, Mr. Chairman. [Laughter.]

The CHAIRMAN. I can barely see you.

## OPENING STATEMENT OF HON. FRED THOMPSON, A U.S. SENATOR FROM TENNESSEE

Senator THOMPSON. Thank you very much. I appreciate your kind words. I am looking forward to the work on this committee very, very much under your leadership. Thank you for this hearing today.

I have a short statement I would like to make part of the record.

If I may join in the welcome to our dear friends. Thank you.

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

The CHAIRMAN. Thank you, Senator Thompson.

Mr. LEADER.

Mr. DOLE. Ted is going to go and take care of the Democrats.

The CHAIRMAN. I was asked to keep him away from there. [Laughter.]

Mr. DOLE. It does not make much difference. But I want to thank him for his outstanding leadership in this and many other areas before he leaves. I appreciate it very much.

The CHAIRMAN. Thank you, Ted.

Senator KENNEDY. Thank you, Mr. Chairman.

## STATEMENT OF HON. ROBERT DOLE, FORMER SENATE MAJORITY LEADER FROM KANSAS

Mr. DOLE. And let me say that I am not certain I miss being here at this time, but it is always good to come back and to be before this committee. And I remember last year when Senator Jeffords and Senator Kennedy had the hearings. And I think that sort of laid the ground work.

And if you have 47 co-sponsors, I think I padded it just a little bit because some people slip and slide a little bit between the time they co-sponsor and passage. So it may be 55, 58, something like that, but I hope there are an equal number of Republicans. And I am certain this will be a strong, bipartisan legislation.

I think Senator Roth made it very clear, this is about people going to work. This is about dignity and opportunity and all the things we talk about when we talk about Americans generally, but particularly many of the people seated behind me have stories that I know will be very impressive. And I am not certain how many will be testifying.

But we have made dramatic improvements in removing barriers, whether they are the architectural barriers or attitudinal barriers, whatever barriers may have existed, but we still have some way to go and certainly the ADA.

And I thank all my colleagues for their assistance and always thank President Bush for being actively supportive of that legislation.

And I will always remember the signing ceremony at the White House where we had, I do not know, hundreds and hundreds of wheelchairs. It has not happened since, but it was an indication that this was an inclusive piece of legislation. And we were trying to make life better for all Americans.

But that did not complete the work, as Senator Kennedy has said, of removing barriers. And access to health care remains an enormous hurdle confronting people with disabilities who want to work. And that is where the Work Incentives Improvement Act of 1999 can make a big difference.

According to a report issued last summer by the National Organization on Disability, 72 percent of unemployed Americans with disabilities want to go to work. Three out of four want to go to work. Yet, not more than 1 in 500 receiving Social Security disability benefits, SSDI, ever returns to work. And that is what this legislation is all about.

And I think as I have checked the numbers, for example, the average SSDI beneficiary collects about $4,596 in cash benefits from the government each year. And if they choose not to work, they will still receive Medicaid benefits. But if they decide to go to work instead of collecting the $4,596 in cash benefits from the government, they will become taxpayers. So this is what it is all about.

And obviously, it is not going to work in every case. And you never know what the final estimate will be. And Senator Kennedy had an estimate of how much it would return. But in any event, even if it does not match or exceed those expectations, the legislation is certainly needed.

Throughout 1997, the GAO conducted interviews of SSDI beneficiaries who had gone back to work. And these people told the Government Accounting Office that the most important factor in making work possible was health care because it helped them function better.

Mr. Chairman, this is very important and not hard to understand. Employer-sponsored health insurance is a key factor in separating SSDI beneficiaries who plan to leave the cash benefit rolls and go back to work from those who stay.

And let me say this again, access to health insurance makes all the difference. It makes all the difference when it comes to making the leap from the disability rolls to the job rolls because if you do not have it, you are not going to make the leap. And if you do not make the leap, you are going to be there forever, not working even though you want to work because of the disincentives in the program.

So what does this bill do? It addresses that particular issue head on. It removes that particular barrier. And it seems to me that it is all because somebody had an idea and somebody kept working on it.

And I know that you are going to have a painless pay-for that everybody will agree on. And it does—my time is about up.

The CHAIRMAN. Take as much as you want.

Mr. DOLE. But the bill does create two new Medicaid options for States. And that is sort of the key to the program. And it also provides a demonstration program that allows people who leave the SSDI program to receive Medicare for 10 years, up from 39 months currently.

But it is not about big government in my view. It is about good government. And I congratulate all those who have taken a leading role. And now that it is before the Finance Committee working with the members of the Labor Committee, it seems to me that it is off to a good start.

Let me just mention one other thing. I think rehabilitation, having had some of that a long time ago, is very, very important. And I want to mention that it is included in my statement. It is a marriage that I think the committee needs to address in addition to what you are addressing in the bill.

One segment of our health care system that is essentially returning the disabled to work was dealt a crippling blow by the Balanced Budget Act of 1997. And I am referring to rehabilitation hospitals, facilities, and units without which our disabled rolls would be much greater as their services retrain and rehabilitate many individuals and return them to the work force.

And I know the staff will check this out, that section 4415 of the Balanced Budget Act of 1997 repealed the full incentive payment percentages for the Prospective Payment System exempt rehabilitation hospitals and units. It also reduced capital payments for PPS-exempt hospitals by 15 percent from fiscal 1998 to the year 2002.

And the combined effect of these provisions severely hamstrung the ability of these facilities to serve disabled individuals.

And I know there is some discussion about the benefits of rehabilitation, but I visited some of the outstanding rehabilitation hospitals in America, particularly the one in Chicago, the rehabilitation institute there.

And I can tell you that it makes a big, big difference, the sort of before and after pictures of those who go into rehabilitation and those who come out of rehabilitation and their attitude and their ability and all the other things that go with it.

So I would just ask this committee without going into further detail if someone would take a look at that part of my statement and assess it.

Maybe, it can be justified, but I know what it means to some of these rehabilitation hospitals. And we have about 100 in the United States. And they are very, very important. And the last thing we want to do, that you want to do is to deprive somebody of that benefit that might make them a productive citizen and a taxpaying citizen.

And the reason is because they are so heavily dependent on Medicare. That is the primary reason. They have few non-Medicare patients. They cannot shift costs because 65 to 70 percent of the patients are Medicare patients. So there is not any shifting that can take place in rehabilitation hospitals. They are a little different than other hospitals.

And I think that is why it would be helpful if you would take a look at this very important matter. And I know that there are a number of outstanding rehabilitation specialists who would be happy to come before the committee at some other time.

But again, I urge the committee to take prompt action on the bill that has this strong, bipartisan support and thank the committee for letting me come up and testify on what I think is a very important piece of legislation.

And it is I think time for some bipartisanship in the Congress. And this would certainly be a good way to start it. If you would just take this bill out today and pass it, I think everybody would be happy. You could write the report later. [Laughter.]

The CHAIRMAN. Well, thank you very much, Senator Dole. Let me go back to your comment on the co-sponsors. I am very pleased that among the original co-sponsors of S. 331 from the Finance Committee, we have Senators Chafee, Grassley, Hatch, Murkowski, Breaux, Graham, Kerrey, Robb, Rockefeller. And I believe Conrad has joined us. The total number that we have right now is 40 Senators. You said 50, 55. That is a good Republican count. [Laughter.]

Mr. DOLE. Right. They thought you had 47, but they always exaggerate.

The CHAIRMAN. Actually, we may have more. But I think it is important that we move ahead.

It is unusual that you get such broad support from liberal to conservative. Why do you think the Work Incentives Improvement Act is attracting such broad support?

Mr. DOLE. Well, I think there is a recognition that nothing costs the government more than keeping creative and intelligent people from doing what they would like to do. I mean, these are people, as I said, who are willing, three out of four who want to work. And I do not know the what the final number is. Senator Kennedy indicated it may be as many as 10 million.

But now, they are trapped at home. They are collecting cash benefits instead of in the work force paying taxes. And as I indicated earlier, there is about a $5,000 average payment under SSDI. And if you have to forego that, many people are not going to go out and work if they do not have appropriate health coverage.

So my view is that it is a recognition that we are all valuable citizens in America regardless of our physical ability or disability. And it has been my view over the years that persons with disabilities are very loyal in the work force. They work long hours. Sometimes, it may take them longer, but the bottom line is they are good, productive workers in the sense I am not just talking about workers. I am talking about whatever the level may be. And that is why I believe that we have had this coming together of different philosophies.

As I said, this is not a big government. It is a good government program. And again, I think the fact that, well, the President did acknowledge the program in his State of the Union message. And that indicates additional support.

The CHAIRMAN. I can think of no group more deserving of help than the disabled. And I think it is encouraging to learn and hear how much these people do want to go to work. That is what we are trying to bring about.

Mr. DOLE. And again, I would say, but without disagreeing with the Chairman, I do not think it is help they are looking for. It is just opportunity.

The CHAIRMAN. That puts it very much——

Mr. DOLE. It is opportunity. It is tearing this down barrier that makes it impossible or almost impossible for men and women with disabilities to go into the work force. And to me, that just creates a whole new opportunity, a whole new horizon for people all across America.

The CHAIRMAN. And I think that something that is not recognized is that we were not just talking about people who were disabled from the beginning. It can happen to anybody, to any of us.

Mr. DOLE. Every day.

The CHAIRMAN. And we want to make sure that there is that opportunity for them.

I appreciate your being here.

And I will now ask Senator Jeffords.

Senator JEFFORDS. Thank you, Mr. Chairman. And I certainly want to again thank Senator Dole for the incredible help he has given us over the years. There is no question in mind that we would not be here today if it were not for your support.

When we met last year and had a broad spectrum of people with disabilities in the Mansfield room, and it was just a most rewarding moment I have had. And you were the star. You were the one that brought them there because you are their hero. And what you have done over the years for the disabled is just incredible. And I just want to thank you for that.

But I think you would agree with me that there is nothing more rewarding to any individual than finally to be unshackled and have the ability to go to work. And the feeling that must come to someone who has finally opened that door.

And would you agree with that?

Mr. DOLE. Well, there is no doubt about it. I look back at my own life. And without getting personal about it, but we had health care. And we had assistance from the government. I had a left-handed typewriter. I had a recording machine I could take to class because I could not take notes. And so we had all these opportunities provided to us. And what was the result?

We also had the GI bill which in my view changed the world, one piece of legislation, but it certainly I think made many of us with disabilities because of World War II productive citizens.

And I am pleased to see that they are going to add a wheelchair to the Roosevelt Memorial, another indication that we are not hiding our disabilities. I do not think FDR ever intended to hide his disability, but we accept people with disabilities. We do not run across the street or run away from somebody with a disability.

We have never done it not because we did not have empathy. It is just because they did not know how to deal with someone with a disability.

So my view is that there are dramatic changes taking place. And this would be another big, big step in the right direction.

Senator JEFFORDS. Also assisted technology has improved so dramatically that now the ability of people to be able to assist themselves with additional help from all the modern technology. Have you observed that aspect of it?

Mr. DOLE. I think before I left the Senate, shortly before, they had a big display in the capitol of all of the assistive technology as far artificial arms and artificial limbs are concerned.

It was really remarkable how far they have come because I recall watching young men 50 years ago. And it is much, much different today. So it is you are never going to be quite like you would like to be, but it is always you are getting closer and closer.

Senator JEFFORDS. Thank you, Mr. Chairman.

The CHAIRMAN. It is now my pleasure to call on Senator Kerrey who is another sponsor of the legislation.

## OPENING STATEMENT OF HON. J. ROBERT KERREY, A U.S. SENATOR FROM NEBRASKA

Senator KERREY. Thank you, Mr. Chairman. I appreciate your emphasis of this legislation, as well as Senator Jeffords, Senator Moynihan, and Senator Kennedy.

And, Senator Dole, I presume you miss us as much as we miss you.

Mr. DOLE. Sometimes. [Laughter.]

Senator KERREY. Well, if you get lonely down there at 1600 Pennsylvania Avenue, I presume you will give me a call and let me come down.

Mr. DOLE. I may have one more shot at it. I do not know. [Laughter.]

Senator KERREY. Well, I do not have really any questions for you, Senator. I appreciate very much your endorsing this legislation.

There is no question that in Nebraska, there will be thousands of people right now who are frustrated by a government rule that makes it impossible for them to pursue the American dream. And that is all they want. They just want to be able to go to work and get an opportunity. And they are told if you promise to stay poor, you will help you.

Mr. DOLE. Right.

Senator KERREY. But if you do not promise to stay poor, you are out of luck. So this is long overdue. And I think with your support it is likely this thing will go relatively quickly. And I know that this change in the law without doubt, there will be thousands of people in my home State who will be able to return to work. And as a consequence, they are going to be happier, their families stronger, and the Nation stronger as a consequence. Thank you.

Mr. DOLE. Well, thank you very much.

Thank you, Mr. Chairman. I think I did ask that my statement be made part of the record.

The CHAIRMAN. It will be done so. And we will look into the other matter you have raised as well.

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

Mr. DOLE. Thank you.

The CHAIRMAN. I would like to publicly acknowledge the leadership role that you have played, Senator Jeffords, in bringing and developing this legislation and bringing it to this point where we have strong bipartisan support. It could not have happened without your help.

Senator JEFFORDS. Thank you very much, Mr. Chairman.

The CHAIRMAN. We will now turn to our second panel of witnesses. [Pause.]

I thought we would call all the witnesses up if that is convenient. First, we will hear from the Secretary of Health and Family Services for the State of Wisconsin, Joe Leean.

Would you please come forward?

Then next, it is my great pleasure to call forward Larry Henderson, who is from my State of Delaware.

Larry, it is a real pleasure to have you here today.

And we are also honored to be joined by Ms. Joann Elliot. She is on her way.

And our final panelist will be Mr. Allan Bergman, President and Chief Executive Officer of the Brain Injury Association.

It is a real honor and pleasure to have such a distinguished group here. And we look forward to your very helpful testimony.

I just want to say how pleased we are to have you here, Mr. Leean. I can say your State has been a leader in developing many innovative, significant programs. So we are looking forward to your testimony.

Mr. LEEAN. Thank you very much, Mr. Chairman.

The CHAIRMAN. May I welcome Ms. Elliot. It is a pleasure to have you here. Excuse me.

## STATEMENT OF HON. JOE LEEAN, SECRETARY, WISCONSIN DEPARTMENT OF HEALTH AND FAMILY SERVICES, MADISON, WI

Mr. LEEAN. Thank you, Mr. Chairman, and members of the committee. I am Joe Leean. I am the Secretary of the Department of Health and Family Services in Wisconsin. And on behalf of Governor Tommy Thompson and Peggy Bartels, my Medicaid Director who is with me today, I really appreciate the opportunity to offer support for the Work Incentives Improvement Act.

Removing barriers to employment is a goal that Governor Thompson and I strongly support. While the cost of the current bill has been reduced by about 75 percent from last year's bill, this act would still make significant progress in removing employment barriers.

I believe this bill offers a fiscally sound, cost-effective way to do the right thing. It is important to avoid pitting one group of vulnerable people against another. And therefore, we are very concerned that the fiscal offsets that are required here, that they not be against either Medicaid or other health and human service programs.

But as people work, and you have heard some of the testimony today in the same vein, they pay Social Security taxes. They pay income taxes. They reduce their dependency on government programs.

If those taxes and savings to all government programs could be taken into account, I doubt quite frankly that few fiscal offsets would really be needed.

When more SSI and SSDI beneficiaries work, it is the Federal Government and the Social Security trust fund that benefits from most of the savings. And that is why it is so important that we at the State level need your help to enable these people with significant disabilities to become employed.

Most people, as Senator Dole and Senator Kennedy said, with permanent disabilities want to work. New drugs, new adaptive aids, advances in personal computers, and other technologies make employment more feasible than ever before. A booming economy, the vast untapped, well-educated pool of people with disabilities makes it more important that we act now to remove employment barriers.

And I so appreciate your sponsorship, all of you on this bill.

We need three things. We need an assurance that of continued health and long-term care coverage. We need a gradual reducing of the cash benefits instead of the current cliffs that exists in our system. And we need a comprehensive approach.

First, the health and long-term care coverage. People with significant disabilities depend on the health care system every day. You and I want a good health care system, but for people with significant disabilities, it is their life-sustaining program.

They depend on the person care attendant who helps the person with quadriplegia get out of bed each morning, get dressed, and eat breakfast. They depend on the drugs that help an individual with mental illness to function every day. They depend on the nurse who assists family members in the maintenance of the ventilator that may keep a person with a spinal cord injury breathing.

SSI and SSDI beneficiaries risk losing that Medicaid or Medicare coverage that provides these services when they earn more $500 per month. And that loss, as I indicated, can be life threatening.

This is why I think the GAO finding that less than 1 percent of SSI and SSDI beneficiaries ever leave those programs in order to go into employment. Quite frankly, if they were going to leave these supportive programs to take employment, it is tantamount to intellectual malpractice. They are too smart to recognize that taking a job and giving up their life threatening supports. They cannot do it.

That is why it is so important that we have this option to purchase Medicaid. It is very generally the only health program that covers the personal care, the drugs, and the specialized transportation needs of people with disabilities, such as a spinal cord injury.

This act also would extend the 4-year period of Medicare eligibility for someone on SSDI. This is very important. It has already been alluded to today. Many people who have recently gone to work with help from our Wisconsin Pathways to Independence Program have told us that they are going to have to quit their jobs if Medicare coverage ends.

And an example, we have in Wisconsin Ken Adell. He is a quadriplegic with only head movement. He operates his computer with the help of adaptive aids. He excels in his job, maintaining Internet sites and a toll-free telephone service. He earns over $27,000 a year. He pays $12,000 towards his health care. He pays Social Security and income taxes.

And his health coverage is scheduled to expire because of the Medicare limit. And when his Medicare expires, he loses his disability status. He will be ineligible to buy into Medicaid. And that is why Ken and others need this bill in order to continue the jobs they already have under our Pathways initiative.

Secondly, reducing the benefits gradually as income rises is so important to make work pay. Currently, cash benefits are reduced to zero after 9 months in which someone on SSDI earns more than $500 per month. This cliff scares people from a future in which employment makes sense.

And I am so pleased to see that the Work Incentives Improvement Act directs the Social Security Administration to conduct demonstrations in which SSDI, the cash benefits, are reduced in a more gradual manner.

Wisconsin would like to be the first enthusiastic State to work with you on such a demonstration, along with obviously Vermont, Massachusetts, New York, Rhode Island, Kansas, Nebraska, and everybody else here. [Laughter.]

Mr. LEEAN. Third, we need a comprehensive approach and are therefore so pleased to see that the Work Incentives Improvement Act contains funding for States to sponsor local demonstration. Coordinating health care, occasional rehabilitation, and employment services in a comprehensive design that is built on a public-private partnership is working in our Pathways to Independence in Wisconsin. And with your continued collaboration, we can demonstrate that success.

Two modest suggestions to make this good bill even better. We would like you to allow States a reasonable time period in which to phase in the new Medicaid options. The proposed bill would require a State to implement the options statewide immediately.

And I am not suggesting a waiver of statewideness, only a nonwaiver provision so that the legislation in a State could be phased in in that approach.

And secondly, we would like you to allow States to set a minimum level of earnings in order for a person to qualify for either of the new Medicaid options because I think it would help us ensure adequate employment outcomes.

On behalf of Governor Thompson, I thank you for the opportunity to speak with you today. With this bill and your partnership in new demonstrations, employers will be able to enlist the full potential of the work force, we can provide for people the experience that new careers as wage earners, taxpayers, and working citizens will enjoy.

I have submitted a short description with my testimony of our Pathways to Independence Program. And I would also like to leave for committee members some pictures here of people who have already succeeded in our Pathways, but need this bill to continue in their work. And I would be delighted later to respond to questions. Thank you, Mr. Chairman.

[The prepared statement and information submitted by Mr. Leean appears in the appendix.]

The CHAIRMAN. Thank you, Mr. Leean.

It is now my pleasure to call on Larry Henderson who I think demonstrates what a person with a disability can do in the way of contributing to society. He is a real doer. And we are looking forward with great pride to hearing from him.

Mr. Henderson.

## STATEMENT OF LARRY D. HENDERSON, EXECUTIVE DIRECTOR, INDEPENDENT RESOURCES, INC., WILMINGTON, DE

Mr. HENDERSON. Thank you, Mr. Chairman. Good morning. My name is Larry Henderson. I am the Executive Director of Independent Resources, Delaware's only statewide center for independent living. The centers for independent living, they are not social service agencies, but rather resource centers for persons with disabilities and the communities in which they reside.

What is the difference? The difference is we do not do a lot for people, but we do a lot with people. What an individual gets from a center is directed by that individual. We respect individual diversity and we support personal choice.

As an organization, we work with individuals with significant disabilities, helping them to live as independently as they want.

First and foremost though, we are an advocacy organization. Other services that we offer consist of independent living skills training, peer support, and information and referral. We are the only consumer-driven organization in the State also. That means that over 51 percent of both staff and board of directors are themselves persons with disabilities.

Most of the individuals we work with want no more than the rest of us do, an opportunity to lead a productive lief and be gainfully employed. Herein lies the problem for many organizations like mine.

We can provide the training to ensure that the individual is prepared to do the job. We can help them arrange the transportation needed to get to and from the job. We can even instruct consumers to ask for reasonable accommodations when necessary.

What we cannot do is take away the fear that surrounds the loss of benefits. In particular, the costs associated with attendant services and other medical coverage that is so difficult for a person with a disability to get.

