

THE WORK INCENTIVES IMPROVEMENT ACT OF 1999

HEARING
BEFORE THE
SUBCOMMITTEE ON
HEALTH AND ENVIRONMENT
OF THE
COMMITTEE ON COMMERCE
HOUSE OF REPRESENTATIVES
ONE HUNDRED SIXTH CONGRESS
FIRST SESSION
ON

H.R. 1180

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THE WORK INCENTIVES IMPROVEMENT ACT OF 1999

TUESDAY, MARCH 23, 1999

HOUSE OF REPRESENTATIVES,
COMMITTEE ON COMMERCE,
SUBCOMMITTEE ON HEALTH AND THE ENVIRONMENT,
Washington, DC.

The subcommittee met, pursuant to notice, at 2:42 p.m., in room 2322, Rayburn House Office Building, Hon. Michael Bilirakis (chairman) presiding.

Members present: Representatives Bilirakis, Upton, Coburn, Lazio, Cubin, Bryant, Brown, Waxman, Green, Barrett, Capps, and Eshoo.

Staff present: Tom Giles, majority counsel; Jason Lee, majority counsel; John Manthei, majority counsel; Penn Crawford, legislative clerk; Brigett Taylor, minority counsel; Karen Folk, minority presidential management intern, and Brendan Kelsay, minority research assistant.

Mr. BILIRAKIS. I call this hearing on H.R. 1180, the Work Incentives Improvement Act of 1999, to order.

The subcommittee's consideration of this legislation today is an important step in improving the quality of life for millions of Americans who live with disabilities. H.R. 1180 was introduced last week by two of our colleagues and members of this subcommittee, Congressman Rick Lazio and Henry Waxman. I commend their efforts and I was proud to be an original co-sponsor of the bill. This proposal has strong bipartisan support, including our subcommittee's ranking member, Mr. Brown; the full committee chairman, Mr. Bliley, and the committee's ranking member, Mr. Dingell.

The Senate companion bill, S. 331, was unanimously approved by the Finance Committee earlier this month. Working together on a bipartisan, bicameral basis, I believe that we can enact this important major legislation into law this year, and hopefully, earlier in the year.

The need for the bill is clear. A recent survey found that 72 percent of Americans with disabilities want to work, but 75 percent are currently unemployed. The disparity exists because the current system forces people to choose between work and health care. Under current law, the Social Security Disability Insurance, SSDI, and Supplemental Security Income, SSI, programs provide cash benefits to persons with disabilities. By qualifying for SSDI and SSI benefits, individuals also become eligible for health coverage through Medicare and Medicaid. These two programs provide comprehensive services that persons with disabilities need, but often

cannot obtain through employer-provided coverage. However, SSDI and SSI benefits are not available to any person engaged in substantial gainful activity that results in earnings of \$500 or more per month. By going to work, therefore, individuals with disabilities also risk losing their health coverage under Medicare and Medicaid.

H.R. 1180 would allow States to expand Medicaid coverage to persons with disabilities through two optional programs. The bill creates a 10-year trial program to extend Medicare Part A benefits to SSDI recipients. In addition, it provides infrastructure and demonstration grants to assist the States in developing their capacity to run these expanded programs.

And finally, the bill creates a new payment system for vocational rehabilitation programs that serve individuals with disabilities. This change will reward successful efforts to obtain employment. Similar provisions were included in the Ticket to Work and Self-Sufficiency Act approved by the House of Representatives last year. The bill before us removes barriers for individuals who want to work. By encouraging work over welfare, it also promotes personal dignity and self-sufficiency. Simply put, H.R. 1180 will help people help themselves.

Our witnesses today include two of our subcommittee colleagues, industry representatives, and Federal, State, and local government officials. We will also hear from several Americans who live with disabilities about the challenges that they have faced. I believe they make the most compelling case for passage of H.R. 1180, and I hope members will pay particular attention to their testimony. I want to thank all of our witnesses for their time and effort in joining us today.