Attendant care is expensive. The average cost for attendant services in Delaware ranges from $14 to $16 an hour. This is an expense that most people entering the work force cannot afford. Individuals can spend as much as 50 percent of their total income on just attendant services.

When people come to us, they are ready to live independently. Reality dictates that employment must be a goal. When faced with this major barrier, it is up to the individual as to whether it is worth the risk.

Out of the 140 consumers that we assisted last year, 75 percent faced the decision between loss of benefits and employment. A mere 5 percent chose to take the risk. The alternative for others is volunteer work. As a result, many qualified individuals are regulated to volunteer positions.

Now, this is not meant to denigrate volunteer positions. However, nothing builds self-esteem like a paycheck. The Work Incentives Act would make our jobs a lot easier because consumers would not be forced to choose between employment and medical coverage.

Under the Work Incentives Act, persons with disabilities entering the work force could maintain the coverage they were previously receiving under Social Security or Medicaid on a sliding scale, creating a no-fear transition for them.

People with disabilities are put in a catch-22 situation. They want to work, but if they work they will lose the medication or attendant services they need to let them work. The Work Incentives Act could end this catch-22 by extending the medical coverage that would allow those individuals who choose to work to do so. Putting people to work where they can pay taxes and contribute to the community would be a much better use of our tax dollars.

This Act would help my organization a great deal in assisting people with disabilities to live independent lives. Thank you.

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

The CHAIRMAN. Thank you very much, Mr. Henderson.

We will continue with the panel and then ask some questions afterwards.

Next is my great pleasure to call on Ms. Elliot.

## STATEMENT OF JOANN ELLIOT, DISABILITY SERVICES CONSUMER, WASHINGTON, DC

Ms. ELLIOT. Hello, Chairman Roth, Senator Moynihan, and other members of the Finance Committee. My name is Joann Elliot. And I would like to thank you all very much for holding a hearing on work incentives for individuals with disabilities like myself. I appreciate the opportunity to tell you my story.

Hopefully, I can make a difference because that is what I am all about, making a difference. I am just one of the Americans with disabilities that can benefit from this bill, but know there are other

Americans like me who want to work, who can work, but would lose health care coverage we need.

Let me tell you my story. I started working when I was 22 years old. I worked at St. Elizabeth's Hospital in food service for almost 20 years. I really enjoyed my work. My job provided basic health coverage. I was saving for retirement through my job, and was on the verge of buying a home.

On the last Friday in January, 1991, I was at work and life was normal. That following Monday, I had a massive stroke which left me paralyzed on my left side. I was devastated. When that happened, my life changed totally.

As you can see, I need a wheelchair to get around as well as other special equipment to function. I require a personal care assistant in the morning to help me bathe, get dressed, among other essential daily activities. In addition, I take medications for my high blood pressure and I get rehabilitative therapy to keep me loose.

Eight years ago, I was healthy and working just like you all. I would have never thought this would happen to me, but it did just as easily as it could happen to anyone else. If not a stroke, it could be a car accident or being diagnosed with a serious disease.

After the stroke, I had to leave my job. Now, I receive my disability benefits, SSDI and Medicare. With no job, my income was low. I also qualified for Medicaid coverage. For me, Medicaid was a Godsend. Medicaid pays my personal care assistance for helping with my basic, living activities. It also covers my prescriptions, special equipment, therapy, and certain transportation. Most insurance plans offered at work do not cover my care.

It would be a nightmare with Medicaid. Without these services, I might as well be in a nursing home. I have already lost a lot of my independence from the stroke. However, without Medicare, I would totally lose my independence.

I do not like staying at home. I want to get out and be productive. However, if I get a job with even a modest income, I would lose my Medicaid coverage. As much as I want to work, I am too scared of losing my Medicaid. What can I do without those services? The irony is I need Medicaid to work, but if I work I lose Medicaid. It is a sad circle.

I am trying to do something with myself. I do volunteer work at the DC Center for Independent Living. Of course, I would like to get paid. I still have bills to pay and rent keeps growing. I was offered a job in 1994 at the DC Center. I would have made almost $7 per hour. That income would help with the bills, but it would have disqualified me for Medicaid. I could not afford that even with the insurance offered at the job. That insurance could not cover all the services I need. So I had to turn down the job offer.

If I could keep my Medicaid while I work, even if I had to pay a modest premium, it would make me so happy. I would go to work tomorrow. I want to be doing something with myself. I am not giving up. I just enrolled in a job-readiness program for a person with disabilities. My goal is to be employed some day.

If you could pass this bill, the Work Incentives Improvement Act, I would have a chance to keep my Medicaid and Medicare and work. It is about work and my independence. You do not know how happy it would make me and other persons with disabilities.

I am glad that the Senate Finance Committee is putting things into light and pushing to remove the negative thoughts about disabled individuals. Chairman, it warms my heart to know you understand my situation and are pushing to make the changes in law necessary to allow me to be self-sufficient.

Thank you again for letting me tell my story. And I am happy to answer any questions.

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

The CHAIRMAN. Thank you, Ms. Elliot, a very moving story. Just let me thank you and congratulate you for your positive attitude. It makes no sense that people like you should have to choose between work and health care. That is what we are going to try to correct.

And now it is my great pleasure to call on Mr. Bergman.

## STATEMENT OF ALLAN BERGMAN, PRESIDENT AND CHIEF EXECUTIVE OFFICER, BRAIN INJURY ASSOCIATION, INC., ALEXANDRIA, VA

Mr. BERGMAN. Thank you, Mr. Chairman, and members of the committee. My name is Allan Bergman. I have submitted a statement for the record.

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

Mr. BERGMAN. I am currently the President and Chief Executive Officer of the Brain Injury Association, the only national association representing the interests of persons with brain injury, 5.1 million today, children and adults and their families, the so-called silent epidemic as part of the larger disability community.

And I think as was pointed out a few times earlier this morning, I think the interest bipartisanally and with a large number of cosponsors in this bill is an increasing awareness that this could be you or your son or your daughter or your grandchild or your spouse or your brother or your sister or any close neighbor or friend because disability does not discriminate. As you just heard from Ms. Elliot, it strikes very often with no notice, whether it is at the birth process or acquired some time during life.

And in terms of traumatic brain injury and other disabilities, what we are seeing is not only the enactment of the Americans with Disabilities Act, what we are seeing is phenomenal breakthroughs as a result of public funds expended on research, on education, on technology, on biomedicine, on approaches to behavioral issues.

And as a result, we continue to raise the bar. And as we raise the bar, people with disabilities have raised expectations. And the independent living movement and the self-advocacy movement in families now are expecting people to contribute.

What we have, however, is a major disconnect between our civil rights laws, our training, and our research and our health care-disability-employment policy. And that is what S. 331 take significant strides to correct with the Work Incentives Improvement Act.

We have an outmoded definition of disability. That is the crux of the issue. If we look at SSI and SSDI which were crafted in the

1950's and 1960's and 1970's, we basically said that substantial gainful activity or the lack of it at $500 a month is what defines severity of disability.

I think we all know individuals who have very severe disabilities who are earning and capable of earning more than $500 a month.

But what we did in our generous public policy, probably a paternalistic and maternalistic public policy of the 1950's, 1960's, and 1970's was say we will give you cash because you probably are not going to be able to do anything. You are kind of helpless and eternally dependent. And in addition, we will give you health insurance card. And will connect the two. And if you get one, you will get the other. And if you go to work, we take away the other.

And that is what we continue to do today is we punish people with disabilities as a statement of public policy if they choose to pursue the American dream and want to go to work.

That is wrong. And it is now time to address it for 8 million people who are locked on the rolls of SSI and SSDI. We do not need to punish. We ought to reward. And we have spent billions of Federal dollars and State dollars to prepare people with disabilities to have the equal opportunity. And then, we shut them off at the real opening door to the world.

The critical issues of health care, and that is what we are talking about today is the need for access to affordable, comprehensive acute care and long-term supports, as you have heard from Ms. Elliot, Mr. Henderson, and the secretary, especially the full range of therapies, prescription drugs, mental health service, durable medical equipment, assistive technology, as the Chairman spoke about in his opening statement, and personal assistant services or attendant care which other than through Medicaid and to some extent Medicare is not available any place in the commercial insurance market today.

And I am sure some people have asked, well, what is the problem? If people go to work, the employer will cover? Well, first of all, most people with disabilities do not go to work for Fortune 500 corporations or the Federal or State government where there are large group plans and fairly good benefits.

Most people with disabilities enter the work force in small or medium-sized businesses where they may be no employer plan. The employer plan may have a premium that is prohibitive. The benefit package may be inappropriate for the individual, particularly if it does not have some of the benefits we have talked about or it has a very narrow definition of medical assistance which has to do with restoration rather than maintenance and essential functions.

So consequently, that option often does not work for people. And the nice part about this piece of legislation is that it is not an unfunded Federal mandate on the States. It is a State option, as the secretary pointed out, and allows the States to gradually with the work of the advocates the provider community and folks in the legislature in the States to make affirmative decisions about how fast to implement this and what level and whether there will or will not be cost sharing or there will be sliding scale premium because the bills provides for that to occur at the State level.

So what are the issues today? The economy is booming. Unemployment rates for the country are at all near highs and lows and less than 2 percent in many States. Yet, with all of this in the economy, 8 million working age adults with severe disabilities are not benefitting from this prosperity and seemed to doomed to a life of dependency and poverty at a cost to the taxpayer of nearly $74 billion this year in cash assistance and if we make no change projected to be over $100 billion in 2002.

As a disability advocate, a policy analyst, and a taxpayer, that is an abomination. And we have to do better. And we can do better. And S. 331 allows us the opportunity to do that.

What it will do is move us toward a 21st century policy that will begin to make severe disability a synonym for personal responsibility, for choice, for empowerment, for interdependence, contribution, and economic self-sufficiency. Then, we can began to reframe disability policy as a social and economic investment with a valued societal performance outcome, employment, contribution, and increased self-esteem. That is a win-win at the State level, the Federal level, the individual, and the family level.

I will be happy to answer any questions.

The CHAIRMAN. Thank you, Mr. Bergman.

Let me go back to you, Mr. Leean. You talked about one change that you would make with respect to the requirement in the draft that the program be adopted statewide. Should there be some flexibility? Should States be allowed the freedom to phase in the program?

Would there be any limitations? I mean, are you talking about 2 years, 3?

Mr. LEEAN. Mr. Chairman, we would be delighted to work with your staff or whatever makes sense. The bill implies that there has to be there statewide immediately. And we have found in almost all our programs in Wisconsin that it helps so much to be able to not only have has to be a coordinated approach, you have to have people available and resources available to coordinate all of these programs in what we have found in Pathways.

On a geographical basis, we can phase it in so that people do not come in with significant disabilities and expect that something is there that we are not prepared for in the same month perhaps as another part of the State.

We believe it needs to be statewide. We would just ask for the flexibility to phase it in. I do not know what makes sense in terms of whether it takes a year or 2 years or a few months. And we would be delighted to work with you.

It is just that when we know something says do it now statewide and it requires some different resources, it can create expectations that you cannot fulfill in some areas and do a good job.

The CHAIRMAN. Let me turn to another matter. At the State level, are you concerned that expansions of eligibility to disabled populations could make Medicaid vulnerable to fraud and abuse?

For example, could people without disabilities access the program?

Mr. LEEAN. Mr. Chairman, and I know Senator Jeffords, too, has properly heard this concern. And I appreciate so much your leadership. The answer is, yes, we are very concerned of any fraud or abuse or use of these programs by anybody that would take it away from those for which it was intended.

But I do not believe that this bill or our Pathways to Independence has any of that jeopardy. We would use the same determination of disability processes that we currently use to determine disability for that first group that would be essentially eligible for Medicaid.

And this bill allows States to also have the flexibility to try and be able to prove the support to keep someone that is currently working from falling back on SSDI. And we would use the same processes to make sure that that person has a significant disability, but may very well need the extension of protease inhibitors to keep them working or some adaptive equipment so that they in fact do not lose their job and become impoverished.

So I think the protections are there with our current disability determination. But I think the most clear prevention of fraud and abuse compared to what we deal with under your direction daily in preventing that is we are talking about a population that wants to work and will be working.

And that is a lot different than people that may try to game a system simply to stay out of work and get benefits. These are folks that I think the greatest protection is they want and will have a job.

The CHAIRMAN. Thank you, Mr. Leean.

Let me turn to you, Mr. Henderson, if I might. Can you explain what happens when a client comes to your center for assistance in becoming more independent? How would the legislation before us assist you in your efforts on behalf of clients?

Mr. HENDERSON. Well, as I mentioned in my testimony, you have to have a job. I think most of the individuals that come to us realize that. We can give them, provide them with all sorts of training, but it is still up to them whether or not they are willing to take the risk to work and lose their benefits or stay at home, keep the benefits, and be unfulfilled because most consumers that come to us want to be independent.

The CHAIRMAN. Are what?

Mr. HENDERSON. They want to be independent. So with this bill, with the passing of it, we could actually help them to become employed without the fear of them losing the benefits, without the fear because the problem comes in when if they do make their choice to work because of the expense of attendant services, a lot of times they will get a friend or a neighbor to work in this capacity for them. That is also very dangerous.

We had an incident in our State where such a thing occurred. And the friend that was acting as an attendant put a catheter in wrong and this person was found lying in a pool of blood some friends had not heard from him for awhile.

The CHAIRMAN. Let me turn to Ms. Elliot and ask a somewhat similar question to what I asked you, Larry.

Ms. Elliot, if you could work and keep your health insurance coverage, what would be the first thing you would do?

Ms. ELLIOT. Well, the first thing I would do after I could work. What would be the first thing I would do? I think I would like to get me a condominium, a house, buy me a house or something. I think I would like to do that. Get me something that would be mine. That is what I would like to do. And I would work if I could take care of my insurance. I would work, too.

The CHAIRMAN. I like your enthusiasm.

Mr. Bergman, I am sure that Ms. Elliot is not alone in her enthusiasm. More broadly, how would you anticipate the disability community responding to the opportunities presented by the bill?

I think the answer is obvious. There would be great enthusiasm. But very frankly as we all know, the devil is in the details. And I think based on——

The CHAIRMAN. Too often.

Mr. BERGMAN [continuing]. History of other attempts to create work incentives in sort of a patchwork quilt that the Congress has done over the last 12 to 15 years, the paper work around it, the bureaucratic red tape, if you will, some of the small print has been a deterrent which is why we have not seen the massive changes in the rolls that some of us hoped and predicted for. And they were not big enough.

I think here, you have addressed several critical pieces. The action on the Medicaid expansion rests with the State. It is an expansion of what you did in the Balanced Budget Act amendments of 1997. And we have seen a number of States beginning to move on that. It is closer to home.

I think the disability determination process is the process. What it will take, and there is a proposal in the bill to do this is a lot of outreach education and training for the constituency community. And that will be very, very important for people to understand it and to assist them through this new process and begin to build some trust and credibility that this is not a false hope, it is not a false promise.

The CHAIRMAN. Now, we will call on Senator Jeffords.

Senator JEFFORDS. Mr. Leean, have you talked to other States? Do you know how they feel about this law or——

Mr. LEEAN. I have not personally, but people in my department, my Medicaid director who is with me and the folks in our department that have designed and are working on our Pathways to Independence meet with other States. We are getting calls from other States because we already have that Pathways which needs this bill and needs the flexibility to expand.

But what we have done there is put together what we call a super coach, the person that can bring together these very complicated things that are supports, whether they are rent subsidies, whether it is transportation or adaptive equipment. And we have other States that have expressed an interest in that.

I do think that a couple of items in the bill that require that States have already taken on the flexibility of the Balanced Budget Act, Medicaid flexibility, and adopt some of these before they can actually have a full-blown, it may be a little discouraging for some States that are not leading the pack.

But I think there is tremendous interest in this across States, particularly as I think both Senators Kennedy and Dole alluded to. When you look at the numbers of people with significant disabilities that want to work, should work, are capable of working and the fact that we have employers crying for jobs, it becomes such a win-win opportunity, we are going to be paying.

You and we at the State level are going to be paying for their health care and their support if they do not work, assuring them of that support so that they not only fill this desperate need for employees, but start paying taxes and become productive, to say nothing of the dignity of those people working. I think a lot of States are going to be very excited about this bill.

Senator JEFFORDS. Mr. Bergman, you are shaking your head up and down. So I would like you to comment.

Mr. BERGMAN. Yes, I have had conversation with a number of States because I have been doing some work with the National Conference of State Legislatures over a number of years. And I think there is an increased awareness among State legislators and key people in State government that we need to break through this barrier that have been creating in public policy. And so I think there will be receptivity.

It will take time. It is going to take education of State legislators because I think since Medicaid has been created as a poverty program, as a welfare program, there is still that mentality: wait a minute, if we are talking about people working, why is it Medicaid?

So I that is going to be part of an ongoing State advocacy legislative process. It started with some of the Balanced Budget Act amendments.

I think there are about 12 States that are working on getting up to 250 percent of poverty for people with disabilities who want to work. And that word spreads from one State to the next. So it will take several years, but at least we have created a new floor and a new opportunity.

Senator JEFFORDS. Mr. Henderson, assisted technology has improved the ability for people to work. How does that get paid for? And what kind of demand will you anticipate if this bill passes? How will ghat get paid for?

Mr. HENDERSON. How would the assisted technology get paid for?

Senator JEFFORDS. Yes, right.

Mr. HENDERSON. I am not certain I really understand what you mean. There are right now, Medicaid pays for adaptive equipment and assisted technology.

Senator JEFFORDS. Okay.

Mr. HENDERSON. It is still too expensive for a consumer, for an individual to afford it. There is still going to be a need for some assistance in purchasing assisted technology.

Senator JEFFORDS. Medicaid would pay for it, Leean?

Mr. LEEAN. That is really the key. We are paying for this anyway. And then, when we provide the adaptive technology for people to be able to be productive, then we say, well, of course, if you get a job and you earn more than $500 a month, we are going to take away some of your SSI, we are going to take away some of your HUD payment, we are going to take away all of SSDI if it is $500 over 9 months. And by the way, that adaptive equipment we paid for is no longer going to be supported. The personal care worker is no longer supported.

So we essentially pay for this through Medicaid or some of it through Medicare and obviously with some State plans. And that is why I think this bill and what we need to do is, and I hate to use the old phrase, win-win.

But for all practical purposes, the expenses are there in the Medicaid support and in some cases for SSDI, the Medicare health, and all of the State programs.

But at that point at which we have with technology allowed people to become productive and employed, we say, oh, by the way if you do this, you are going to lose all of this support. That is why this bill is so important.

Senator JEFFORDS. Mr. Bergman, do you have a comment?

Mr. BERGMAN. Well, I think I would like to make it concrete if I may, Senator Jeffords. Let us take someone who is part of their technology uses power mobility and electric wheelchairs, as we call it. In the market place today, those are anywhere from $10,000 to $25,000. Unless one is having a very substantial salary, that is a lot of capital outlay every five to 6 years because they wear down. They do break. And they do have to be replaced.

What this bill provides since Medicaid does purchase that type of equipment on an individual medical necessary basis is for the State plan to purchase it, for the individual based on his or her income and based on the State legislation to have a co-pay and partially be sharing in the premium so that it is not again a free ride. It is up to the State to decide what the contribution is of the individual.

And most people with disabilities, as you have heard from the two witnesses here today and others you know want to contribute and want to carry as much of the freight as they can, but we have got to incentivize the system rather than punish people.

Senator JEFFORDS. Ms. Elliot, now that you have listened to all of this, do you feel that you will be able to go back to work now if this bill passes?

Ms. ELLIOT. If this is bill is passed, yes, sir. I will if this bill is passed.

Senator JEFFORDS. Thank you.

Ms. ELLIOT. If not, I am going to stay at home. I am staying at home. [Laughter.]

There is no reason for me to work. I am staying at home.

Senator JEFFORDS. That is a good place for me to end.

The CHAIRMAN. Thank you, Senator Jeffords.

Senator Robb, who was a co-sponsor of this legislation, your turn.

## OPENING STATEMENT OF HON. CHARLES S. ROBB, A U.S. SENATOR FROM VIRGINIA

Senator ROBB. Thank you, Mr. Chairman. And let me apologize. An event that was held downtown, widely attended by members of Congress ran way over this morning.

I had hoped to be here earlier and to hear the testimony of our two colleagues, one present and one former. And I have heard some of the responses and I was coming through the office some of the opening testimony of our witnesses this morning.

But let me say, first of all, thank you, Senator Jeffords, for your leadership in putting this bill before us. I am indeed proud to be a co-sponsor.

Almost two decades ago, I had the privilege when I was serving as Governor of Virginia to sponsor and put through the Virginians with Disabilities Act. We have participated in the Americans with

Disabilities Act. I do not think there is anything that I have participated in that gave me more personal satisfaction in terms of the response of those that we were intending to try to assist in striking down some of the obstacles to their full and independent participation on anything that I have done.

And I feel exactly the same way about this particular legislation and the suggestion that it really is win-win, that if you put in the green eye shades as I frequently do and assess programs that we have an opportunity to avoid costs and expenses that the government is making, but much more importantly we can find a way to increase the number of those who have disabilities who want to either participate in or return to the work place and strike down the obstacles that keep it from making it possible.

With so many people wanting to come into the work place and so few people who have disabilities either being able to do so because of government obstacles or having a disincentive which this legislation is designed to address, it seems to me right on the right mark.