I yield to Mr. Brown for his opening statement.

Mr. BROWN. Thank you, Mr. Chairman.

First, I would like to ask unanimous consent to enter into the record Mr. Dingell's opening statement and opening statements of anyone on either side.

Mr. BILIRAKIS. Without object, the opening statements of all members of the subcommittee on either side can be made a part of the record.

[The prepared statement of Hon. John D. Dingell follows:]

PREPARED STATEMENT OF HON. JOHN D. DINGELL, A REPRESENTATIVE IN CONGRESS
FROM THE STATE OF MICHIGAN

Last week, I joined Congressman Rick Lazio, Congressman Henry Waxman, Chairman Tom Bliley, Subcommittee Chairman Mike Bilirakis, and ranking minority member Sherrod Brown in cosponsoring the Work Incentives Improvement Act of 1999. I am pleased that the Commerce Committee is holding a hearing on this bill today, and I hope that we take the additional steps that are necessary to enact this bill into law.

Over the past few decades, many people with disabilities have benefitted from tremendous developments in assistive technologies, more sophisticated medical care, and improved access to public facilities and public transportation. However, one area of life that has not improved for many people with disabilities is the opportunity to earn a living. While nearly 80% of non-disabled adults of working age are employed full- or part-time, less than 30% of disabled adults of working age hold full- or part-time jobs. This gap between the disabled and non-disabled population in the area of employment has not improved since the passage of the Americans with Disabilities Act earlier in this decade.

Almost three-quarters of people with disabilities who are not employed say that they want to work. Yet many adults with disabilities know that earning a paycheck

may disqualify them from receiving Medicaid or Medicare health benefits, which are absolutely necessary for keeping them healthy enough so that they are able to work. Many people with disabilities, quite understandably, choose health benefits over a job.

This bill would ensure that people with disabilities no longer have to choose between working and getting health care. States would have additional options to extend Medicaid coverage to working adults with disabilities. In addition, the bill would lengthen the current period of extended eligibility for Medicare for disabled beneficiaries who return to work.

This bill is sound public policy. It has strong bipartisan support in both the House and the Senate, and the Administration has included the bill in its budget proposal. I hope that we in Congress will act swiftly to pass the Work Incentives Improvement Act, which would provide people with disabilities with the opportunity they deserve—the opportunity to earn a living.

Mr. BROWN. Mr. Chairman, thank you and thank you especially to Congressman Waxman and Congressman Lazio for taking the lead on this very important bill.

In 1990 Congress passed the Americans With Disabilities Act. The objective behind ADA is to wipe out discriminatory practices, active and passive, that undermine equal opportunity for disabled individuals. Other major laws, including IDEA, the 1998 Workforce Investment Act, and the newly reauthorized Rehabilitation Act, also promote full participation of disabled Americans in the community and in the workforce. Yet, less than .5 percent of the 7,500,000 Americans receiving Social Security Disability benefits ever return to jobs that could supplant those benefits. There is a straightforward reason for this and it is not the loss of a monthly disability check. SSI and SSDI provide subsistence level benefits, if that. Full or even part-time work would be the clear economic choice if not for an impossible tradeoff, access to health coverage.

For many disabled individuals, the ability to work may hinge on reliable healthcare for personal attendant services. Yet, under current law, working means losing access to these very services. By providing continued access to Medicare and Medicaid, the Work Incentives Improvement Act eliminates this Catch-22. In addition, H.R. 1180 provides for enhanced job training and job placement services. It empowers disabled individuals to shop for the public and private career services that best fit their talents and their aspirations.

Finally, H.R. 1180 would bolster outreach and assistance programs that help disabled individuals negotiate the red tape associated with reentering the workforce. H.R. 1180 taps into tremendous human potential and takes us closer to a time when equal opportunity for disabled individuals is no longer an objective; it is a fact.

I am proud to be the original co-sponsor and I yield back my time.