So, Mr. Chairman, I am grateful to you for your leadership. I am proud to be a co-sponsor because I am already running late for a meeting with several of other colleagues on this committee that I will not ask any questions, but I found the responses that your distinguished panel of witnesses gave to be very persuasive, notwithstanding the fact that I was already a co-sponsor.

And I hope that this message can reach even more people because it is an important piece of legislation. And I suggest that it really is in my judgment win-win.

So, Mr. Chairman, with that, I thank you. And I thank our panel for joining us and helping us spread the word.

The CHAIRMAN. Well, thank you for coming. This is a very important piece of legislation, and we are particularly pleased to have such broad, bipartisan support for it.

Well, ladies and gentlemen, we all have other matters before us today. And we are running late. But I want to express my appreciation to each of you for being here today. I cannot tell you how helpful it is to have your advice, interest, and recommendations.

I particularly want to thank you, Larry, and you, Ms. Elliot, for coming here. We look forward to working with you as this legislation proceeds through the legislative process.

Thank you very much.

The committee is in recess.

[Whereupon, at 11:16 a.m., the hearing was concluded.]

# APPENDIX

## ADDITIONAL MATERIAL SUBMITTED FOR THE RECORD

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### PREPARED STATEMENT OF ALLAN I. BERGMAN

#### INTRODUCTION

My name is Allan Bergman. I am the President and Chief Executive Officer of the Brain Injury Association. Founded in 1980, BIA is the only national voluntary association dedicated to the full range of issues related to traumatic brain injury: from prevention to trauma care to acute care to in and outpatient rehabilitation to long term supports for community integration and quality of life as well as research and public awareness. What began as a small group of concerned family members and professionals has grown into a national organization with 43 State Associations, over 800 local support groups and thousands of individual members.

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. During the past fifteen years I have devoted a significant portion of my career to disability and health policy—both acute care and long term care—as well as the opportunities and challenges in the use of managed care technology for people with severe, lifelong disabilities and chronic illnesses. I also bring the perspective of the father of a young woman with disabilities in the work force and a 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 BIA, we are pleased lend our support to S.331. The Work Incentives Improvement Act of 1999, and commend its lead sponsors, Senators Jeffords, Kennedy, Roth and Moynihan as well as the numerous cosponsors on both sides of the aisle 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 for prescription drugs, therapies, durable medical equipment, mental health services and personal assistance services. The sponsors 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.

We are also pleased to note the support of President Clinton and the Administration as part of the President's FY 2000 Budget.

#### TRAUMATIC BRAIN INJURY

Traumatic brain injury (TBI) is defined as an insult to the brain, not of a degenerative or congenital nature but caused by an external physical force, that may produce a diminished or altered state of consciousness, which results in an impairment of cognitive abilities and/or physical functioning. TBI can also result in the disturbance of behavioral or emotional functioning.

Traumatic brain injury has become the number one killer and cause of disability of young people in the United States. Almost one half of all traumatic brain injuries result from transportation—related incidents. Most of the remainder result from falls, assaults, sports and recreation and firearm—related injuries. Each of us and the members of our family and our friends are at risk everyday of joining this population!

Long known as the "silent epidemic," TBI can strike anyone—infant, youth or elderly persons—without warning, and often with significant and life long consequences. Traumatic brain injury affects the whole family and often results in huge medical and rehabilitation expenses over a lifetime. Advances in medical technology and improvements in regional trauma services have increased the number of survivors of T.B.I., producing the social consequences and medical challenges of a daily growing pool of people with disabilities on the road to recovery.

An estimated 2 million Americans experience traumatic brain injuries each year. About half of these cases result in at least short-term disability, and 51,000 people die as a result of their injuries. Each year, approximately 260,000 persons require hospitalization for TBI (30% of which show disabilities a year post injury), and over 1 million people receive emergency medical care for TBI. The Brain Injury Association estimates the cost of TBI in the United States at more than $48 billion annually. Every year about 90,000 people sustain severe brain injuries leading to long term disability. CDC has recently estimated that there are 5.1 million persons living with long term, severe disability as a result of brain injury and as many as 6.5 million person living with some form of injury including mild and moderate brain injuries.

A recent report on Rehabilitation for Traumatic Brain Injury prepared by the Oregon Health Sciences University for the NIH Consensus Conference on T.B.I.in October 1998 states that "Class II evidence indicates that supported employment can improve the vocational outcomes of T.B.I. survivors. (Studies rated as Class II were randomized controlled trials—RCT's—with design flaws; well done, prospective, quasiexperimental or longitudinal studies, and case control studies).

Persons with a long term disability as a result of traumatic brain injury want to work and are capable of remmenative employment with appropriate supports. In order to remain employed, however, persons with T.B.I., like most people with disabilities, need consistency and continuity of health care services and long term supports. The need for these services is documented in a February 27, 1998 report from the U.S. General Accounting Office to the Honorable Thomas J. Bliley, Jr., Chairman, Committee on Commerce of the House of Representative and the Honorable James Greenwood of the House of Representatives (GAO/HEHS 98—55 TBI). "Both the private and public sectors finance acute care services to adults with T.B.I. When the individual progresses past the acute phase, private health insurance typically limits coverage of rehabilitation therapies and does not cover long term care or community based support services. As families exhaust their financial resources, the public sector pays for a greater share of the services received—exceptions are those individuals injured on the job and thus covered by worker's compensation." Many individuals with T.B.I. and commercial insurance often exhaust their policy lifetime cap of $5000,000 or $1 million within 3-5 years after the injury and then fully access public benefits.

## 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 my 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[1] |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | 1970 | 1975 | 1979 | 1982 | 1985 | 1988 | 1989 | 1990 | 1991 | 1992 | 1993 | 1994 | 1995 | 1996 | |
| Age: | | | | | | | | | | | | | | | |
| 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 |
| Sex: | | | | | | | | | | | | | | | |
| 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 |
| Education (years of school completed): | | | | | | | | | | | | | | | |
| No schooling[2] | 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 |

[1] Derived from 1990 census. Figures for age based on population aged 18–64. Figures for education based on persons aged 25 and over.

[2] 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[1] | 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[2] | 100 | 100 | 100 | 100 | 100 | 100 | 100 | 100 | 100 | 100 | 100 | 100 | 100 | 100 |

[1] Beginning in 1990, AIDS/HIV cases are included in this category.

[2] 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

### *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[1]

[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[2] | 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[3] | 4,375,650 | 23,101 | 34,909 |

[1] 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.

[2] 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.

[3] 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*
Medial 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
Arkansas
California
Delaware
District of Columbia
Idaho
Iowa
Kansas
Maine
Maryland
Massachusetts
Michigan
Minnesota
Missouri
Montana
Nebraska
Nevada
New Hampshire
New Jersey
New York
North Carolina
Oklahoma
Oregon
Rhode Island
South Dakota
Texas
Utah
Vermont
Washington
West Virginia
Wisconsin

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 persons 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.

## 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.331 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 1998 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 many of the "Choice" Employment Projects funded 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.331 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 session 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 1999 demand that we shift our income support and health insurance public polices 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.331 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; and to maintain their Medicare and/or Medicaid coverage at an affordable premium based on their earnings; This foundation along with other provisions in S.331 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:

> "(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."

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## PREPARED STATEMENT OF HON. JOHN H. CHAFEE

Good morning. I want to welcome everyone here today. I am especially pleased to welcome Senator Dole, a strong leader on disability issues, among his many other achievements. Today we are going to explore the health care barriers facing those who are disabled and want to work. I am pleased that Senators Jeffords, Kennedy, Roth and Moynihan have introduced legislation to address this problem. I strongly support this legislation and am an original cosponsor.

The magnitude of this problem is considerable. At present, there are approximately eight million disabled adults receiving Federal benefits under the Social Security Disability Insurance (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: working provides self-esteem, and helps to achieve financial independence.

Despite the strong desire to work, only about 0.2% of SSDI recipients actually return to work 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 are considering a return 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 return to work. I want to congratulate Chairman Roth and Senators Moynihan, Jeffords and Kennedy for their hard work in this area, and I look forward to working together to try to get this legislation passed.

Thank you, Mr. Chairman.

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## PREPARED STATEMENT OF HON. BOB DOLE

Chairman Roth, Senator Moynihan, thank you for the opportunity to testify today on an issue that I believe in strongly and personally—helping remove the barriers to work confronting people with disabilities.

Over the past decade, we have made dramatic improvements in removing many barriers. In particular, I am proud of the Americans with Disabilities Act. It is helping people with disabilities lead more active and integrated lives, and our society is richer for it.

But ADA did not complete the work of removing barriers. Access to health care remains an enormous hurdle confronting people with disabilities who want to work. That is where the "Work Incentives Improvement Act of 1999" can make a big, big difference.

According to a report issued last summer by the National Organization on Disability, 72 percent of unemployed Americans with disabilities want to go to work. Yet, not more than 1 in 500 receiving Social Security disability insurance benefits (SSDI) ever returns to work.

Throughout 1997, the General Accounting Office conducted interviews of SSDI beneficiaries who had gone back to work. These people told GAO that the most important factor in making work possible was health care—because it helped them function better.

Mr. Chairman, this is very important—and not hard to understand. Employer-sponsored health insurance is the key factor in separating SSDI beneficiaries who plan to leave the cash benefit rolls and go back to work, from those who stay. Let me say this again—access to health insurance makes all the difference when it comes to making the leap from the disability rolls to the job rolls.

The "Work Incentives Improvement Act" addresses the health insurance issue head on- by removing the most fundamental barrier to employment for people with disabilities eager to become tax-paying contributors to our society. We don't find people eager to pay taxes too often—I say we take these folks up on their offer.

I support the "Work Incentives Improvement Act" and I congratulate members of this Committee for your efforts to move this important legislation forward. It is particularly encouraging to see such strong bipartisan support for the bill in the Finance Committee.

Let me address head-on an objection I have heard raised to this bill—that this bill would expand entitlement programs.

Let's look at that. The bill creates two new Medicaid options for States to provide health care to people with disabilities. The bill also provides for a demonstration program that allows people who leave the SSDI program to receive Medicare for 10 years, up from 39 months currently.

But, Mr. Chairman, this bill is not about big government, but good government. This bill will help people break their dependency on cash benefits. This is what Republicans did in welfare reform and we should put the same philosophy to work here.

Because health insurance is vital to enabling people with disabilities to go to work, the bill gives each State the option to allow disabled individuals to purchase Medicaid. And this is not a freebie. States can require people with disabilities to pay 100 percent of premium costs.

No doubt about it, this is a limited, responsible proposal that will help remove the most fundamental barrier to employment for people with disabilities. For a health care bill, its cost is reasonable—perhaps $1.2 billion over five years.

The bill was introduced without a specific offset. As you prepare for markup, I would strongly encourage you to avoid pay-for provisions that make reductions in other crucial health care programs.

In the long term, the bill should pay for itself. The cash benefit rolls will decline and more disabled Americans will become workers and taxpayers.

I would be remiss if I did not urge Congress to focus attention on several areas not yet included in the bill. One segment of our health care system that is central to returning the disabled to work was dealt a crippling blow in BBA 97. I am referring to rehabilitation hospitals, facilities and units, without which our disabled rolls would be much greater as their services retrain and rehabilitate many individuals and return them to the work force.

Section 4415 of the Balanced Budget Act of 1997 (BBA) repealed the full incentive payment percentages for PPS-exempt rehabilitation hospitals and units. The BBA also reduced capital payments for PPS-exempt hospitals and units by 15% for FY 1998—2002. The combined effect of these provisions has severely hamstrung the ability of these facilities to serve disabled individuals.

Prior to the BBA, qualifying PPS-exempt hospitals were eligible to obtain an incentive payment for keeping their costs below their TEFRA limits. The federal government and these facilities shared in the savings. This system encouraged these facilities to incorporate efficiencies without compromising service or quality for their patients.

The earlier formula actually worked as it was intended. It provided an incentive for PPS-exempt hospitals to keep costs below TEFRA limits while still retaining high quality care. This is evidenced by the fact that patient outcomes have remained the same, despite a decrease in average lengths of stay in PPS-exempt hospitals.

The BBA provision reduces incentive payments so significantly that the payments are unlikely to motivate facilities to further reduce lengths of stay. And there could easily be additional negative ramifications to this misguided policy.

Compounding this situation is the fact that a rehabilitation provider does not have the same opportunity as other providers to shift costs to other payers. Because rehabilitation hospitals are heavily dependent on Medicare, they have few non-Medicare patients on whom they can shift costs. That is because 70% of admissions and 65% of days in rehabilitation are covered by Medicare fee for service. This rate of Medicare utilization is unique among provider groups.

Until the PPS system authorized by the BBA is fully implemented, capital cuts should not be imposed on PPS-exempt rehabilitation hospitals and units. Full payment of capital should continue under the cost-based system because, unlike providers in a PPS system, PPS-exempt providers have no opportunity to make up the loss of capital payments through operating efficiencies. If operating costs go down, so do reimbursements.

For this reason, almost all rehabilitation providers will be paid below cost under the BBA. Please revisit these policies or we will surely see a commensurate increase in the number of disabled receiving payments from Social Security and Supplemental Security, as well as those receiving Medicare and Medicaid.

Finally, a foremost concern of rehabilitation providers is that disabled patients enjoy access to necessary specialists. The disabled frequently face unique health challenges and as Congress considers patient protection legislation, I would hope that Members take these unique needs into account and ensure access to appropriate specialists.

Without access to rehabilitation providers and the extraordinary, comprehensive services they provide, disabled people cannot be reunited with the community where they can achieve maximum independence and flexibility.

Mr. Chairman, I urge this committee to take prompt action. Senators Roth, Moynihan, Jeffords, and Kennedy, I thank you for your leadership, and I thank the committee for the opportunity to appear before you today.

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## PREPARED STATEMENT OF JOANN ELLIOT

Hello, Chairman Roth, Senator Moynihan and other members of the Finance Committee. My name is Joann Elliot and I would like to thank you all very much for holding a hearing on work incentives for individuals with disabilities like myself. I appreciate this opportunity to tell you my story. Hopefully, I can make a difference because that is what I am all about—making a difference. I am just one of the Americans with disabilities that can benefit from this bill but know that there are other Americans just like me who want to work, who can work but would lose health care coverage I need.

Let me tell you my story. I started working when I was 22 years old—I worked at St. Elizabeth's Hospital in food service for almost 20 years. I really enjoyed my job. My job provided basic health coverage. I was saving for retirement through my job, and was on the verge of buying a home. On last Friday in January, 1991, I was at work and life was normal.

That following Monday, I had a massive stroke, which left me paralyzed on my left side. I was devastated when that happened. My life changed totally. As you can see, I need a wheelchair to get around as well as other special equipment to function. I require a personal care assistant in the morning to help me bathe, get dressed among other essential daily activities. In addition, I take medications for my high blood pressure and I get rehabilitative therapy to keep me loose.

Eight years ago, I was healthy and working just like you all. I would have never thought this would happen to me. But it did just as easily as it could happen to anyone else. If not a stroke, it could be a car accident or being diagnosed with a serious disease.

After the stroke I had to leave my job. Now, I receive my disability benefits (Social Security Disability Insurance or SSDI) and Medicare. With no job, my income was so low, I also qualified Medicaid coverage. For me, Medicaid was god-send: Medicaid covers my personal care assistance for helping with my basic daily activities. It also covers my prescriptions, special equipment, therapy and certain transportation. Most insurance plans offered at work do not cover my care.

It would be a nightmare without Medicaid. Without these services, I might as well be in a nursing home. I have already lost a lot of my independence from the stroke. However, without Medicaid, I would totally lose my independence.

I don't like staying at home. I want to get out and be productive. However, if I get a job with even a modest income, I would lose my Medicaid coverage. As much as I want to work, I am too scared of losing my Medicaid. What would I do without those services? The irony is I need Medicaid to work but if I work I lose Medicaid. It's a sad circle.

So, I am trying to do something with myself. I do some volunteer work at the DC Center for Independent Living. Of course, I would like to get paid. I still have bills to pay and rent that keeps growing. I was offered a job in 1994 at the DC Center. I would have made about $7 per hour. That income would have helped with the bills but it would have disqualified me for Medicaid. I couldn't afford that even with the insurance offered at that job. That insurance would not cover all the services I need. So, I had to turn down the job offer.

If I could keep my Medicaid while I work, even if I had to pay a modest premium, it would make me so happy. I would go to work tomorrow. I want to be doing something with myself. I am not giving up. I just enrolled in a job-readiness program for persons with disabilities. My goal is to be employed someday.

If you could pass this bill—the Work Incentive Improvement Act—I would have a chance to keep my Medicaid and Medicare AND work. It's about work and it's about my independence. You don't know how happy that would make me and other people with disabilities.

I am glad that the Senate Finance committee is putting things into light and pushing to remove the negative thoughts about disabled individuals. Chairman, it warms my heart to know you understand my situation and are pushing to make the changes in law necessary to allow me to be self-sufficient.

Thank you again, for letting me tell my story and I am happy to answer any of your questions.

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## PREPARED STATEMENT OF HON. ORRIN G. HATCH

I want to commend Senators Jeffords, Roth, Kennedy, and Moynihan for going the extra mile to work out the provisions of this legislation. I am sure it was not easy; dealing with Medicaid and SSDI never is.

As a veteran of many negotiations and collaborations with both Ted Kennedy and Bob Dole on disability issues, I want to welcome them to this hearing and thank them for taking the time to be here. This will be like old home week for Bob Dole . . . Ted, of course, is the emissary from the newly named "HELP" Committee.

I don't believe anyone can top Bob Dole as a champion for individuals with disabilities, and I have long admired his commitment to this area of public policy. In fact, I have tried to follow his example of supporting progressive policy that does not also beget more bureaucracy and irresponsible spending. I do not believe that improving life for those with disabilities and fiscal responsibility have to be mutually exclusive goals if we take the time to do it right.

That is why I appreciated the modifications made in this bill prior to its reintroduction. I know my colleagues on this committee and Senator Kennedy worked very hard to accomplish this goal, and I think that, by and large, they have succeeded. They can be proud to have produced a bill with such solid bipartisan support.

I look forward to reviewing the testimony today and to working with my colleagues on the Finance Committee to move this legislation forward.

## PREPARED STATEMENT OF LARRY HENDERSON

Good morning, my name is Larry Henderson; I'm the executive Director of Independent Resources. Delaware's only statewide Center for independent living.

Centers for Independent Living are not social service agencies, but rather, resource centers for persons with disabilities and the communities in which they reside. What's the difference . . . . . . we don't do much FOR people, we do a lot WITH people. What an individual gets from a Center is directed by that individual. We respect individual diversity and we support personal choice.

As an organization, we work with individuals with significant disabilities, helping them live as independently as they want.

First and foremost, we are an advocacy organization. Other services we offer consists of: independent living skills training, peer support, information and referral. We are the only consumer driven organization in the state, that means that over 51% of both staff and board of directors are themselves persons with disabilities.

Most of the individuals we work with want no more than the rest us do; an opportunity to lead a productive life and be gainfully employed. Herein lies the problem for many organizations like mine.

We can provide the training to insure that the individual is prepared to do the job, we can help them arrange the transportation needed to get to and from the job site, we can even instruct a consumer to ask for reasonable accommodations when necessary; what we can't do is take away the fears that surround the loss of benefits. In particular the costs associated with attendant services and other medical coverage that is so difficult for a person with a disability to get.

Attendant care is expensive. The average cost for attendant services, in Delaware, ranges from $14.00 to $16.00 an hour. This is an expense that most people entering the workforce cannot afford. Individuals can spend as much as 50% of their total income on just attendant services.

When people come to us they are ready to live an independent life. Reality dictates that employment must be a goal. Out of the 140 consumers that we assisted last year 75% faced the decision between loss of benefits verses employment. A mere 5% chose to take the risk. The alternative for others is to do volunteer work. As a result, many qualified individuals are relegated to volunteer positions.

This is not meant to denigrate volunteer positions; however, nothing builds self-esteem like a pay check. The Work Incentives Act would make our jobs easier because consumers would not be forced to choose between employment and medical coverage. Under the Work Incentives Act, persons with disabilities entering the workforce, could maintain the coverage they were previously receiving under Social Security or Medicaid on a sliding scale, creating a "no fear" transition for those individuals we work with.

People with disabilities are in a catch-22 situation. They want to work but if they work They'll lose the medication or attendant services they need to let them work. The Work Incentives Act would end this Catch-22 by extending the medical coverage that would allow those individuals who choose work to do so. Putting people to work, where they can pay taxes and contribute to the community would be a much better use of our tax dollars.

This would help my organization a great deal in assisting people with disabilities to live independent lives.

## PREPARED STATEMENT OF HON. JAMES M. JEFFORDS

Mr. Chairman, I wish to thank you for joining me as an original sponsor of the Work Incentives Improvement Act of 1999 and scheduling this hearing on the bill.

You, Senators Kennedy and Moynihan, the Administration, state agencies, governors, individuals with disabilities and their advocates, and I have worked together for a long time. Our collaboration has paid off.

Last Thursday, with 35 of our colleagues, the four of us introduced the Work Incentives Improvement Act of 1999, S. 331. The reason for this broad bipartisan effort is both compelling and simple. Presently, individuals with disabilities must choose between working or getting health care. Such a choice is absurd. But, current federal law forces individuals with disabilities to make that choice. As a result less than one half of one percent of the 7.5 million individuals on the Social Security disability rolls leave them.

Do these individuals really want to work? The answer is a resounding, "Yes." Over the last 10 years, national surveys consistently have confirmed that people with disabilities of working age want to work, but only about one-third are working.

Are the numbers low because ' of discrimination or because of lack of skills? Congress has tackled these issues. We passed the Americans with Disabilities Act in 1990. It is against the law to discriminate against an individual on the basis of disability in employment. The Individuals with Disabilities Education Act, the Rehabilitation Act, and most recently the Workforce Investment Act of 1998 contribute to the access of individuals with disabilities to the education and training they need to become qualified workers. In S. 331 we offer additional access to job training and placement assistance. We include provisions from the Ticket to Work and Self-Sufficiency Act, Senator Bunning's legislation that passed the House, 410 to 1, last Congress.

However, protection against discrimination is not enough. Access to education and training is not enough. Colleagues, the biggest remaining barrier is health insurance. Individuals with significant disabilities who meet the rigorous eligibility criteria of the Social Security disability programs cannot often get reasonably priced, appropriate health insurance coverage from the private sector. These individuals can only get health insurance from the government, and the government gives it to them only if they stay home, or at best, work a minimal amount.

It is difficult to measure fully the effect of having a job on an individual's life. It has a positive impact on a person's identity, sense of self-worth. Having a job results in satisfaction associated with supporting oneself and one's family or at least not being a burden on it. If only one percent of the 7.5 million SSI and SSDI recipients go to work and forgo cash payments from the Social Security Administration (SSA), this would result in a cash savings of $3.5 billion to the federal Treasury over the lifetimes of these individuals. If we factor in the income taxes these individuals would pay, their lack of need for food stamps, subsidized housing, and other forms of assistance, that $3.5 billion dollar figure would be even higher.

Beyond the individual, there is another factor. Recently we learned that our unemployment rate, 4.3 percent, is the lowest it has been since 1956. Our economy, to stay vibrant and strong, needs access to a qualified and enthusiastic pool of potential workers from which to draw. SSI and SSDI recipients are an untapped resource. Many of the jobs that currently go unfilled, in the service sector and technology industry, are the very jobs that many SSI and SSDI recipients are ready and willing to fill, if only they could have access health care.

The Work Incentives Improvement Act of 1999 is targeted, fiscally responsible legislation. It would enable individuals with significant disabilities to enter the work force for the first time, reenter the work force, or avoid leaving it in the first place. These individuals would need not worry about losing their health care if they choose to work a forty hour week, to put in overtime, or to go for a career advancement or change with more income potential.

The bill would allow states to expand Medicaid coverage to workers with disabilities. These options build on previous reforms including a recent provision enacted in the Balanced Budget Act of 1997 (BBA). The BBA provision permitted states to offer a Medicaid buy-in to those individuals with incomes below 250 percent of poverty who would be eligible for SSI disability benefits but for their income.

The first option in our legislation would build on the BBA provision. States may elect to offer a Medicaid buy-in to people with disabilities who work and have earnings above 250 percent of poverty. Even so, participating States may also set limits on an individual's unearned income, assets, and resources and may require cost-sharing and premiums on a sliding scale up to a full premium.

The second option in our legislation would allow states that elect to do so to also cover individuals who continue to have a severe medically determinable impairment but lose eligibility for SSI or SSDI because of medical improvement. Although medical improvement for individuals with disabilities is inextricably linked to ongoing interventions made possible through insurance coverage, under current law improvement can jeopardize continued eligibility for that coverage.

The legislation also includes access to health care for other working individuals with disabilities through time limited provisions and through time limited demonstrations with capped costs.

This legislation is a vital link that will make the American dream a reality for many Americans with disabilities.

Just as we began the 105th Congress by renewing our commitment to educating children with disabilities, so should we begin this Congress by fulfilling the promise we make to those children—that ours is a country of equal opportunity. All of us have worked to open doors to disabled Americans, in education, in training, in employment and in civil rights. But our efforts may amount to little if we do not open this last door to the freedom and opportunity of the workplace. S. 331 will do just that.

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## PREPARED STATEMENT OF HON. EDWARD M. KENNEDY

Mr. Chairman, Senator Jeffords, Senator Moynihan and other members of the Committee, I commend you for holding this hearing today on our bipartisan legislation to remove the barriers that prevent citizens with disabilities from living independent and productive lives.

We know that a large proportion of the 54 million disabled men and women in this country want to work and are able to work, but they are denied the opportunity to do so. They deserve their fair share of our country's prosperity.

For too long, Americans with disabilities have faced unfair penalties if they take jobs and go to work. They are in danger of losing their medical coverage, which could mean the difference between life and death. They are in danger of losing their cash benefits, even if they earn only modest amounts from work. Too often, they face the harsh choice between buying a decent meal and buying their medication.

The Work Incentive Improvement Act which we have proposed will remove these unfair barriers facing people with disabilities who want to work.

—It will continue to make health insurance available and affordable when a disabled person goes to work, or develops a significant disability while working.

—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 give people with disabilities greater access to the services they need to become successfully employed.

Many leaders on these issues are here today and have worked long and hard and well to help us reach this milestone. They are consumers, family members, citizens, and advocates. They see everyday that the current job programs for people with disabilities are failing them and forcing them into poverty.

They have spent many months helping us develop effective ways to right that wrong—and to them I say thank you for helping us to prepare this needed legislation. It truly represents legislation by the people and for the people.

When we think of people with disabilities, we tend to think of people who are disabled from birth. But fewer than 15% of all people with disabilities are born with their disabilities. A bicycle accident or fall from a ladder, cancer or HIV can render the healthiest and most physically capable persons among us disabled in an instant. This legislation is important because it offers a lifeline to all of us today and in the years to come. A disability need not end the American dream. That was the promise of the Americans with Disabilities Act, and this legislation dramatically strengthens our commitment to that promise.

Our goal is to reform and improve existing disability programs, so that they do more to encourage and support every disabled person's dream to work and live independently, and be a productive and contributing member of their community. That goal should be the birthright of all Americans—and when we say all, we mean all.

A story from the debate over the Americans with Disabilities Act illustrates the point. A postmaster in a town was told that he must make his post office accessible. The building had 20 steep steps leading up to a revolving door at the only entrance. The postmaster questioned the need to make such costly repairs. He said, "I've been here for thirty-five years and in all that time I've yet to see a single customer come in here in a wheelchair."

The road to economic prosperity must be accessible to all Americans—no matter how many steps stand in the way. That is our goal in this legislation. It is the right thing to do, and it is the cost effective thing to do. And now is the time to do it. For too long, our fellow disabled citizens have been left out and left behind. A new and brighter day is on the horizon for them, and together we can make it a reality.

I commend Chairman Roth, Senator Jeffords, and Senator Moynihan for their bipartisan leadership on this legislation, and I commend the Committee for this early hearing. We now have an excellent opportunity to enact this long overdue legislation, and I look forward to working with the Committee to do so as soon as possible.

## PREPARED STATEMENT OF JOE LEEAN

Mr. Chairman and members of the committee, I am Joe Leean, Secretary of the Wisconsin Department of Health and Family Services. On behalf of Governor Tommy Thompson, our Medicaid Director Peggy Bartels and myself, I appreciate the opportunity to offer support for the Work Incentives Improvement Act.

Removing barriers to employment is a goal that Governor Thompson and I strongly support.

Almost one year ago Governor Thompson indicated support for the intent behind this bill. But he also expressed concern about the cost of the earlier proposal. And since it is important to avoid pitting one group of vulnerable people against another, we want to assure that no fiscal offsets are required from Medicaid or other health and human service programs.

We are pleased that the current bill is responsive to our previous concerns. While the costs have been reduced by 75% compared to the earlier bill, the Act would still make significant progress in removing employment barriers.

As a former chairman of our legislature's Finance Committee, I never supported anything I did not think was fiscally responsible. I believe this bill offers a fiscally sound, cost-effective way to do the right thing.

As more people work, they will pay taxes, climb the economic ladder, and reduce dependency on government programs. If those taxes and savings to all government programs could be taken into account, it is likely that few fiscal offsets would be needed. When more SSI or SSDI beneficiaries work, it is the federal government and social security trust fund that benefits from most of the savings. We at the State level therefore need your help as we try to enable more people with disabilities to become employed.

Most people with permanent disabilities want to work. New drug regimens, new adaptive aids, advances in personal computers and progress in other technologies make employment more feasible than ever before. A booming economy and the vast, untapped, well-educated talent pool of people with disabilities make it even more important that we act to remove employment barriers now.

We ought to match new private sector advances with new public sector thinking. We need three things:

- An Assurance of Continued Health and Long Term Care Coverage
- A Gradual Reduction of Cash Benefits Instead of "Cliffs"
- A Comprehensive Approach

Allow me to explain how reforms in these three areas would help.

First, health and long term care coverage: People with significant disabilities depend on the health care system every day. They depend on the personal care attendant who helps a person with quadriplegia get out of the bed each morning, get dressed and eat breakfast. They depend on the drugs that help an individual with mental illness to function every day. They depend on the nurse who trains and assists family members in the cleaning and suctioning of a ventilator that may keep a person with spinal cord injury breathing.

SSI or SSDI beneficiaries risk losing the Medicaid or Medicare coverage that provides these services when they earn more than $500 per month. Such a loss can be life-threatening. This helps to account for the GAO's finding that less than 1% of SSI and SSDI beneficiaries leave those programs as a result of paid employment.

I am therefore enthusiastic about the proposed options to permit people with disabilities to purchase Medicaid coverage. Why is Medicaid so important? It is the only health program that can cover the personal care, drugs and specialized transportation needs of people with disabilities such as spinal cord injury.

The Act would also extend the current 4-year period of Medicare eligibility for someone on SSDI. This is very important. Many people who have recently gone to work with help from our Pathways to Independence Program have told us they will need to quit their new jobs if Medicare coverage ends.

One such person is Ken Adell. Ken has quadriplegia. Even though he can move only his head, Ken operates his computer expertly with the help of some adaptive aids. He excels in his job maintaining Internet sites and a toll-free telephone service. In 14 months Ken's health coverage under Medicare is scheduled to expire. Ken does not have private health insurance. When his Medicare terminates, Ken will also lose his "disability status" and be ineligible to buy into Medicaid. Because Medicare and Medicaid pay for the health care he needs to live, Ken does not see a possibility for continued work if his Medicare coverage ends.

Second, reduce benefits gradually as income rises: This second reform is important to "make work pay." SSDI beneficiaries are often shocked to learn that their cash payments are reduced to zero after nine months in which they earn more than $500 per month. This "cliff" scares people off from being able to see a future in which they might become employed.

I am therefore pleased to see that the Work Incentives Improvement Act directs the Social Security Administration to conduct some demonstrations in which the SSDI cash benefits are reduced in a more gradual manner. We would like to be the first enthusiastic state you select to work with you on such a demonstration. (After, perhaps, Vermont, Mass, NY and Delaware!).

A Comprehensive Approach: We are very pleased to see that the Work Incentives Improvement Act contains funding for states to sponsor local demonstrations.

We would like to demonstrate the value of health care, vocational rehabilitation, and employment services in a single comprehensive, coordinated design that is built on a public-private partnership. With help from the Social Security Administration, we recently developed a program called Pathways to Independence to assist thousands of people with disabilities to work— but we need your continued collaboration. I leave with you a short description of our program.

I look forward to working with you to make Pathways a success and appreciate the new tools which this Act would provide.

## SUGGESTIONS

What would make this good bill even better?

Two modest suggestions:

First, allow states a reasonable time period in which to phase in the new Medicaid options. The proposed bill would require a state to implement the options statewide, immediately. It would be more feasible for us to begin with certain geographical areas and then expand to statewideness in a reasonable period of time. We suggest not a waiver of statewideness, but simply a non-waiver provision in the legislation allowing states a little time to achieve statewideness in the new Medicaid options.

Second, allow states to set a minimum level of earnings in order for a person to qualify for either of the new Medicaid options. This would help states to ensure adequate employment outcomes.

Conclusion

On behalf of Governor Thompson and myself, I would like to thank you for the opportunity to speak with you today. With this bill and your partnership in new demonstrations, we hope employers will be able to enlist the full potential of the workforce, and that many more people like Ken Adell will experience new careers as wage-earners, taxpayers, and working citizens in our communities.

Tommy G. Thompson
Governor

Joe Leean
Secretary, DHFS

Linda Stewart
Secretary, DWD

State of Wisconsin

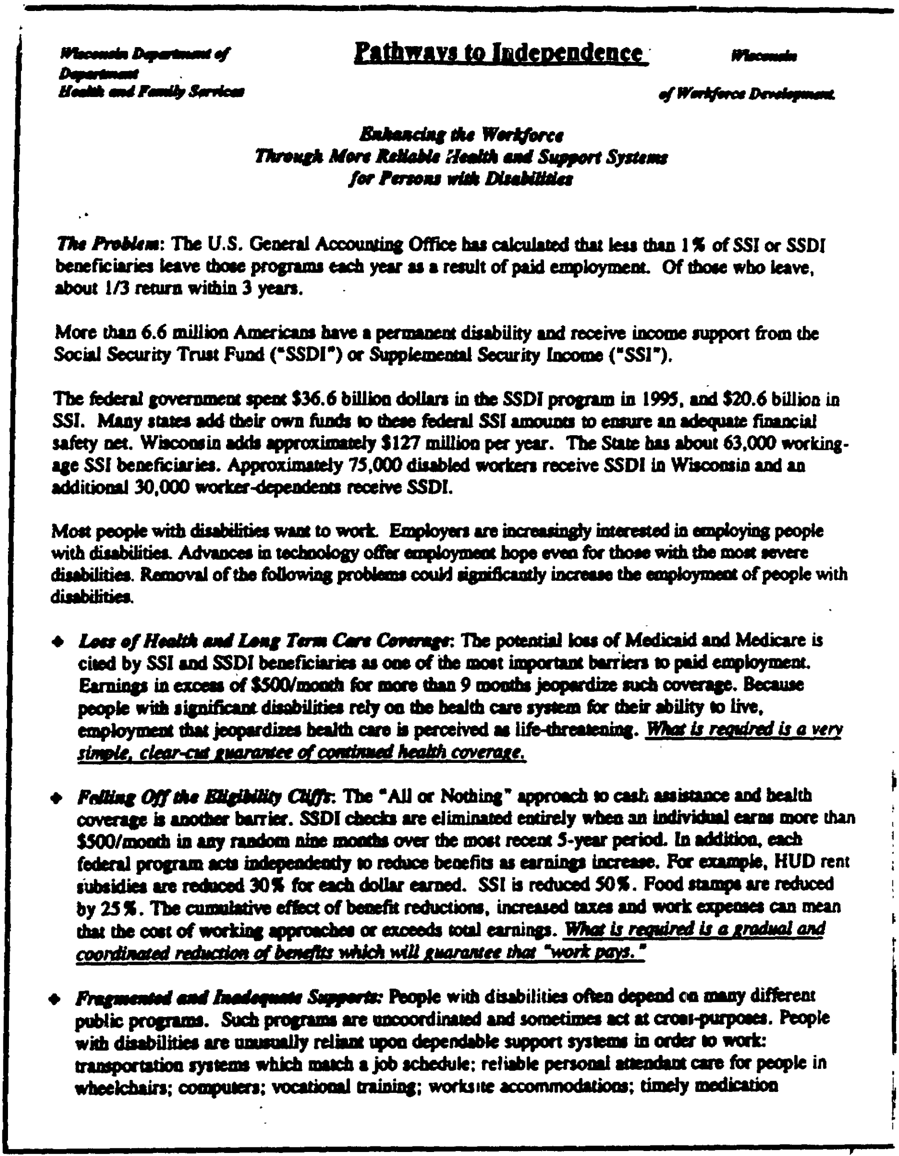
Department of Health and Fami
Services, P.O. Box 7850 Madison, WI

Department of Workforce
Development

# Pathways to Independence

## *Enhancing the Wisconsin Workforce Through More Reliable Health and Support Systems For People with Disabilities*

January 1999



*Wisconsin Department of*
*Department*
*Health and Family Services*

# Pathways to Independence

*Wisconsin*
*of Workforce Development*

## *Enhancing the Workforce*
## *Through More Reliable Health and Support Systems*
## *for Persons with Disabilities*

***The Problem***: The U.S. General Accounting Office has calculated that less than 1% of SSI or SSDI beneficiaries leave those programs each year as a result of paid employment. Of those who leave, about 1/3 return within 3 years.

More than 6.6 million Americans have a permanent disability and receive income support from the Social Security Trust Fund ("SSDI") or Supplemental Security Income ("SSI").

The federal government spent $36.6 billion dollars in the SSDI program in 1995, and $20.6 billion in SSI. Many states add their own funds to these federal SSI amounts to ensure an adequate financial safety net. Wisconsin adds approximately $127 million per year. The State has about 63,000 working-age SSI beneficiaries. Approximately 75,000 disabled workers receive SSDI in Wisconsin and an additional 30,000 worker-dependents receive SSDI.

Most people with disabilities want to work. Employers are increasingly interested in employing people with disabilities. Advances in technology offer employment hope even for those with the most severe disabilities. Removal of the following problems could significantly increase the employment of people with disabilities.

◆ ***Loss of Health and Long Term Care Coverage***: The potential loss of Medicaid and Medicare is cited by SSI and SSDI beneficiaries as one of the most important barriers to paid employment. Earnings in excess of $500/month for more than 9 months jeopardize such coverage. Because people with significant disabilities rely on the health care system for their ability to live, employment that jeopardizes health care is perceived as life-threatening. *What is required is a very simple, clear-cut guarantee of continued health coverage.*

◆ ***Falling Off the Eligibility Cliffs***: The "All or Nothing" approach to cash assistance and health coverage is another barrier. SSDI checks are eliminated entirely when an individual earns more than $500/month in any random nine months over the most recent 5-year period. In addition, each federal program acts independently to reduce benefits as earnings increase. For example, HUD rent subsidies are reduced 30% for each dollar earned. SSI is reduced 50%. Food stamps are reduced by 25%. The cumulative effect of benefit reductions, increased taxes and work expenses can mean that the cost of working approaches or exceeds total earnings. *What is required is a gradual and coordinated reduction of benefits which will guarantee that "work pays."*

◆ ***Fragmented and Inadequate Supports:*** People with disabilities often depend on many different public programs. Such programs are uncoordinated and sometimes act at cross-purposes. People with disabilities are unusually reliant upon dependable support systems in order to work: transportation systems which match a job schedule; reliable personal attendant care for people in wheelchairs; computers; vocational training; worksite accommodations; timely medication management; mental health assistance. *There exist no programs which can "pull all the pieces together." There is no program which can intercede quickly when there are breakdowns.*

***Implications for Action***: Since almost no beneficiaries leave SSI/SSDI as a result of paid employment, it would be of virtually no cost to the State and Federal governments to continue the Medicaid/Medicare coverage of current beneficiaries if they can secure paid employment. This would remove the impediment which people with severe disabilities fear most. If employment rates increase it would also be of little cost to remove the current "cliffs" in cash assistance in SSI, SSDI, and HUD programs.

## Wisconsin Pathways to Independence

The Wisconsin Department of Health and Family Services and the Department of Workforce Development are working jointly to create a powerful initiative to increase employment on the part of people with significant disabilities.

Federal waivers and passage of some of the provisions in the federally-proposed Work Incentives Improvement Act would be necessary for *Pathways* to achieve its full potential. The key concepts are:

***A. Simplified Access to Comprehensive Help***: Enrollees will be able to consult with a single team which can offer coordinated access to all professionals and programs that may assist them in achieving their employment goals. These local ***Comprehensive Assistance Networks*** mobilize all available vocational, educational, health and supportive services. Each organization works with the local vocational rehabilitation district to assure needed training, worksite accommodations and adaptive aids. The organization recruits employers to match abilities of the individual with the employers' requirements. The goal is to break down the barriers between isolated health, long term care, vocational, educational, and cash assistance programs so that all services can be aligned in support of vocational goals. Greater coordination as well as new flexibility in funding among all support programs will reduce fragmentation.

> Current Status: With assistance from the Robert Wood Johnson Foundation, local pilot tests have confirmed the value of team-based comprehensive approaches for both persons with physical disabilities and people with mental illness. Research associated with these efforts indicates a strong potential for benefits to the individual and for public financial savings. With assistance from the Social Security Administration, a request for proposals was issued in December 1998 to expand this concept. Over 70 public and private agencies have indicated their intent to submit a proposal to establish a local Comprehensive Assistance Network. Selections will be made in March 1999 for the initial 10 expansion sites.

***B. Remove Employment Barriers***: In *Pathways to Independence* we seek to remove systemic barriers to employment which result from public policy. The plan is to incorporate the following features:

- ***Health/LTC Security***: Guarantee continued Medicaid and/or Medicare coverage for up to1800 current SSI and SSDI beneficiaries in 15-20 sites who enroll in the work program over a five-year period. If enrollees secure employment paying over $500/ month, they would be assured of continued coverage regardless of earnings (and regardless of assets which result from earnings.) People with physical disabilities, mental illness, developmental disabilities, or HIV-AIDS would be included.

  Current Status: A Medicaid waiver will be submitted in March 1999 to add security and to simplify eligibility for people already receiving Medicaid, provided they become employed or increase their earnings. A Medicare waiver to extend Medicare beyond the current 39-month period will be submitted if the Social Security Administration's authority to grant waivers is restored by Congress.

  In addition, the Pathways Medicaid Purchase Plan has been designed to provide access to health care on the part of people without current Medicaid coverage but who meet the SSDI disability test. Governor Thompson's proposed budget for 1999-2001 contains legislation to permit people with significant disabilities to purchase Medicaid coverage if their net family incomes are less than 250% of the federal poverty level and they are employed or enroll in a work program. This would implement an important State option in the Balanced Budget Act passed by Congress in 1997.