Mr. BILIRAKIS. And I thank the gentleman. The Chair now yields to the vice chairman of the subcommittee, Dr. Coburn.

Mr. COBURN. I have no opening statement, Mr. Chairman.

Mr. BILIRAKIS. Ms. Eshoo, for an opening statement.

Ms. ESHOO. Thank you, Mr. Chairman. I'll try to be as brief as possible.

First of all, thank you to our two distinguished colleagues that are here today. It is always a source of pride to me as a Member of the House when some of the great bills that come before us are

originated and brought to us by members of our committee and our colleagues. So, thank you for doing this. I am pleased, and I am proud to be a co-sponsor of the legislation.

The fact that over 70 percent of Americans with disabilities want to work, yet three-quarters of them remain unemployed, I think that we have failed America when we see these numbers, but, happily, we have the solution before us in the very fine piece of legislation that Representatives Lazio and Waxman have placed before the Congress and I think that—I mean, the idea that we would be forcing Americans with disabilities to be choosing between working and health benefits is absolutely absurd. If someone were to come in here and propose that kind of system, we'd all vote against it, and yet that is the system that we have right now.

So, I think that we have a great, great opportunity. Not only to hear from the original sponsors, the carriers, the introducers of the legislation, but from the noble Americans that are going to add their eloquent voices. And I think that this is a bill that deserves, not only the support of everyone from both sides of the aisle, but that it should make its way right to the rose garden and we will all celebrate when it does.

Thank you, and I yield back.

Mr. BILIRAKIS. I thank the gentlelady.

Mr. Upton, for an opening statement.

Mr. UPTON. Thank you, Mr. Chairman. I'm going to insert my lengthy opening statement into the record. I just want to compliment my friends, Mr. Lazio and Mr. Waxman, for this piece of legislation. I, too, join as a co-sponsor of the legislation. I know plenty of folks in my district that really do feel like they are prevented from working and feeling good about the services that they do because of the lack of adequate health care, and it is with great joy that I join as a co-sponsor and look forward to this legislation moving swiftly in a bipartisan matter to this awesome committee.

I yield back the balance of time.

[The prepared statement of Hon. Fred Upton follows:]

PREPARED STATEMENT OF HON. FRED UPTON, A REPRESENTATIVE IN CONGRESS FROM
THE STATE OF MICHIGAN

Mr. Chairman, thank you for holding this hearing today on the Work Incentives Improvement Act, launching this landmark legislation on its way through the House legislative process. I want to commend my colleague and friend Rick Lazio for his leadership in developing this comprehensive measure. It will benefit not only people with disabilities, but our nation as a whole by removing the substantial barriers in the way of persons with disabilities who wish to enter or re-enter the workforce. We will all benefit from the contributions they are eager to make to our nation's economy and future.

If I had to make one recommendation for a change in this bill, I'd recommend changing its title from the Work Incentives Improvement Act to the Work Empowerment Act. Persons with disabilities don't need incentives to join the workforce. The vast majority are eager to do so. As one of our witnesses will testify, a Harris poll found that 72 percent of people with disabilities age 16 to 64 who are not employed would prefer to be working. They want the chance to share their skills, talents, and dedication in the workforce.

But they face tremendous barriers. Chief among them is the loss of Medicare and Medicaid coverage. Another is loss of income. They and their families are often worse off if persons with disabilities go to work. They are caught in the proverbial "catch-22" situation.

The plight of one of my constituents brought this situation home to me in a way statistics can't. She is a middle-aged, talented lady who suffers from post-polio syndrome and has limited mobility. She is receiving Supplemental Security Income and

Medicaid. Because she wants very much to use her talents and give back to the community, she serves as a volunteer receptionist for their local Disabilities Resource Center and provides excellent assistance. As much as she would like to get a paying job, she cannot, because in all likelihood she would earn too much to keep her SSI and hence her Medicaid coverage and too little to pay out of pocket for the housekeeping assistance and medical care she needs to remain in her own home.