- ***Gradual Reduction of Cash Assistance***: Replace the "all or nothing cliff" in eligibility for SSDI payments in favor of a sliding scale. Coordinate the benefit reductions of other federal and state programs so that a reasonable amount of discretionary net income remains, and "work pays."

  Current Status: An SSI waiver will be submitted in February 1999. An SSDI waiver will be submitted if Congress restores the authority of the Social Security Administration to grant demonstration waivers.

- ***Research:*** A strong research design will document demonstration results for the three target groups. Analysis of comparison or control groups, together with comprehensive tracking of changes in public costs, will enable us to assess the potential impact of any larger-scale public policy changes.

***Building on Experience:*** Essential elements of this demonstration have already been pre-tested in Wisconsin with help from the Robert Wood Johnson Foundation. The Vocational Futures Planning model developed through such RWJ-F assistance has assisted many people with significant physical disabilities to become employed. However, the successes are fragile. The experiences of such people indicate that without removal of key employment barriers described earlier, successes achieved so far will be hard to replicate or sustain.

One such successful person is Ken Adell. Ken has quadriplegia. Even though he can move only his head, Mr. Adell operates his computer with consummate skill. With help from adaptive aids, Ken excels in his job maintaining Internet sites and operating a toll-free telephone service. Ken earns about $27,000 per year. Not only has he worked off his SSDI payments, but he also contributes about $12,000 per year toward the cost of his medical care and pays over $2,000 per year in taxes. The problem is that in 14 months Ken's health coverage under Medicare is scheduled to expire. Ken does not have private health insurance. When his Medicare ends Ken will also lose his "disability status" and be ineligible to buy into Medicaid. Because Medicare and Medicaid pay for the health care he needs to live, Ken does not see a possibility for continued work if his Medicare coverage ends.

Governor Tommy Thompson has committed his Administration to securing both the funds and federal waivers necessary for *Pathways to Independence* to be a success. In his 1998 "State of the State" address he urged a speedy solution:

***"We are wasting too much talent by allowing legitimate fears over health care to keep people with disabilities out of the workforce. Give them their freedom by protecting their health."***

***State of Wisconsin***

***Department of Health and Family Services***
***Department of Workforce Development***

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## PREPARED STATEMENT OF HON. DANIEL PATRICK MOYNIHAN

I would like to thank Chairman Roth for holding this hearing on the Work Incentives Improvement Act of 1999. The bill (S. 331) would address some of the barriers and disincentives that individuals with disabilities face when trying to seek employment. Senators Jeffords and Kennedy should also be commended for their leadership in this area. Last year, they introduced a bill that addressed one of the major barriers for disabled Americans who want to work—access to health care.

On January 28, Chairman Roth and I joined with Senators Jeffords and Kennedy to introduce the Work Incentives Improvement Act of 1999. Currently, we have a total of 41 cosponsors—14 Republicans and 27 Democrats. And the list is growing each day. Thirteen members of the Finance Committee—6 Republicans and 7 Democrats—support the bill.

Our former Leader and Chairman, Bob Dole, should also be commended for pioneering legislation to address work disincentives for people with disabilities. In March, 1986, Senator Dole introduced "The Employment Opportunities for Disabled Americans Act"—a bill that would continue Medicaid coverage for Supplemental Security Income (SSI) beneficiaries who return to work. I was an original cosponsor of that bill, which passed the Senate by a voice vote. On November 11, 1986, President Reagan signed the bill into law.

### BARRIERS TO WORK

Persons with disabilities often need the health coverage that accompanies their eligibility for disability benefits. Under current law, as they return to work, beneficiaries lose their cash benefits and their health coverage. The risk of losing health benefits may deter disabled individuals from returning to work and, instead, encourage them to continue to receive cash benefits despite their ability to work.

### THE WORK INCENTIVES IMPROVEMENT ACT OF 1999 (S. 331)

As we will hear from these witnesses, our bill would address several of the barriers to work for Americans with disabilities--including access to health care. The Work Incentives Improvement Act would offer health care coverage options as well as providing job training and rehabilitation to assist individuals seeking employment. The bill would permit new categories of disabled individuals to buy into Medicaid: individuals whose income and assets exceed current limits and those who lose their eligibility for Medicaid because of improvements in their health conditions. A ten-year trial program would continue Medicare coverage for SSDI beneficiaries who return to work. In addition, the bill would create incentives for vocational rehabilitation providers to help beneficiaries in finding work and achieving sufficient income.

The bill also contains another provision of interest: it would provide a one-time open season in which members of the clergy, who are not now covered by Social Security, could choose to participate in Social Security. This provision is identical to the bill (S. 170) that Senator Bob Smith and I introduced on this issue.

Chairman Roth and I are committed to marking up the Work Incentive Improvement Act in early spring. At that time, the Chairman's Mark will include offsets to the proposed spending.

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## PREPARED STATEMENT OF HON. FRANK MURKOWSKI

Mr. Chairman, I am pleased to be an original co-sponsor of this important legislation. I applaud my colleagues, Senator Kennedy, Senator Jeffords and Chairman Roth for their leadership on this bill. Not only does this bill make good moral sense, it makes good fiscal sense.

Currently, 8 million disabled Americans of working age receive more than $50 billion a year in cash benefits from Social Security and Supplemental Security Income. Fewer than I percent return to work -although 72% of them want to return to work according to a recent Harris poll. Why do they feel they can't return to work? For one reason alone—a fear of losing their health insurance.

I would like to submit into the record the Statement of Robert B. Briggs of the Disability Law Center of Alaska.. Mr. Briggs has done much to advance the needs of Alaska's disabled. In his statement he explains why this legislation is important to my state of Alaska:

> "By virtue of the remoteness of its communities. the rigors of life in Alaska and the relative youth of its populace, Alaska has one of the highest, if not the highest disabling accidents in the nation. Loggers, fishers, miners and oil field workers in Alaska face some of the harshest, most dangerous working environ-

> ments in the world . . . The courage and willingness of Alaskans to encounter those risks, unfortunately, leads to higher rates of disabling injuries."

Let me share another part of Mr. Briggs' statement that tells the story of Davin Pedersen of Juneau. Dawn, a 29-year-old who suffered liver failure due to a rare liver and blood disease. Fortunately, she received a successful liver transplant and overcame tremendous physical obstacles as a result of her disease.

Dawn was not about to sit around on public benefits for the rest of her life. She had labored hard in the fishing industry of Southeast Alaska before her liver was damaged, but now needed a physically less demanding job. Dawn then re-trained as a payroll clerk for a fish processing company in Juneau. In getting this job, Dawn unwittingly walked off the "benefits cliff."

Dawn's new job included health benefits, but until she had worked on the job for 6 months. Dawn expected her public health benefits to remain with her until her private insurance benefits began. However, shortly after she was employed, Dawn received a letter from the Social Security Administration and Alaska's Department of Health and Social Services cutting her health and other benefits because now she was successfully employed. Dawn had to forgo her doctor's orders and medical treatment simply because she could now no longer afford it.

Before this legislation, Dawn's most sensible option was to quit her job and go back on the government dole. Dawn didn't take that option, instead, she had to forego medical treatment. Fortunately, the story has a happy ending: Dawn has had no complications with her liver and she now advocates for the rights of the disabled.

Mr. Chairman, this legislation is important to Dawn and others like her—individuals who want to live a productive life—but not at the cost of their health. As Mr. Briggs so eloquently stated in his testimony which I submit today, 'This legislation will go far to help bridge the gap of dependency."

Mr. Chairman, I ask that the balance of Mr. Briggs statement be included in the record, and I thank the Chair.

Attachment.

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MEMBER·OF·THE NATIONAL ASSOCIATION·OF PROTECTION·& ADVOCACY SYSTEMS

### Statement of Robert B. Briggs
### Staff Attorney, Disability Law Center of Alaska, Inc.

### Testimony Before the Senate Committee on Finance

### Hearing on S. 331, Work Incentives Improvement Act of 1999

February 4, 1999

Mr. Chairman Roth and distinguished Members of the Committee, thank you for this opportunity to testify on S. 331, which shows great promise as a bridge to help persons with disabilities, including many Alaskans, to cross the chasm of public dependency, and gain employment. Many Members of the Committee and their staffs, in consultation with national leaders of disability advocacy organizations, have worked long, long hours to produce S. 331, and that effort is to be applauded. It is with great pride and gratitude to see that our two Alaskan senators, Senator Frank Murkowski of this Committee and Senator Ted Stevens, are co-sponsors of this legislation so important to persons with disabilities and their families.

My eyes were opened to the difficulties faced by a person with a severe disability seeking to become employed when Dawn Pedersen of Juneau, Alaska, then 29 years old, came to me in 1997 asking for legal assistance. Dawn has a rare disease of the liver and blood system called Budd-Chiari syndrome, and through complications her liver had been destroyed. She received a successful liver transplant at the Mayo Clinic, and with life-saving immunosuppressant medication is alive and well today. She had overcome tremendous physical obstacles, only to be confronted with financial obstacles that seemed insurmountable.

At her young age, Dawn was not about to sit around on public benefits for the rest of her life. She had worked vigorously in the fishing industry of Southeast Alaska before her liver was damaged, but realized that her disease would require a change to a less physically-demanding job. She re-trained for office clerical work, and in January 1997 was hired as a payroll clerk by Taku Smokeries, a medium-sized fish processing company in Juneau. In getting this job, Dawn unwittingly walked off the "benefits cliff."

Dawn's new job included health insurance benefits, but those benefits did not appear to be available until she had worked a full six month probationary period, and the insurance company could decline to cover the expenses of her pre-existing condition for up to a year – or might even decline to provide her with any health insurance at all.[1] Moreover, the Taku Smokeries insurance policy did not provide

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[1] ADA law in this area is unsettled and developing, but some insurance companies have successfully declined to provide health insurance to a person with a severe disability. *See, e.g.,Lenox v. Healthwise of Kentucky, Ltd.*, 13 Nat'l Disab. Law Rep. ¶ 92 (6th Cir. 1998)(No. 96-6319).

coverage for prescription medications, yet this was Dawn's greatest health care expense: she spends about $990 per month on medications, including the life-giving immunosuppressants, plus another $300 for regular blood tests and other medical monitoring. With net earnings of $1200 per month, Dawn was given the Hobson's choice of paying for food and rent, or obtaining her prescribed medications and medical care. She could not do both.

Dawn had expected public health benefits to be there for her until her private health benefits began. Her expectation was frustrated when she received letters from the Social Security Administration and the Alaska Department of Health and Social Services cutting off health and other benefits – because she was now successfully employed.[1] By virtue of her vigorous work history, Dawn's SSDI benefits were high enough to make her ineligible for the Section 1619(b) program, which allows a narrow class of SSI beneficiaries to continue to receive Medicaid despite a return to work. People like Dawn, who have an established work history and receive high enough SSDI payments, will never be eligible to receive SSI and therefore will never be eligible for the Section 1619(b) program.

The Impairment Related Work Expense (IRWE) provisions of existing Social Security regulations were of little assistance to Dawn, since to successfully claim IRWEs, she would have to provide receipts showing that her earnings were below $500 after payment of medical expenses. She could do this, but it was virtually impossible for her to eat and pay her medical expenses at the same time. Instead she chose to forego necessary blood tests, thereby placing the success of her liver implant at risk. With credit from medical providers and pharmacies, and gifts from family, she was able to barely survive. Her prospects were dim.

Dawn's story does not have an unhappy ending. Her employer changed the health insurance policy to provide coverage for medications. The health insurance company, **Blue Cross of Washington and Alaska**, extended coverage to her and did not require a one-year wait before covering expenses of her pre-existing condition. Dawn's state legislators **Reps. Bill Hudson, Kim Elton and Sen. Jim Duncan persuaded Governor Tony Knowles'** administration to find some financial support for Dawn until the medical coverage changes were in place. Dawn was able to resume her full medical regimen. She had no complications to her liver despite not following doctors orders. Dawn kept her job. She was very lucky.

Dawn resolved that no one should have to go through what she went through, when she came into my office in the summer of 1997 and I had to tell her to either quit her job and go back

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[1] Dawn had used up her "trial work period" and "extended period of eligibility" at other short-term, seasonal employment.

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on the government dole, or try to live on less than $100 a month for food and shelter despite her full-time employment.

Dawn's experience helped in the passage of Alaska House Bill 459. Under the leadership of **Rep. Con Bunde** of Anchorage, Alaska became one of the first states in the Union to implement Section 4733 of the Balanced Budget Act of 1997. Section 4733 provides states an option to offer Medicaid to persons with disabilities who need it and who contribute a premium on a sliding scale. Ironically, Dawn's advocacy to implement Section 4733 of the BBA ***would not have benefited her personally***, because that option is limited to those who currently receive SSI, or who would be receiving SSI but for earned income. "High-end" SSDI recipients – like Dawn – whose work history is vigorous enough that their unearned income makes them ineligible for SSI are still left out by Section 4733 of the BBA, still stare across the chasm of public dependency.

Passage of S. 331 will help bring Dawn Pedersen's story to full closure, and truly ensure that her story is not repeated. It will provide an option for states to offer Medicaid on a buy-in basis to all those who need it, and help bridge the gap of dependency. The Alaska Legislature will have to write the final chapter.

There are Alaskans today who will benefit immediately by this change in the law. **Howard Hedges** of Homer, Alaska, was a world-class trombonist who toured nationally with big bands and Broadway shows until his work life was interrupted by a diabetes-related stroke in 1993. He experiences partial paralysis, cardiac impairment, and other diabetes-related complications. He had no health insurance when his stroke occurred. His return to work has been impeded in the same way as Dawn Pedersen's almost was, by the lack of affordable health insurance benefits. Unlike Dawn, he has not stepped off the precipice, but instead stands at the edge of it.

Today, Howard, his wife and his six year old child are dependents of the SSDI benefits he receives, unable to leap the chasm of public dependency because of the lack of affordable health insurance that Howard needs to survive. With health insurance benefits, Howard believes he can begin to put together a career as a music teacher. Without sure benefits, he and his family cannot afford to make the leap toward employment. There are other Alaskans like Howard who will benefit by passage of S. 331.

By virtue of the remoteness of its communities, the rigors of life in Alaska, and the relative youth of its populace, Alaska stands to benefit more than most states from this bill. Alaska has one of the highest, if not the highest, disabling accident rates in the nation. Loggers, fishers, miners and oil field workers in Alaska face some of the harshest, most dangerous working environments in the world. Half of Alaska's population resides in areas defined as rural, living close to the land and the risks of such living. The courage and willingness of Alaskans to encounter those risks, unfortunately, leads to higher rates of disabling injury.

From 1980 to 1990, as shown by analysis of national census statistics, Alaska rated first in the nation in the rate of increase of nonsevere work disability, third nationally behind Montana and Wyoming in the rate of increase of severe work disability, and first overall in the rate of increase of work disability.[3] It is recognized that as the nation's population ages, the rates of disability will increase;[4] as one of the nation's demographically youngest states, Alaska stands to see its rates of disability continue to increase fastest in the nation.

The prospect of increased quality of life offered by S. 331 will benefit many Alaskans; the national rate of disability has been reported at approximately 15% of the population.[5] Although it has a very small population compared to the nation, Alaska has shown that it can be a leader in this subject. Through their leadership in Congressional action to help foster employment by persons with disabilities, Alaska's delegation will leave a legacy not just for Alaskans but for the entire country.

Affordable health insurance is only one part – a very important, essential girder – in the bridge to employment. S. 331 has been carefully crafted to provide not just a thin, rickety catwalk but a healthy, solid span for persons with diverse disabilities to cross over to employment. The Ticket to Work and other provisions of S. 331 have been thoughtfully put together with help from the nation's leaders in the disability community to provide a comprehensive solution, to change the appalling statistic that less than 1 in 500 Social Security disability recipients become employed after receiving disability benefits. The many individuals and organizations who have studied this subject, including the National Council on Disability and the National Council on Independent Living and many others, have suggested that a comprehensive approach is necessary to overcome the complexity of the existing barriers to employment of persons with disabilities. Something less than a comprehensive solution runs the risk of repeating the problems of the existing, piecemeal system of work incentives.

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[3] M.P. LaPlante and J.K. Cyril, *Disability in the States*, DISABILITY STATISTICS ABSTRACT NO. 6 , Table 2 (May 1993), *reprinted at* http://dsc.ucsf.edu/reps/index.html.

[4] H.S. Kaye, et al., *Trends in Disability Rates in the United States, 1970-1994*, DISABILITY STATISTICS ABSTRACT No. 17, page 3 (Nov. 1996), *reprinted at* http://dsc.ucsf.edu/reps/index.html.

[5] Statistics on percentages of populations experiencing a disability depend upon how disability is defined. The age-adjusted rate of the national population with activity limitations has been reported at15% as of 1994. *Trends in Disability Rates in the United States, 1970-1994, supra* note 4, at page 1 and Fig. 1.

Having a job is the single most valuable attribute of this society. It provides tangible proof, in the form of wages and other benefits, of the value placed on the labor of an individual. A job is not the only way that a person's value is recognized, but it is one of the most important ones. People who experience disabilities severe enough to force them onto Social Security benefits crave nothing more than to join the ranks of the employed – the valued in this society. S. 331 will help realize that dream, help bridge the chasm of public dependency. Senator Roth, Senator Murkowski, and other Members of the Committee, I urge you to favorably recommend this bill for passage, and thank you for your consideration of this important subject.

# Disability Statistics Abstract

Number 6

## *Disability in the States*

by Mitchell P. LaPlante and Juliana K. Cyril

Disability is highly related to social and environmental conditions.[1] The 50 states and the District of Columbia differ widely in the wealth, educational attainment, racial and ethnic composition, and social beliefs of their populations, as well as in their built and natural physical environments. In response to some of these differences, the rate of disability can be expected to vary by region and from state to state.

### The Census

Statistically, the census is the most precise source of state data on disability. It is better than any major national survey in approximating the true range of variation between states in rates of disability. The 1980 and 1990 censuses provide estimates on work disability in the 50 states and the District of Columbia (hereafter called the "states"). The 1990 census also provides estimates of the number of people with mobility or self-care difficulties for states.

### Work Disability

The census measures work disability, due to a physical, mental, or other health condition that has lasted at least six months, in the following categories: (1) limitation in the kind or amount of work a person can do (nonsevere work disability); (2) prevention from working at a job (severe work disability); and (3) any work disability (either 1 or 2).

In 1990, 12.8 million Americans aged 16 to 64 had a work disability, 6.6 million could not work at all, and 6.2 million could work but were limited in the kind or amount of work they could do. In 1990, the five states with the highest rates of work limitation were West Virginia, Kentucky, Arkansas, Mississippi, and Louisiana (Table 1). From 1980 to 1990, rates declined for 30 states, mainly in the South, and increased for 21 states, mainly in the Midwest and West. Disability rates increased substantially in Alaska, Montana, and Wyoming, for example, while rates decreased substantially in the District of Columbia, Georgia, and Florida during the same ten year period.

From 1980 to 1990, national rates for both severe and nonsevere work disability decreased (by 3.9% and 4.7% respectively). However, severe work disability remained a consistent problem for states that had high rates in 1980. None of the five highest ranking states in terms of severe work disability ranks high in terms of nonsevere work disability, which suggests that different factors may influence rates of severe and nonsevere work disability.

### Mobility and Self-Care Difficulty

The 1990 census is the first to provide estimates of outside mobility limitation (any difficulty going outside the home alone) and self-care limitation (any difficulty taking care of personal needs, such as bathing dressing, or getting around inside the home).

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Number 6, May 1993.

**TABLE 1. Rate of Work Disability per Thousand People Aged 16 to 64 in 1980 and 1990 and Percent Change, by Severity and State**

| | | With a work disability | | | | | | Nonsevere work disability | | | | | | Severe work disability | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | | 1980 | | 1990 | | | | 1980 | | 1990 | | | | 1980 | | 1990 | | | |
| | | Rate per 1,000 | Rank | Rate per 1,000 | Rank | Change (%) | Rank | Rate per 1,000 | Rank | Rate per 1,000 | Rank | Change (%) | Rank | Rate per 1,000 | Rank | Rate per 1,000 | Rank | Change (%) | Rank |
| United States | | 85.2 | — | 81.5 | — | -4.3 | — | 41.6 | — | 39.6 | — | -4.7 | — | 43.6 | — | 41.9 | — | -3.9 | — |
| State | Code | | | | | | | | | | | | | | | | | | |
| West Virginia | WV | 123.4 | 2 | 126.2 | 1 | 2.3 | 18 | 44.2 | 22 | 42.5 | 21 | -3.7 | 27 | 79.2 | 1 | 83.7 | 1 | 5.7 | 16 |
| Kentucky | KY | 113.9 | 4 | 114.3 | 2 | 0.4 | 21 | 45.5 | 18 | 41.5 | 26 | -8.7 | 39 | 68.4 | 4 | 72.8 | 2 | 6.4 | 15 |
| Arkansas | AR | 127.3 | 1 | 111.7 | 3 | -12.2 | 48 | 54.0 | 2 | 45.9 | 9 | -14.9 | 49 | 73.3 | 2 | 65.8 | 4 | -10.2 | 43 |
| Mississippi | MS | 117.6 | 3 | 109.8 | 4 | -6.6 | 38 | 47.0 | 9 | 39.0 | 35 | -16.9 | 51 | 70.6 | 3 | 70.8 | 3 | 0.3 | 26 |
| Louisiana | LA | 95.6 | 15 | 102.9 | 5 | 7.6 | 8 | 41.2 | 35 | 38.9 | 38 | -5.6 | 32 | 54.4 | 9 | 64.0 | 5 | 17.6 | 5 |
| Oklahoma | OK | 107.5 | 5 | 101.6 | 6 | -5.6 | 35 | 53.4 | 3 | 51.4 | 6 | -3.8 | 28 | 54.1 | 10 | 50.2 | 9 | -7.4 | 38 |
| Maine | ME | 97.5 | 14 | 101.5 | 7 | 4.2 | 12 | 47.9 | 8 | 53.0 | 3 | 10.7 | 2 | 49.6 | 14 | 48.5 | 10 | -2.1 | 29 |
| Oregon | OR | 98.5 | 11 | 100.1 | 8 | 1.6 | 20 | 58.4 | 1 | 59.4 | 1 | 1.7 | 18 | 40.1 | 26 | 40.7 | 24 | 1.5 | 24 |
| Tennessee | TN | 103.7 | 7 | 97.3 | 9 | -6.2 | 36 | 43.2 | 28 | 39.0 | 36 | -9.7 | 43 | 60.5 | 6 | 58.4 | 7 | -3.6 | 31 |
| Montana | MT | 81.4 | 28 | 97.0 | 10 | 19.3 | 2 | 49.0 | 6 | 51.7 | 5 | 5.5 | 6 | 32.4 | 37 | 45.3 | 18 | 40.1 | 1 |
| Alabama | AL | 105.9 | 6 | 96.8 | 11 | -8.6 | 42 | 43.6 | 23 | 37.7 | 43 | -13.7 | 48 | 62.2 | 5 | 59.1 | 6 | -5.0 | 34 |
| South Carolina | SC | 98.1 | 12 | 91.1 | 12 | -7.2 | 40 | 42.3 | 31 | 37.8 | 42 | -10.6 | 45 | 55.9 | 8 | 53.3 | 8 | -4.6 | 33 |
| Washington | WA | 87.6 | 20 | 90.9 | 13 | 3.7 | 14 | 51.1 | 5 | 51.9 | 4 | 1.6 | 19 | 36.5 | 31 | 39.0 | 25 | 6.8 | 14 |
| Michigan | MI | 92.8 | 16 | 90.4 | 14 | -2.5 | 29 | 46.9 | 10 | 43.9 | 14 | -6.5 | 34 | 45.8 | 17 | 46.6 | 15 | 1.6 | 23 |
| Idaho | ID | 87.4 | 21 | 90.4 | 15 | 3.4 | 15 | 52.1 | 4 | 53.1 | 2 | 1.9 | 17 | 35.3 | 34 | 37.3 | 30 | 5.7 | 17 |
| Ohio | OH | 88.0 | 19 | 90.1 | 16 | 2.4 | 17 | 42.5 | 29 | 42.4 | 22 | -0.3 | 22 | 45.6 | 18 | 47.8 | 12 | 4.9 | 18 |
| Georgia | GA | 103.6 | 8 | 88.4 | 17 | -14.6 | 50 | 45.6 | 15 | 40.0 | 33 | -12.3 | 47 | 58.0 | 7 | 48.5 | 11 | -16.4 | 48 |
| New Mexico | NM | 81.7 | 27 | 88.3 | 18 | 8.1 | 7 | 39.4 | 42 | 41.5 | 28 | 5.3 | 8 | 42.3 | 23 | 46.8 | 14 | 10.6 | 11 |
| North Carolina | NC | 97.6 | 13 | 87.3 | 19 | -10.4 | 45 | 44.6 | 19 | 39.8 | 34 | -10.7 | 46 | 52.9 | 12 | 47.5 | 13 | -10.1 | 42 |
| Florida | FL | 99.3 | 9 | 86.6 | 20 | -12.8 | 49 | 45.3 | 17 | 42.7 | 19 | -5.7 | 33 | 54.0 | 11 | 43.9 | 19 | -18.8 | 51 |
| Rhode Island | RI | 86.3 | 22 | 85.8 | 21 | -0.6 | 23 | 41.8 | 33 | 42.9 | 18 | 2.6 | 12 | 44.5 | 20 | 42.9 | 21 | -3.6 | 30 |
| Missouri | MO | 91.3 | 17 | 85.4 | 22 | -6.5 | 37 | 45.1 | 18 | 41.5 | 27 | -8.0 | 38 | 46.2 | 16 | 43.9 | 20 | -5.1 | 35 |
| D.C. | DC | 98.8 | 10 | 84.0 | 23 | -15.0 | 51 | 46.0 | 13 | 39.0 | 37 | -15.4 | 50 | 52.8 | 13 | 45.1 | 17 | -14.6 | 46 |
| Nevada | NV | 78.0 | 32 | 83.4 | 24 | 7.0 | 9 | 46.7 | 12 | 47.8 | 7 | 2.3 | 16 | 31.3 | 39 | 35.7 | 32 | 14.0 | 7 |
| Arizona | AZ | 90.7 | 18 | 83.1 | 25 | -8.4 | 41 | 46.0 | 14 | 41.8 | 25 | -9.1 | 40 | 44.8 | 19 | 41.4 | 22 | -7.6 | 39 |
| Pennsylvania | PA | 84.7 | 24 | 82.6 | 26 | -2.5 | 28 | 38.2 | 44 | 38.2 | 39 | 0.0 | 21 | 46.5 | 15 | 44.4 | 18 | -4.6 | 32 |
| Indiana | IN | 79.8 | 30 | 79.0 | 27 | -1.0 | 24 | 42.3 | 30 | 40.3 | 32 | -4.8 | 31 | 37.5 | 29 | 38.7 | 26 | 3.3 | 21 |
| Vermont | VT | 85.1 | 23 | 79.0 | 28 | -7.2 | 39 | 43.6 | 24 | 44.7 | 12 | 2.4 | 15 | 41.5 | 24 | 34.3 | 35 | -17.3 | 50 |
| Colorado | CO | 72.3 | 42 | 78.4 | 29 | 8.3 | 5 | 43.6 | 25 | 45.8 | 10 | 5.1 | 9 | 28.7 | 43 | 32.5 | 38 | 13.3 | 8 |
| South Dakota | SD | 75.6 | 36 | 78.1 | 30 | 3.4 | 16 | 46.9 | 11 | 45.8 | 11 | -2.3 | 25 | 28.7 | 44 | 32.3 | 39 | 12.7 | 9 |
| Delaware | DE | 79.1 | 31 | 77.4 | 31 | -2.1 | 27 | 41.0 | 36 | 42.0 | 24 | 2.4 | 14 | 38.1 | 28 | 35.4 | 33 | -7.0 | 37 |
| Texas | TX | 76.3 | 34 | 76.0 | 32 | -0.4 | 22 | 39.7 | 41 | 37.9 | 41 | -4.6 | 30 | 36.7 | 30 | 38.1 | 28 | 4.0 | 20 |
| Iowa | IA | 72.4 | 41 | 75.8 | 33 | 4.8 | 11 | 42.7 | 28 | 43.8 | 15 | 2.5 | 13 | 29.6 | 40 | 32.0 | 40 | 8.0 | 12 |
| Virginia | VA | 84.4 | 25 | 75.4 | 34 | -10.6 | 46 | 40.1 | 39 | 37.0 | 45 | -7.8 | 37 | 44.3 | 21 | 38.5 | 27 | -13.1 | 45 |
| New York | NY | 76.8 | 33 | 74.3 | 35 | -3.2 | 31 | 33.2 | 50 | 33.3 | 50 | 0.3 | 20 | 43.6 | 22 | 41.0 | 23 | -5.9 | 36 |
| California | CA | 81.9 | 26 | 74.2 | 36 | -9.5 | 43 | 40.5 | 38 | 36.7 | 46 | -9.3 | 42 | 41.5 | 25 | 37.4 | 29 | -9.7 | 41 |
| Minnesota | MN | 70.4 | 43 | 73.9 | 37 | 4.9 | 10 | 44.4 | 21 | 47.4 | 8 | 6.6 | 4 | 26.0 | 47 | 26.5 | 49 | 2.0 | 22 |
| Wisconsin | WI | 67.6 | 46 | 73.2 | 38 | 8.2 | 6 | 38.4 | 43 | 40.4 | 30 | 5.4 | 7 | 29.3 | 41 | 32.8 | 36 | 11.9 | 10 |
| Utah | UT | 75.4 | 37 | 72.9 | 39 | -3.3 | 32 | 48.1 | 7 | 44.5 | 13 | -7.6 | 36 | 27.3 | 46 | 28.5 | 48 | 4.3 | 19 |
| Wyoming | WY | 61.4 | 49 | 72.7 | 40 | 18.4 | 3 | 39.8 | 40 | 42.7 | 20 | 7.3 | 3 | 21.6 | 50 | 30.1 | 44 | 38.8 | 2 |
| New Hampshire | NH | 75.1 | 38 | 72.7 | 41 | -3.2 | 30 | 41.9 | 32 | 43.5 | 16 | 3.7 | 10 | 33.1 | 38 | 29.2 | 46 | -11.9 | 44 |
| Massachusetts | MA | 72.9 | 39 | 72.0 | 42 | -1.2 | 25 | 36.8 | 46 | 36.2 | 47 | -1.6 | 24 | 36.1 | 32 | 35.8 | 31 | -0.8 | 28 |
| Kansas | KS | 76.1 | 35 | 72.0 | 43 | -5.4 | 34 | 44.6 | 20 | 40.5 | 29 | -9.2 | 41 | 31.5 | 38 | 31.5 | 41 | -0.1 | 27 |
| Nebraska | NE | 70.1 | 44 | 71.4 | 44 | 1.8 | 19 | 42.8 | 27 | 42.3 | 23 | -1.4 | 23 | 27.3 | 45 | 29.2 | 47 | 6.9 | 13 |
| Maryland | MD | 80.0 | 29 | 70.5 | 45 | -11.9 | 47 | 41.0 | 37 | 37.9 | 40 | -7.5 | 35 | 39.0 | 27 | 32.6 | 37 | -16.5 | 49 |
| North Dakota | ND | 67.0 | 47 | 69.7 | 46 | 4.0 | 13 | 41.8 | 34 | 40.3 | 31 | -3.5 | 28 | 25.2 | 49 | 29.3 | 45 | 16.4 | 6 |
| Illinois | IL | 72.6 | 40 | 68.9 | 47 | -5.0 | 33 | 37.4 | 45 | 33.6 | 49 | -10.3 | 44 | 35.1 | 35 | 35.3 | 34 | 0.6 | 25 |
| → Alaska | AK | 54.0 | 51 | 66.3 | 48 | 22.8 | ① | 35.7 | 48 | 43.2 | 17 | 20.8 | ① | 18.3 | 51 | 23.1 | 51 | 26.7 | ③ ← |
| Hawaii | HI | 59.2 | 50 | 65.9 | 49 | 11.4 | 4 | 33.7 | 49 | 35.7 | 48 | 6.1 | 5 | 25.5 | 48 | 30.2 | 43 | 18.4 | 4 |
| Connecticut | CT | 65.1 | 48 | 63.8 | 50 | -1.9 | 26 | 36.1 | 47 | 37.3 | 44 | 3.3 | 11 | 29.0 | 42 | 26.5 | 50 | -8.4 | 40 |
| New Jersey | NJ | 68.6 | 45 | 61.8 | 51 | -10.0 | 44 | 32.7 | 51 | 31.3 | 51 | -4.1 | 29 | 36.0 | 33 | 30.5 | 42 | -15.3 | 47 |

Sources: 1980 Census: Bowe, F. (1984). U.S. Census and Disabled Adults: The 50 States and the District of Columbia. (Report #1250). Arkansas Rehabilitation Research and Training Center, University of Arkansas; U.S. Bureau of the Census (1983). 1980 Census of the Population: General Social and Economic Characteristics. (PC80-1-C). Washington, DC: U.S. GPO. 1990 Census: Unpublished tabulations from the U.S. Bureau of the Census; U.S. Bureau of the Census (1993). 1990 Census of Population and Housing. Summary Social, Economic, and Housing Characteristics. United States. (CPH-5-1). Washington, DC: U.S. GPO.

**TABLE 2. Rate of Difficulty in Mobility or Self-care per Thousand People Aged 16 and Older, by Age Group and State: 1990 Census**

| | Ages 16+ | | | | | | | Ages 16-64 | | | | | | | Ages 65+ | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | Population | Mobility or Self Care | | Self Care | | Mobility | | Population | Mobility or Self Care | | Self Care | | Mobility | | Population | Mobility or Self Care | | Self Care | | Mobility | |
| | (1,000s) | Rate | Rank | Rate | Rank | Rate | Rank | (1,000s) | Rate | Rank | Rate | Rank | Rate | Rank | (1,000s) | Rate | Rank | Rate | Rank | Rate | Rank |
| U.S. | 186,887 | 70.4 | — | 47.7 | — | 43.2 | — | 157,324 | 45.9 | — | 34.2 | — | 21.9 | — | 29,564 | 201.0 | — | 119.2 | — | 156.0 | — |
| State | | | | | | | | | | | | | | | | | | | | | |
| MS | 1,864 | 104.1 | 1 | 71.9 | 1 | 65.2 | 2 | 1,558 | 70.1 | 2 | 52.8 | 2 | 34.4 | 2 | 307 | 276.9 | 1 | 169.3 | 1 | 221.5 | 1 |
| AL | 3,029 | 95.3 | 2 | 65.0 | 3 | 59.9 | 4 | 2,530 | 61.8 | 4 | 46.5 | 5 | 29.8 | 5 | 500 | 264.7 | 2 | 158.5 | 2 | 212.1 | 2 |
| WV | 1,385 | 94.7 | 3 | 58.1 | 8 | 67.8 | 1 | 1,127 | 58.4 | 6 | 38.5 | 9 | 35.6 | 1 | 258 | 253.7 | 3 | 143.8 | 5 | 208.5 | 3 |
| DC | 484 | 94.4 | 4 | 71.8 | 2 | 47.5 | 12 | 411 | 70.8 | 1 | 58.8 | 1 | 25.9 | 9 | 72 | 228.6 | 11 | 145.9 | 4 | 170.2 | 13 |
| AR | 1,756 | 89.5 | 5 | 58.5 | 7 | 59.5 | 5 | 1,426 | 54.6 | 8 | 38.9 | 8 | 29.0 | 6 | 330 | 240.8 | 7 | 143.3 | 7 | 191.4 | 8 |
| LA | 3,022 | 89.3 | 6 | 62.5 | 4 | 54.2 | 7 | 2,582 | 61.9 | 3 | 47.2 | 4 | 29.9 | 4 | 439 | 251.3 | 4 | 152.6 | 3 | 197.5 | 6 |
| SC | 2,564 | 87.0 | 7 | 61.5 | 5 | 50.3 | 8 | 2,183 | 61.3 | 5 | 47.8 | 3 | 27.0 | 8 | 380 | 234.5 | 9 | 140.8 | 8 | 184.3 | 10 |
| KY | 2,763 | 85.8 | 8 | 53.0 | 12 | 60.5 | 3 | 2,321 | 54.5 | 9 | 36.7 | 14 | 32.6 | 3 | 442 | 250.1 | 5 | 138.8 | 9 | 207.0 | 4 |
| NY | 13,895 | 81.6 | 9 | 58.6 | 6 | 46.5 | 15 | 11,656 | 57.0 | 7 | 44.5 | 6 | 25.0 | 10 | 2,239 | 209.5 | 15 | 131.7 | 12 | 158.3 | 17 |
| FL | 10,102 | 79.9 | 10 | 54.1 | 9 | 48.8 | 11 | 7,810 | 50.2 | 12 | 37.1 | 13 | 24.0 | 14 | 2,292 | 181.1 | 30 | 111.8 | 28 | 133.2 | 34 |
| TN | 3,709 | 79.7 | 11 | 51.2 | 13 | 54.3 | 6 | 3,123 | 49.7 | 13 | 34.8 | 16 | 27.5 | 7 | 586 | 239.6 | 8 | 138.3 | 10 | 197.1 | 7 |
| NC | 5,004 | 78.2 | 12 | 53.0 | 11 | 48.9 | 10 | 4,244 | 50.6 | 11 | 38.0 | 11 | 24.2 | 13 | 761 | 232.4 | 10 | 136.9 | 11 | 186.3 | 9 |
| GA | 4,781 | 78.2 | 13 | 53.3 | 10 | 47.0 | 13 | 4,161 | 53.0 | 10 | 39.9 | 7 | 24.5 | 12 | 620 | 246.8 | 6 | 143.5 | 6 | 198.4 | 5 |
| OK | 2,320 | 73.9 | 14 | 47.3 | 19 | 49.8 | 9 | 1,923 | 44.6 | 21 | 31.2 | 25 | 24.5 | 11 | 397 | 215.4 | 13 | 125.1 | 14 | 171.9 | 11 |
| PA | 9,204 | 73.3 | 15 | 48.0 | 16 | 46.5 | 14 | 7,475 | 43.5 | 23 | 31.8 | 22 | 21.9 | 18 | 1,729 | 201.9 | 18 | 118.9 | 18 | 152.8 | 22 |
| NJ | 6,015 | 72.2 | 16 | 50.6 | 14 | 41.2 | 21 | 5,030 | 47.6 | 15 | 37.2 | 12 | 20.3 | 25 | 985 | 198.0 | 22 | 119.1 | 17 | 148.2 | 24 |
| MO | 3,843 | 71.9 | 17 | 46.9 | 20 | 46.1 | 16 | 3,172 | 43.2 | 25 | 31.1 | 26 | 21.9 | 19 | 671 | 207.8 | 16 | 121.6 | 16 | 160.7 | 15 |
| OH | 8,182 | 70.0 | 18 | 45.1 | 24 | 44.9 | 17 | 6,861 | 44.4 | 22 | 31.6 | 24 | 23.0 | 16 | 1,321 | 203.1 | 17 | 115.5 | 23 | 158.1 | 18 |
| IL | 8,613 | 69.9 | 19 | 47.7 | 17 | 41.8 | 20 | 7,262 | 45.5 | 19 | 34.7 | 17 | 20.8 | 23 | 1,351 | 201.4 | 20 | 117.7 | 19 | 154.8 | 20 |
| RI | 780 | 69.3 | 20 | 45.4 | 23 | 43.1 | 19 | 639 | 41.5 | 28 | 30.1 | 29 | 21.1 | 22 | 141 | 196.0 | 24 | 114.8 | 25 | 143.1 | 29 |
| MI | 6,980 | 69.2 | 21 | 46.0 | 22 | 43.6 | 18 | 5,925 | 45.7 | 18 | 33.3 | 20 | 23.1 | 15 | 1,055 | 201.7 | 19 | 117.4 | 20 | 158.5 | 16 |
| CA | 22,150 | 67.8 | 22 | 48.5 | 15 | 38.2 | 30 | 19,164 | 48.7 | 14 | 38.0 | 10 | 21.3 | 21 | 2,986 | 190.0 | 25 | 115.9 | 22 | 147.2 | 25 |
| TX | 12,311 | 67.5 | 23 | 46.7 | 21 | 41.0 | 22 | 10,696 | 45.1 | 20 | 34.0 | 19 | 21.3 | 20 | 1,616 | 215.8 | 12 | 131.0 | 13 | 171.3 | 12 |
| MD | 3,629 | 67.3 | 24 | 47.4 | 18 | 37.2 | 32 | 3,137 | 46.4 | 16 | 36.6 | 15 | 18.5 | 32 | 491 | 200.7 | 21 | 116.8 | 21 | 156.5 | 19 |
| NM | 1,084 | 66.3 | 25 | 44.8 | 25 | 40.8 | 23 | 928 | 46.3 | 17 | 34.1 | 18 | 22.5 | 17 | 157 | 184.2 | 29 | 106.6 | 30 | 149.2 | 23 |
| IN | 4,160 | 66.0 | 26 | 43.3 | 29 | 40.7 | 24 | 3,510 | 41.7 | 26 | 30.5 | 28 | 19.9 | 27 | 650 | 197.1 | 23 | 111.9 | 27 | 152.8 | 21 |
| DE | 505 | 64.8 | 27 | 44.2 | 26 | 38.8 | 29 | 429 | 43.3 | 24 | 33.1 | 21 | 19.9 | 26 | 77 | 185.5 | 28 | 106.5 | 31 | 144.6 | 28 |
| VA | 4,594 | 64.6 | 28 | 43.4 | 28 | 39.8 | 27 | 3,967 | 41.5 | 27 | 30.8 | 27 | 19.5 | 30 | 627 | 210.6 | 14 | 123.3 | 15 | 168.6 | 14 |
| MA | 4,712 | 62.4 | 29 | 40.8 | 31 | 40.3 | 26 | 3,945 | 37.7 | 32 | 26.9 | 33 | 19.8 | 29 | 767 | 189.6 | 26 | 112.2 | 26 | 146.1 | 26 |
| AZ | 2,720 | 62.2 | 30 | 40.6 | 32 | 39.1 | 28 | 2,256 | 41.2 | 29 | 29.7 | 30 | 20.4 | 24 | 463 | 165.0 | 43 | 93.4 | 42 | 130.3 | 39 |
| CT | 2,554 | 61.8 | 31 | 42.9 | 30 | 36.0 | 34 | 2,137 | 37.3 | 33 | 28.8 | 31 | 16.4 | 37 | 417 | 187.3 | 27 | 115.1 | 24 | 136.7 | 31 |
| HI | 794 | 60.9 | 32 | 43.7 | 27 | 33.1 | 39 | 673 | 40.2 | 30 | 31.8 | 23 | 16.4 | 36 | 121 | 175.7 | 32 | 111.4 | 29 | 126.3 | 42 |
| ME | 927 | 59.0 | 33 | 36.2 | 36 | 40.6 | 25 | 773 | 35.0 | 34 | 23.7 | 35 | 19.8 | 28 | 154 | 180.3 | 31 | 98.9 | 33 | 144.9 | 27 |
| IA | 2,083 | 58.4 | 34 | 37.8 | 35 | 36.7 | 33 | 1,691 | 31.7 | 38 | 22.8 | 36 | 15.7 | 40 | 392 | 173.5 | 33 | 102.6 | 32 | 127.6 | 41 |
| KS | 1,814 | 58.1 | 35 | 38.3 | 33 | 36.0 | 35 | 1,495 | 33.9 | 35 | 25.5 | 34 | 15.6 | 41 | 318 | 172.0 | 34 | 98.5 | 34 | 131.8 | 35 |
| OR | 2,156 | 56.5 | 36 | 35.6 | 37 | 38.1 | 31 | 1,781 | 32.8 | 36 | 22.8 | 37 | 18.1 | 33 | 375 | 169.1 | 37 | 96.3 | 37 | 133.3 | 33 |
| NV | 913 | 56.5 | 37 | 38.0 | 34 | 33.0 | 40 | 789 | 39.2 | 31 | 28.7 | 32 | 18.5 | 31 | 124 | 166.4 | 39 | 96.7 | 36 | 125.2 | 43 |
| WI | 3,659 | 53.5 | 38 | 34.5 | 38 | 34.7 | 36 | 3,054 | 31.3 | 40 | 22.1 | 39 | 16.9 | 35 | 605 | 165.3 | 41 | 96.9 | 35 | 124.8 | 44 |
| WA | 3,623 | 52.2 | 39 | 32.8 | 39 | 34.6 | 37 | 3,077 | 32.0 | 37 | 21.9 | 40 | 17.5 | 34 | 546 | 165.7 | 40 | 94.0 | 41 | 131.2 | 36 |
| NE | 1,155 | 50.6 | 40 | 32.7 | 40 | 32.2 | 43 | 950 | 29.1 | 42 | 21.3 | 41 | 14.3 | 46 | 205 | 150.3 | 47 | 85.5 | 45 | 115.5 | 49 |
| CO | 2,446 | 49.4 | 41 | 31.6 | 42 | 31.4 | 44 | 2,134 | 31.8 | 39 | 22.5 | 38 | 16.2 | 39 | 311 | 171.0 | 35 | 94.2 | 40 | 135.8 | 32 |
| MN | 3,256 | 49.0 | 42 | 31.6 | 41 | 31.8 | 46 | 2,753 | 27.8 | 44 | 20.1 | 43 | 14.1 | 47 | 504 | 165.1 | 42 | 94.8 | 39 | 124.5 | 45 |
| SD | 498 | 48.9 | 43 | 30.1 | 43 | 32.5 | 42 | 404 | 29.3 | 41 | 20.9 | 42 | 15.5 | 43 | 94 | 133.0 | 51 | 69.4 | 51 | 105.2 | 50 |
| MT | 584 | 48.8 | 44 | 29.7 | 44 | 33.8 | 38 | 485 | 28.7 | 43 | 19.8 | 44 | 16.3 | 38 | 99 | 147.2 | 49 | 78.4 | 49 | 119.3 | 48 |
| NH | 843 | 47.1 | 45 | 29.5 | 45 | 30.8 | 47 | 726 | 27.6 | 45 | 18.9 | 45 | 14.7 | 44 | 117 | 167.9 | 38 | 95.1 | 38 | 130.8 | 38 |
| ID | 714 | 46.3 | 46 | 27.6 | 47 | 32.9 | 41 | 599 | 26.7 | 47 | 17.8 | 47 | 15.6 | 42 | 115 | 148.1 | 48 | 78.5 | 48 | 122.8 | 46 |
| UT | 1,135 | 45.4 | 47 | 28.2 | 46 | 29.6 | 48 | 991 | 27.1 | 46 | 18.9 | 46 | 13.9 | 48 | 144 | 170.9 | 36 | 92.2 | 43 | 137.3 | 30 |
| ND | 460 | 43.7 | 48 | 26.7 | 48 | 29.2 | 49 | 377 | 23.6 | 50 | 15.9 | 51 | 12.6 | 50 | 83 | 134.8 | 50 | 75.4 | 50 | 104.5 | 51 |
| VT | 428 | 42.4 | 49 | 25.5 | 49 | 31.3 | 45 | 366 | 23.9 | 49 | 16.0 | 49 | 14.5 | 45 | 62 | 152.0 | 46 | 82.0 | 47 | 131.0 | 37 |
| WY | 323 | 40.7 | 50 | 25.1 | 50 | 27.0 | 50 | 279 | 23.0 | 51 | 16.0 | 50 | 12.0 | 51 | 44 | 152.3 | 45 | 82.1 | 46 | 121.3 | 47 |
| AK | 364 | 32.7 | 51 | 21.8 | 51 | 19.6 | 51 | 343 | 25.0 | 48 | 17.6 | 48 | 12.8 | 49 | 21 | 156.9 | 44 | 90.5 | 44 | 129.8 | 40 |