That is why I see this as an empowerment act. It will ensure that working doesn't cost people with disabilities the very health and social services that enable them to work. It will empower them to choose the rehabilitation services, public or private, that best meet their unique needs and talents.

In enacting the Americans with Disabilities Act a decade ago, we ensured that persons with disabilities would not experience discrimination in the workforce. Now, we need to knock down the barriers keeping them from entering or trying to enter the workforce. The legislation we are considering today will do that.

Mr. BILIRAKIS. He knows what to say, doesn't he?

Ms. Capps for an opening statement.

Ms. CAPPS. Thank you, Mr. Chairman.

Thank you for holding this hearing. I want to welcome——

Mr. UPTON. If I could just ask unanimous consent to see if my friend from Florida might have an extra ticket in St. Petersburg for the Michigan fans down there?

Monday night.

Mr. BILIRAKIS. Without objection, you can ask, but the answer is no.

Ms. CAPPS. Thank you. I want to add my word of welcome and admiration for my two colleagues for initiating this legislation. I am in the process of becoming a co-sponsor. I am going to submit my full statement for the record, but I want to just highlight for you and for myself now to recall a high moment in my short legislative career, but a high moment in my life.

Last winter I had the privilege of providing a key note address to a group of about 200 consumers of a regional center in my State, the Tri-Counties Regional Center. This is an organization which is serving, but also comprised of, the disabled community in Santa Barbara. The goal of the group is to help this population, developmentally and physically disabled, to become fully participating and productive members of society. In fact, the title of the event was Leadership and Community Involvement for the Disabled and they invited their soon-to-be elected representative to come to share legislative ideas. It was an amazing inspirational group of people who refused to let their disabilities keep them from attaining their goals and held me to a commitment, which I was pleased to give—the commitment that I would do something about this.

This is a part of my obligation today; to be able to hear your testimony; to be a part of this hearing; and now to be able to go back to that same group and say, "Yes, we are beginning to work." There are a counterpart organization in San Luis Obispo County. SLO-CO access is also deeply involved in the challenge of getting disabled clients into the workforce. The key message in this day-long conference repeated over and over again to me was "we want to work. You, in the government, are preventing us from being able to exercise our full potential as citizens. We want to work." They chanted it to me. I can't get it out of my mind. So, I'm here today thanking you for giving me something now to carry back to my constituents.

I yield back the balance of my time.

Mr. BILIRAKIS. Thank you, Ms. Capps.

Ms. Cubin for an opening statement.

Mrs. CUBIN. Thank you, Mr. Chairman.

It is no secret that the vast majority of Americans with disabilities would like to work. Congress has an obligation, I think, to look at the legal barriers that force persons with disabilities to rely on cash benefits.

I want to thank all of you for coming here today. I appreciate your time and I look forward to hearing your unique perspective and insights on this issue. I also want to thank my little buddy, Congressman Lazio, and my other buddy, Congressman Waxman, for introducing this legislation.

As with any legislation, there could be some haggling over the details, but I think the fact that we are discussing this today is vitally important and will help all of us on the subcommittee to fully understand this issue. Removing the barriers to employment is a common goal among all of us, and I expect that today's hearing will help us accomplish this goal. So, thank you again.

Mr. BILIRAKIS. Thank you. I think that completes the opening statements from up here.

[Additional statements submitted for the record follow:]

PREPARED STATEMENT OF HON. NATHAN DEAL, A REPRESENTATIVE IN CONGRESS
FROM THE STATE OF GEORGIA

Thank you, Mr. Chairman, for holding this important hearing today regarding the Work Incentives Improvement Act. I am supportive of the intent of this legislation. We must enable people with disabilities to assume greater control over their lives and allow them to contribute more fully to society. Rapid advancements in technology continue to provide important new tools to help individuals with disabilities become more independent and participate in activities related to home, school, work, and community. However, current health care programs create barriers to individuals with disabilities trying to increase their independence and productivity through work. I thank you and look forward to hearing the testimony from our witnesses.