Sources: Unpublished tabulations from the U.S. Bureau of the Census. U.S. Bureau of the Census (1993). 1990 Census of Population and Housing. Summary Social, Economic, and Housing Characteristics, United States. (CPH-5-1). Washington, DC: U.S. GPO.
Note: Civilian noninstitutional population.

About 13.2 million Americans aged 16 and over have some difficulty in outside mobility or self care. The prevalence of outside mobility difficulty is slightly lower than self-care difficulty (8.1 versus 8.9 million). About 29% of the 13.2 million people who experience mobility or self-care difficulty have both types of limitation.

At ages 65 and over, the rate of difficulty in outside mobility or self care is 20.1%, over four times higher than the rate at ages 16 to 64 (4.6%). Though the rate of mobility difficulty and, to a lesser extent, self-care difficulty increases with age, age does not account for much variation in rates of mobility or self-care difficulty across states.[2]

The rate of self-care difficulty exceeds the rate of mobility difficulty for ages 16 to 64. As might be expected, the opposite is true at ages 65 and over, due to the high rate of increase in mobility difficulty with age. It is notable, however, that about 43% of people with a mobility difficulty are aged 16 to 64, and 60% of people with a self-care difficulty are aged 16 to 64. Thus, the majority of people experiencing self-care difficulty are nonelderly.

The states that rank the highest on the rate of mobility and self-care difficulty are Mississippi, Alabama, West Virginia, District of Columbia, and Arkansas (Table 2). As with work disability, southern states rank highly on rates of mobility and self-care difficulty.

## Notes

1. This Abstract is summarized from: LaPlante, M.P. (1993). *State Estimates of Disability in America.* Disability Statistics Report (3). Washington, D.C.: National Institute on Disability and Rehabilitation Research.
2. The correlation between rates of mobility and/or self-care limitation at ages 16 to 64 and ages 65 and above is r=0.899, p<.001.

## Credits

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This abstract is one of a series presenting statistical information on disability in the U.S. Statistics presented have negligible sampling error but nonsampling error may arise. Comparisons and relationships discussed may be affected by other unanalyzed factors.

# Disability Statistics Abstract

Number 17

## *Trends in Disability Rates in the United States, 1970–1994*

**H. Stephen Kaye, Mitchell P. LaPlante, Dawn Carlson, and Barbara L. Wenger**

The proportion of the U.S. population with disabilities has risen markedly during the past quarter-century. As the data presented in this abstract show, two distinct trends have contributed to the increasing overall prevalence of disability: a gradual rise, due largely to demographic shifts associated with an aging population, as well as a rapid increase that has taken place during the past several years. This recent change seems to be due not to demographics, but to greater numbers of children and young adults reported as having disabilities.

Data in this abstract come from the National Health Interview Survey (NHIS), a household survey of the noninstitutionalized U.S. population conducted by the Census Bureau for the National Center for Health Statistics. Disability data from the NHIS have been available annually since 1970 (with the exception of 1982, which is omitted due to a problem with the survey), continuing until 1994, the most recent year for which the survey has been analyzed. Because the NHIS questionnaire was changed substantially in 1982, the observed disability rates change markedly beginning in 1983. This discontinuity, which is an artifact of survey improvements rather than a real difference in the number of people with disabilities, should be kept in mind when examining the graphs presented in Figures 1 and 2. Data on work disability (Figure 3) and personal assistance needs (Figure 4) are only available for the period 1983–94.

Figure 1 shows the overall trend in the proportion of the U.S. population with disabilities, defined as limitations in activity due to chronic health conditions and impairments. In 1970, 11.7 percent of the population experienced activity limitation, increasing gradually over the next decade to 14.4 percent in 1981. During the 1980s, following the change in the survey, the rate remained roughly constant at about 14.0 percent, and then rose rapidly from 13.7 percent in 1990 to 15.0 percent in 1994.

The trends for men and women match each other closely. The 1982 changes to the NHIS resulted in more equal measurement of disability for both sexes in the survey, and since then, men have consistently reported lower disability rates than women. The greater average longevity of women is the main reason for this difference. Before 1982, men were asked specifically about work-related activity limitations, while women were asked about housekeeping; as a result, disability rates for women were artificially low, both for the working ages and for the elderly. Age-adjusted figures show almost identical rates for men and women after 1982, but widely divergent rates under the older version of the survey questionnaire.

The long-term increase in disability rates is largely due to demographic shifts.

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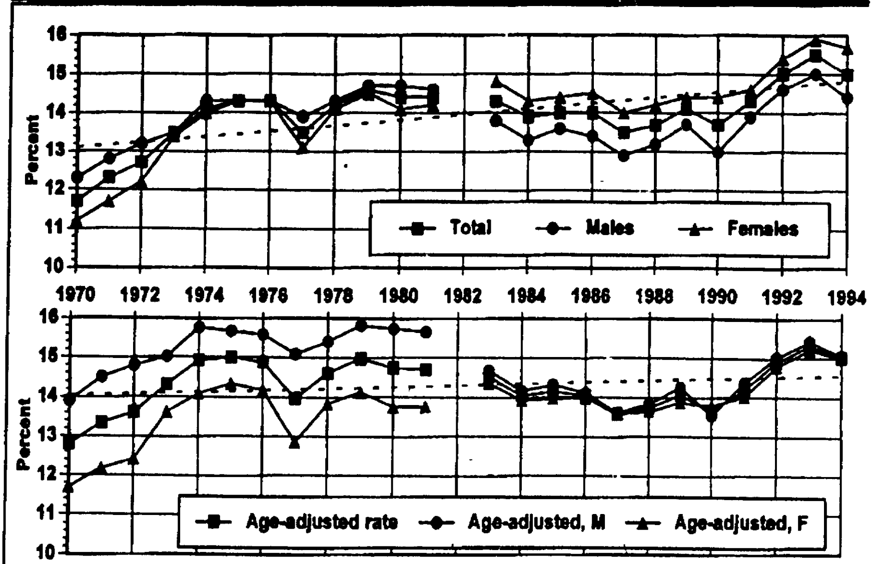
**Figure 1: Proportion of U.S. Population with Activity Limitation, 1970–1994.**



Source: National Health Interview Survey. National Center for Health Statistics tabulations compiled by the Disability Statistics Rehabilitation Research and Training Center, University of California, San Francisco.

Note: Age-adjusted rates are adjusted to the 1994 population in 4 age groups.

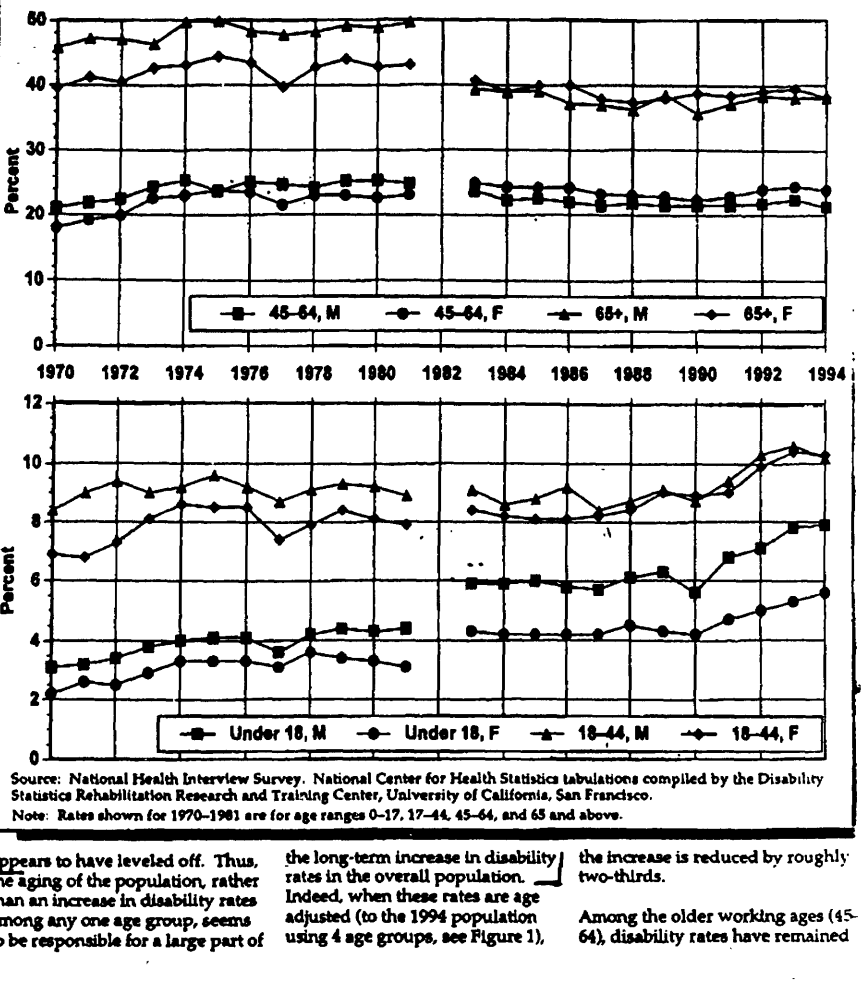
## Age-Specific Disability Trends

When disability rates are computed separately for various age groups (Figure 2), the long-term increase in the proportion with disabilities is much less apparent. Among those 65 years of age and over, the disability rate held roughly constant during the 1970s, at about 48 percent for men and 42 percent for women, and again during the 1980s and early 1990s (using the revised survey questionnaire), at about 38 percent for men and 39 percent for women. The lower rates after 1982 are due to questions in the NHIS that mention self-care activities, rather than work or housekeeping, as the locus of disability within the elderly population.

The elderly experience disability at roughly twice the rate of those in the older working ages (45–64) and four times the rate of the younger working-age group (18–44). A still smaller fraction of children have disabilities. Therefore, the proportion of the overall population with disabilities is heavily influenced by the disability rate among the elderly (which has remained roughly constant) and by the proportion of the population that is elderly. This proportion increased rapidly during the 1970s and more slowly during the 1980s, from 9.5 percent in 1970 to 11.0 percent in 1980 and 12.1 percent in 1990; since then it

Disability rates for children and younger adults have risen considerably since 1990.

**Figure 2: Proportion of U.S. Population with Activity Limitation, by Age and Gender, 1970–1994.**



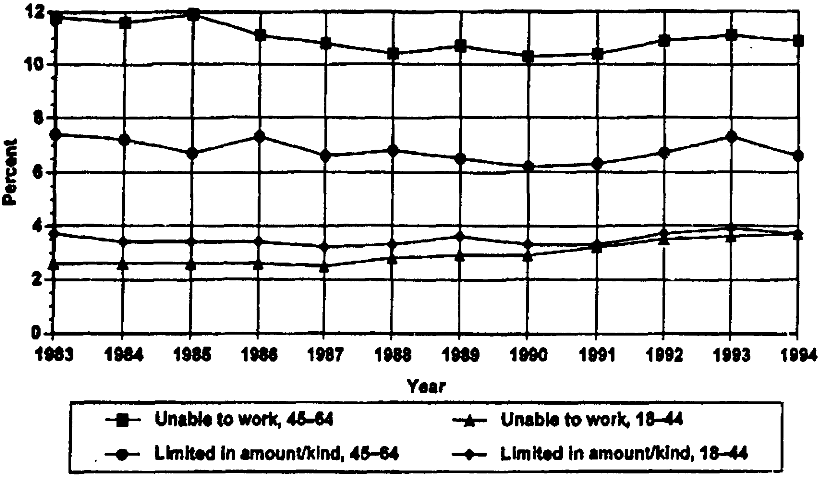
Source: National Health Interview Survey. National Center for Health Statistics tabulations compiled by the Disability Statistics Rehabilitation Research and Training Center, University of California, San Francisco.

Note: Rates shown for 1970–1981 are for age ranges 0–17, 17–44, 45–64, and 65 and above.

appears to have leveled off. Thus, the aging of the population, rather than an increase in disability rates among any one age group, seems to be responsible for a large part of the long-term increase in disability rates in the overall population. Indeed, when these rates are age adjusted (to the 1994 population using 4 age groups, see Figure 1), the increase is reduced by roughly two-thirds.

Among the older working ages (45-64), disability rates have remained

**Figure 3: Proportion of U.S. Population with Work Disability, by Age, 1983–1994.**



Source: National Health Interview Survey.

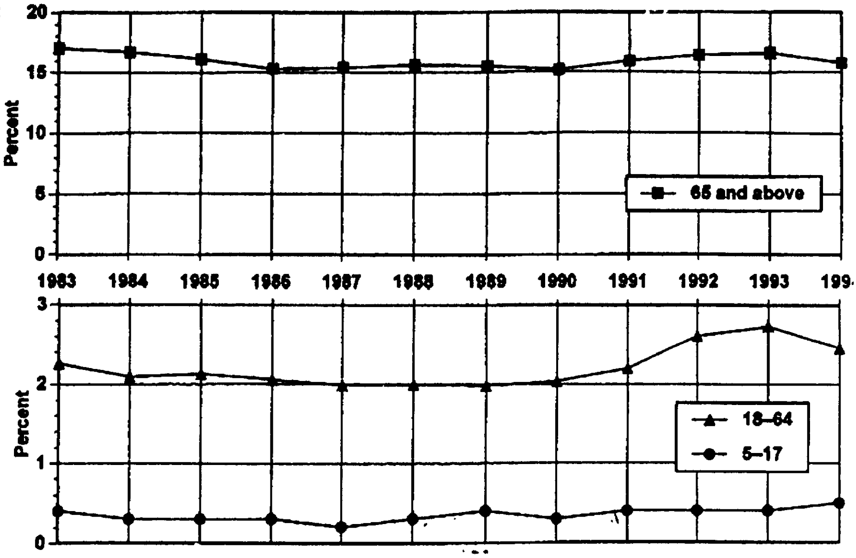
roughly constant from the mid-1970s through the early 1990s (Figure 2). The rates were about 25 percent for men and 23 percent for women before 1982, and 22 percent for men and 23 percent for women after 1982. The proportion with disabilities did increase during the early 1970s, from 21.1 percent of men in 1970 to 25.3 percent in 1974, and from 18.0 percent of women in 1970 to 23.0 percent in 1974. This change may be another consequence of demographic shifts, with a greater fraction of this age group nearing retirement age, and experiencing greater likelihood of disability as a result.

Among people under 45 years of age, the most dramatic changes in disability rates have occurred during the 1990s. Among younger adults (18–44), the proportion with activity limitation increased from 8.7 percent of men and 8.9 percent of women in 1990 to 10.2 percent of men and 10.3 percent of women in 1994. Among children under 18, disability rates underwent a similar increase between 1990 and 1994: from 5.6 percent to 7.9 percent for boys and from 4.2 percent to 5.6 percent for girls. These changes may be partly accounted for by the increases in the prevalence of asthma, mental disorders (including attention deficit disorder), mental retardation, and learning disabilities that have been noted among children in recent years. Among younger adults, rates of orthopedic impairments and mental and nervous disorders have gone up during the same period.[1]

Greater numbers of younger Americans have experienced work disability and personal assistance needs during recent years.

Because about 70 percent of the population is under age 45, these steep increases in disability prevalences are responsible for the recent rise in the proportion of the

**Figure 4: Proportion of U.S. Population Needing Personal Assistance, 1983–1994.**



Source: National Health Interview Survey.

overall population with disabilities, as shown in Figure 1. The higher rate amounts to an additional 1.5 million children and 3.1 million working-age adults reported as having disabilities in 1994, compared to 1990. Although Social Security Administration has also seen an increase in the number of younger disability beneficiaries during this same period, the number of people involved is much smaller: between 1990 and 1994, the Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI) rolls grew by 0.6 million children and 1.7 million working-age adults. Thus, the NHIS hints at a much broader phenomenon than that reflected by the increase in Social Security recipients.

Before 1990, disability rates for both children[2] and younger adults[3] had held steady for nearly 2 decades. Among children, girls had a (post-1982) disability rate of about 4.5 percent, while boys had a higher rate, roughly 6 percent. The rate for boys is consistently higher due to a greater prevalence of mental retardation and developmental disabilities. Among adults under 45, the disability rate for men was about 9 percent, and for women about 8.5 percent. Again there is some evidence for an increase in disability rates for bot of these age groups during the early 1970s.

## Work Disability

Work disability is measured as a limitation in a person's ability to work due to a chronic health condition or impairment. Figure shows the rates of work disability—both for people unable to work and those who are limited i the amount or kind of work they can do—for the working-age U.S. population from 1983 through 1994. No significant trend is observed for the older working ages, among whom roughly 11 percent are unable to work and 7 percent are limited in amount or kind of work.

Among the younger working ages, the rate of work disability is generally much lower, with roughly 3 percent unable to work and about 3.5 percent limited in amount or kind of work. Beginning in 1990, a trend is apparent among those younger adults who are unable to work, echoing that found in the activity limitation data: an increase from 2.9 percent unable to work in 1990 to 3.7 percent in 1994.

## Personal Assistance Needs

Figure 4 shows the trend in personal assistance needs from 1983 to 1994. People who need the assistance of another person in order to perform basic life activities—the so-called activities of daily living (ADL), such as bathing, dressing, and feeding oneself, and the instrumental activities of daily living (IADL), including household chores, handling money, and shopping—are considered to have fairly severe disabilities. No trend is visible among the elderly population, of whom roughly 16 percent require personal assistance.

Among the working-age population (ages 18–64), however, the personal assistance rate rises from roughly 2.0 percent during the 1980s to 2.7 percent in 1993. Among youth (ages 5–17), the rat rises from 0.3 percent in 1990 to 0. percent in 1994. Thus the need fo personal assistance is another indicator of the increase in the prevalence of disability among younger Americans during the pa several years.

## Notes

[1] Disabling condition trend data from unpublished tabulations by Mitchell P. LaPlante.

[2] This category includes persons under 17 year of age for 1970–81 and under 18 for 1983–94.

[3] Age range for younger adults is 17–44 for the years 1970–81 and 18–44 for 1983–94.

## Credits

The Disability Statistics Abstract Series is produced by the Disability Statistics Rehabilit tion Research and Training Center, Institute f Health & Aging, School of Nursing, Universit of California, Box 0646, Laurel Heights, 3333 California St., San Francisco, CA 94143-0646, with funding from NIDRR. Layout by Barbar L. Wenger.

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**NARIC Accession Number:** O12581.

## DISABILITY WATCH: THE STATUS OF PEOPLE WITH DISABILITIES IN THE UNITED STATES.

**Author(s):** Kaye, H S.
**Institution:** Disability Rights Advocates; Disability Statistics Rehabilitation Research and Training Center (RTC); University of California, San Francisco.
**Report Number:** H133B30002.
**Publication Year:** 1998.
**Number of Pages:** 86p.
**Abstract:** Report on the status of people with disabilities in the United States, with data on demographics, employment and income, social integration, and access barriers in public establishments, housing, and transportation. Demographic data include trends in the rate of disability, with detail by cause, age, gender, race / ethnicity, and educational attainment.
**Descriptor Terms:** STATISTICS; DEMOGRAPHICS; EMPLOYMENT; INCLUSION; ACCESSIBILITY; BARRIERS; TRANSPORTATION.

Learn more about the project(s) that created this document.

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**Source:** REHABDATA Main database, National Rehabilitation Information Center, 8455 Colesville Road, Suite 935, Silver Spring, MD 20910-3319; 800/346-2742 (Voice); 301/495-5626 (TTY); 301/587-1967 (fax).
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**NARIC Accession Number:** O12956.

## TRENDS IN DISABILITY PREVALENCE AND THEIR CAUSES: PROCEEDINGS OF THE FOURTH NATIONAL DISABILITY STATISTICS AND POLICY FORUM, MAY 16, 1997, WASHINGTON, DC.

Disability Forum Report, N4.
**Author(s):** Kaye, H S.
**Institution:** Disability Statistics Rehabilitation Research and Training Center, University of California/San Francisco, Institute for Health and Aging.
**Report Number:** H133B30002.
**Publication Year:** 1997.
**Number of Pages:** 61p.
**Abstract:** Proceedings of a conference on trends in disability prevalence. Trends in disability prevalence are related to trends in conditions that cause disability, trends in the age distribution of the population, an apparent reduction in functional limitations among persons with disabilities, the statistical effects of expectations and environment (e.g., environmental changes that make certain conditions less disabling), changes of definition in the medical community, inadequacies of statistics, and socioeconomic factors. Research methodology is discussed.
**Descriptor Terms:** PREVALENCE; DISABILITIES; DEMOGRAPHICS; AGING; FUNCTIONAL LIMITATIONS; CONFERENCE PROCEEDINGS; RESEARCH METHODOLOGY.

Learn more about the project(s) that created this document.

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**Source:** REHABDATA Main database, National Rehabilitation Information Center, 8455 Colesville Road, Suite 935, Silver Spring, MD 20910-3319; 800/346-2742 (Voice); 301/495-5626 (TTY); 301/587-1967 (fax).
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Retrieval software: DB/Text *WebPublisher*, provided by INMAGIC

## PREPARED STATEMENT OF HON. WILLIAM V. ROTH, JR.

Today, the Committee is holding its first health care hearing in the 106th Congress.

We are here to discuss a simple goal—helping individuals with disabilities go to work if they so choose. In 1990, Congress made a first giant stride toward realizing this goal with the passage of the Americans with Disabilities Act. It is not a coincidence that our first witnesses today are two of the people most responsible for the landmark passage of the ADA—Senator Bob Dole and Senator Ted Kennedy.

The Americans with Disabilities Act made an important statement about this nation's commitment to independence and opportunity for people with disabilities. Since then, barriers that had made even the simplest daily tasks difficult or even impossible have been lifted. Millions of Americans now lead more active and integrated lives.

Despite the real progress that has been made in the ensuing eight years, serious obstacles still face many people with disabilities—obstacles that stand in the way of their getting a job. "Joining with Senators Moynihan, Jeffords, and Kennedy, I have introduced legislation to address some of the remaining impediments to employment for people with disabilities. Our bill, S. 331, the Work Incentives Improvement Act of 1999, promotes access to health insurance and fundamental job assistance.

I am particularly pleased that so many colleagues on this committee have decided to join us in supporting this important legislation. Original cosponsors of S. 331 from the Finance Committee include Senators Chafee, Grassley, Hatch, Murkowski, Breaux, Graham, Kerrey, Robb, and Rockefeller. I understand that Senator Conrad has also joined us as a cosponsor, and we now have a total of 40 Senators on board.

At a hearing held by our Subcommittee on Social Security and Family Policy last July, lack of health insurance access was identified as a primary barrier to employment facing disabled individuals eager to work. The Work Incentives Improvement Act will empower states to lift this barrier.

We do this by creating two new, entirely voluntary, state Medicaid options. The first option builds on a change enacted in the Balanced Budget Act of 1997 to permit people disabled enough to qualify for Supplemental Security Income but with incomes higher than the SSI eligibility cut-off to buy into Medicaid.

The second option allows states to permit individuals with a severe, medically determinable impairment who would otherwise lose eligibility because of medical improvement to buy into Medicaid.

I should point out that under either option, Medicaid remains the "payor of last resort," meaning that any private sector insurance an individual possesses would be the primary payor for health care services. States would be free to require beneficiaries with access to employer-based health insurance to take advantage of that employer coverage.

The bill also extends Medicare Part A coverage for a ten-year trial period for individuals on SSDI who return to work.

The simple fact is that people with disabilities are often presented with a Catch-22 between working and losing their Medicaid or Medicare. This is a choice they should not have to make. But even modest earnings can result in a loss of eligibility for Medicaid or Medicare. Without health insurance, medical treatment often becomes prohibitively expensive for individuals with disabilities. Without medical treatment, it becomes impossible for many to work.

My constituents in Delaware have made it clear that lack of access to health insurance is a real barrier to employment. We will hear today from Larry Henderson, Chair of Delaware's Developmental Disabilities Planning Council, about the importance of changing a system that penalizes persons with disabilities who try to work.

In addition to these health coverage innovations, the bill also provides a user-friendly, public-private approach to job placement. Because of a new, innovative payment system, vocational rehabilitation agencies will be rewarded for helping people remain on the job, not just getting a job.

This combination of health care and job assistance will help disabled Americans succeed in the work place. And our society will be enriched by unleashing the creativity and industry of people with disabilities eager to work."

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## PREPARED STATEMENT OF HON. FRED THOMPSON

Mr. Chairman, I want to thank for you for holding this hearing this morning on the Work Incentives Improvement Act. I must say that I am very glad to be sitting here with you all. I also want to welcome my friend Senator Dole back to the Committee. It's great to see you, Bob.

I think we all agree that helping move disabled Americans into the workplace so that they can be self-sufficient and productive is a worthy goal. The federal government should not erect impediments that keep the disabled who want to work from doing so. In fact, we should encourage the disabled who can work to become less dependent upon the government. That's a win/win.

I look forward to working with you, Mr. Chairman, to accomplish this goal in a manner that does not unduly burden our already shaky entitlement system, and does not establish a whole new set of inequities between those who qualify for federal disability assistance and those who don't but may have similar health problems and expenses.

I look forward to hearing the testimony of the witnesses.

# COMMUNICATIONS

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## STATEMENT OF HON. PETE STARK

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

Mr. Chairman:

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

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

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

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

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

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

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

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

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

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

1) A huge percentage of ESRD patients qualify for

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

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

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

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

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

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

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

3) Renal dialysis networks, which are designed to help

ensure ESRD center quality, should be able to apply for designation as rehab agencies and for demonstration grants under this legislation.

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

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

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

4) Kidney failure remains a medical mystery. It often happens very quickly, with no warning. But for thousands of others, there is a gradual decline of kidney function. I am told by medical experts that in many cases the descent to terminal or end-stage renal disease can be slowed by (1) nutrition counseling, or (2) medical treatment by nephrology specialists.

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

Also in the 'preventive area,' some of the leaders in the renal community are reporting exciting results from more frequent, almost nightly dialysis. Like frequent testing by diabetics for blood sugar levels, it may be that more frequent dialysis can result in

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

a less disrupted life and a better chance to contribute to the workforce. We should watch these medical developments and if there is a chance that some additional spending on more frequent, but less disruptive dialysis would encourage return to work, we should be supportive.

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

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

Thank you for your consideration.

# Kidney Failure and the Federal Government

*Richard A. Rettig* and *Norman G. Levinsky, Editors*

Committee for the Study of the Medicare
End-Stage Renal Disease Program

Division of Health Care Services

INSTITUTE OF MEDICINE

NATIONAL ACADEMY PRESS
Washington, D.C. 1991

*Rehabilitation Services*

The publicly financed Medicare and Medicaid programs cover the elderly, the disabled, and the poor, all of whom are weakly tied to the labor force. As a consequence, Medicare policy is not geared to returning individuals to work, and HCFA has few statutory, organizational, or financial resources to help individuals do so. In fact, in the 1972 statute, ESRD patients are "deemed to be disabled" for purposes of Medicare coverage. Many ESRD patients, once they establish their eligibility for Medicare benefits, apply for Social Security disability status. Eligibility for disability benefits provides monthly income. In early 1990, about one-half of Medicare ESRD beneficiaries between the ages of 18 and 64 were also classified as disabled for purposes of receiving Social Security benefits. Social Security monthly disability benefits, not subject to income tax, often replace income from prior employment. Consequently, problems associated with reentering the labor force lead many patients to regard Social Security disability benefits as their first line of economic support.

Efforts to address the problems of rehabilitation encounter several obstacles. First, ESRD patients are not always able to return to their prior employment, especially to physically demanding jobs. Second, employers are not always receptive to having ESRD patients as employees, for reasons of both dependability and effect on insurance premiums. Third, federal regulations governing the Social Security disability programs provide disincentives to patients' return to work. Finally, Medicare does not finance rehabilitation other than through payment for outpatient treatment, and social services (discussed in Chapter 10) have been decreasing over time.

Rehabilitation services are no more available for kidney transplant recipients than for dialysis patients. Such patients, however, are more likely to be employed. Evans and co-workers (1990) surveyed patients between 30 and 44 months after their transplant. Of those with a functioning primary graft, 44 percent were working either full- or part-time; of patients who had received a second transplant, 44 percent were working; only 18 percent of the patients on dialysis had a job. Age, gender, primary diagnosis, and education of transplant recipients all have an effect on their ability to return to work. Younger transplant recipients are twice as likely to be working than those older than 60; men are 1.5 times more likely to be employed than women; nondiabetics are 1.5 times as likely to have a job as diabetics; and college graduates are nearly twice as likely to be working as those with less education.

Rehabilitation services for ESRD patients deserve sustained attention, especially in light of the report that EPO reduces the fatigue of dialysis patients and equips them to engage in more active pursuits, and because transplant patients should be encouraged to take advantage of their better functional status. The issue of rehabilitation also should be examined in the context of all chronic disease patients as the challenges of ESRD are apt to be encountered elsewhere.

**MY TURN**

# CATCH-22 FOR A TRANSPLANT

## Given the gift of life, how can I repay my donor family, my surgeons and society?

BY SCOTT SUTTON

I WAS JUST A KID, 10 YEARS OLD. I WANTED TO BE SOME KIND of hero when I grew up. Most kids do. It was Mt. Horeb, Wis. German. English. Work hard. Stiff upper lip. Be a man. Even now those ethics scream out against this essay. It's hard for me to tell you about myself. Actually, it's also hard for me to be me. At 6 feet 2 inches and 220 pounds, I'm what they call a "strapping fellow." Maybe that's how I caught the eye of a Secret Service recruiter one day in college.

I had just voted for Ronald Reagan (my very first election) because of my anger for those trapped in the American Embassy in Iran. I wanted to do something. And now here was a guy telling me I could. I dropped my English major, substituted criminal justice and threw all my energy into applying for the Secret Service. It was a cold slap when the rejection letter came. If I hadn't been so naive I would have known my ambition was doomed from the start.

The recruiter hadn't noticed a certain something about me. That certain something has cost you, the taxpayer, hundreds of thousands of dollars. I would like to pay you back. There's a catch, though. Death is a risk I take if I get a job. Not from hazards in the workplace, but from hazards in the bureaucracy. What happened when I was just a kid of 12 was the diagnosis of juvenile diabetes. It didn't stop me from triple-lettering in sports as a teenager, but by my early 30s I needed new kidneys.

I got them, thanks to the kindness of a wonderful donor family and the skill of dedicated physicians. I also got a new pancreas. My diabetes was cured.

But transplants aren't covered by many private insurance carriers, and I didn't have several hundred thousand dollars of my own to pay for the ongoing procedures. So I, like thousands of other patients, was advised to deliberately impoverish myself in order to qualify for government medical benefits. When you've already flat-lined, gone blind in one eye and had three heart attacks, well, whatever they tell you makes sense. At that point your only career goal is to stay alive.

And alive I am. After dropping out of college for several years, I've finished my bachelor's degree, graduating two years to the day after receiving my new organs. My professors at Ottawa University in Arizona tell me they were shocked. I'm such a big, burly guy they had no idea I was a transplant patient.

But they learned the truth about me from my research paper. They also learned that any transplant's new life—not just mine—is frequently dominated by welfare.

There are now more than 20,000 whole-organ transplant recipients every year. This number doesn't include bone-marrow patients. As the technology improves there will be even more. The drugs I take daily to prevent organ rejection and other complications cost about $1,800 per month. Most of us, in what should be the most productive years of ou lives, would like to trot those fabulous new organs to a work site. We'd be glad to pay taxes. It would be a privilege and a joy.

Instead, I know transplants (that's what we call ourselves) who work furtively at small projects payable in cash. Earnings o $200, if reported, would disrupt medical benefits. I know transplants who, on paper, are married. Each spouse has moved on to other relationships, but the insurance plan—now irreplaceable—is still intact.

How else do we cope? We hoard our drugs. We call it inventory. We keep any excess cataloged, stored and ready. This i our "cache of life" to guard against the da red tape chokes off those precious pills. "You need some cyclosporine? I've got extra," I've heard. Don't judge harshly, please. Until you have a foreign heart beating in your chest or someone else's liver washing your blood, you won't know how we feel.

So here's the question: now that we're alive, how do we get back into the swing o things? How do I get off welfare?

Most mornings I go to a coffee shop nearby. I toy with my mug of joe and watc other men—construction guys—heading off to work. I look like I should be one of them. They probably think I am. The diabetes that began ravaging my body as a child makes that unrealistic, though. Sometimes I wonder just what I'm fit for. When my mind starts playing tricks like that, I remember my bachelor's thesis: "Some Psychological Consequences of Transplant Surgery." I wanted to know what happens to the mind while the kidneys, heart, liver and lungs are being replaced.

While I can't work construction, I am fit for quite a few things. With my background—I've worked as a patrolman, enforcing state-park laws while pursuing my original major, law enforcement—I would make a good investigator. I'm great with kids, having lettered in football, basketball and track in high school and coached several sports in public schools. I was a relief counselor in a boys' home. Now that I have a degree in psychology, I am qualified for any of those types of jobs, and my health wouldn't be a drawback. There are plenty of men who wouldn't be "fit" for construction. Why should my heart squeeze with envy as those fellows shuffle out of the coffee shop in the mornings? It does because they are leaving me behind. They are contributing.

You've probably heard this before, but people who have had a near-death experience, as I have had, feel a need to help others. I didn't see Elvis; I just slumped over. But those amazing doctors wouldn't give up. And when I came back I felt that time was no longer my own. I had survived so much, surely this life of mine was a borrowed thing. I felt I should make a difference.

My professors think I can accomplish that by telling my story. By calling attention to the plight of the transplant. How odd it feels to use that word, plight. We transplants are blessed. We were all—every single one—supposed to be dead. But we really didn't mean to borrow so much. We're ready to give back. We want to repay all our surgeons and donor families and the miraculous society that made it all possible. We want to work!

SUTTON *lives in Arizona.*

## STATEMENT OF THE NATIONAL ALLIANCE FOR THE MENTALLY ILL

[SUBMITTED BY PATRICIA WARBURG CLIFF, ESQ.]

Chairman Roth, Senator Moynihan and members of the Finance Committee, I am Patricia Warburg Cliff of New York, New York, and I serve on the Board of the National Alliance for the Mentally (NAMI).

At the outset, I would like to thank you for holding this hearing on this very important legislation for people with severe mental illnesses. 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. The Work Incentives Improvement Act of 1999 (S 331) is integral 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 nearly 1,200 affiliates and state offices, NAMI represents more than 200,000 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, support, education, and advocacy aimed at reducing stigma and discrimination 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 joining the disability rolls at an earlier age. 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 principle barriers to the employment of individuals with serious 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 in order 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 more feasible 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 use 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 who may experience acute occurrence of severe symptoms several times in their lives.

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) beyond the current 45-month transition 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.

NAMI believes that it is the issue of access to medical coverage that is absolutely critical for 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 medications and other treatments for disorders such as schizophrenia and major depression, many people find it hard to maintain a stable life in the community, let alone achieve complete independence through employment. Moreover, for many people with severe mental illnesses, the first step in the process toward competitive employment is supported employment or low-wage, service-sector jobs. Few of these opportunities offer employer-provided health insurance, especially for someone with a serious brain disorder.

S 331 would begin 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 331?

1. It directly addresses the issue of extended health coverage in a way that accommodates the unique treatment needs 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 simplifies 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.

### *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 allow 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 into 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 whole in the Medicare program is a major concern for NAMI as we try 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 331 addresses these issues head-on by extending Medicare coverage for many SSDI beneficiaries for 10 years. More importantly, it will "catch people on the way down," filling the gaps that exist in both private plans and Medicare to prevent people from having 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.

More importantly, S 331 gives states the option to extend Medicaid coverage to working people with disabilities through a "buy-in" program. This option is critically important for adults with severe mental illnesses because it offers the potential to extend outpatient prescription drug coverage to individuals with income and/or assets above current Medicaid restrictions. SSDI recipients and low-income earners with disabilities will therefore be able to get coverage for the medications they need to either enter or stay in the workforce—allowing many to get off of cash benefits altogether. Moreover, the state incentives grant in the bill will make it easier for states to enact creative approaches that reach more disabled workers. The underutilized provision in the Balanced Budget Act of 1997 that allows states to extend Medicaid coverage to working people with disabilities up to 250% of the poverty level (Section 4733) is already proving inadequate in reaching consumers. The "buy-in" initiative in S 331 is a vast improvement and gives states the tools they need to get more people into the workforce.

*Reforming the SSDI "cash cliff"*

S 331 requires Social Security to conduct a demonstration of a sliding-scale reduction in SSDI cash benefits. This study is critically important in 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 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 them 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 not based on a careful evaluation of data generated from actual experience of declining cash assistance on a sliding-scale basis. Rather, these estimates appear to be based on untested assumptions regarding "induced entry" or "woodworking" among persons not currently in the SSDI program. NAMI believes that 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) in order 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.

*Promoting consumer choice through the "ticket to independence"*

NAMI is pleased that S 331 includes a "ticket to independence" proposal. 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 for 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 VR. By receiving a ticket directly, consumers will be able to select a provider on the basis of his or her relative experience serving people with severe mental illnesses and his or her record 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 with the current system, when coupled with extended health coverage it offers a positive step forward.

### *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 (sometimes) 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.

### *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. 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 in 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 be independent of the current CDR requirement for beneficiaries in terms of both timing and the evidentiary standard for future eligibility. Finally, NAMI urges that protections be added to both the ticket and health care 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, setbacks during which time they suffer acute symptoms.

### *Benefits all Americans*

S 331 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 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. They must not only catch people with disabilities as they fall out of work, but also give them a boost back into work when they are ready.

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 health care 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 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 stand 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 331 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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