PREPARED STATEMENT OF ED BRYANT, A REPRESENTATIVE IN CONGRESS FROM THE
STATE OF TENNESSEE

Thank you Mr. Chairman. Good morning.

First of all I would like to thank Chairman Bilirakis for holding this hearing today.

I believe this legislation is very important in terms of removing the governmental disincentives that make it very difficult—if not impossible—for so many individuals with disabilities to return to work or go to work.

It is troubling that nearly 75 percent of people with disabilities are unemployed, yet surveys show that the vast majority of these people want to go to work and be productive members of society. I also find it troubling that every year only one-half of one percent of individuals with disabilities successfully make the transition from unemployment to employment.

I look forward today to examining the current situation and proposed legislation aimed at breaking the cycle of dependency on government. I appreciate the time and energy that went into crafting this bill, and I am eager to work with my colleagues on both sides of the aisle in taking a closer look at it.

Finally, I would like to thank the witnesses who are with us today for their time and testimony. I look forward to hearing from each of you.

Thank you, Mr. Chairman. I yield back the remainder of my time.

PREPARED STATEMENT OF HON. GENE GREEN, A REPRESENTATIVE IN CONGRESS FROM
THE STATE OF TEXAS

Thank you Mr. Chairman for scheduling this important hearing.

I also want to thank Mr. Waxman and Mr. Lazio for taking the lead on this issue which I believe will give disabled individuals the chance to choose work over dependency.

I am a cosponsor of H.R. 1180 because I believe it strikes at the core of human dignity and represents the proper balance of government support for independent living.

A recent study showed that nearly three quarters of disabled individuals want to work. Yet $\frac{3}{4}$ of this same population are unemployed.

How is this possible and what can Congress do to help?

Well, the answer to the first part of the question is that disabled individuals have unique health care needs that often times can only be met by Medicaid or Medicare.

The answer to the second part of the question is pass H.R. 1180.

This bill gives disabled Americans the opportunity to gain employment and continue to receive the medical care they need and deserve.

While it is an expensive proposal, I believe it is money well spent. The cost in dollars will pale in comparison to the sense of accomplishment and independence thousands of Americans will get from supporting themselves and their families.

Again, I want to thank Chairman Bilirakis for scheduling this hearing so quickly. Hopefully, this fast-track process will allow this bill to become law very soon.

Mr. BILIRAKIS. The Chair is very proud to introduce our two colleagues, the writers of this legislation, and I'm going to start off with the man who was here first. I was going to extend to you the courtesy.

All right, at his request, we'll introduce Rick Lazio, a member of this committee. Rick, we appreciate so very much the job you've done on this. Please tell us more about it.

STATEMENT OF HON. RICK LAZIO, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF NEW YORK

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

Let me begin by thanking you and the ranking member, Mr. Brown for the opportunity to appear before the committee. I'd like to also send a special thanks to both of you for co-sponsorship of this bill and appearing at the press conference which sent an enormously strong message to the advocacy community and to all Americans about the prospect for passage this year. You are two very important players. I want to thank the rest of the members here and my friends, and in particular, Mr. Waxman, who is appropriately on my left, who is my partner in this, and I am very appreciative of him.

The Work Incentives Improvement Act has one goal and one goal only: enabling individuals with disabilities to pursue, if they want, work. Over the past decade, we have made dramatic improvements in removing many of the barriers that have kept people with disabilities out of the mainstream of American life. The Americans With Disabilities Act, for example, successfully helps people with disabilities lead more active and integrated lives. But the ADA did not complete the work of removing all barriers. In fact, it not even remove all Federal Government barriers. Access to healthcare coverage remains an enormous hurdle confronting people with disabilities who want to work.

Let me tell you about a man from my district. He is a Navy veteran from Bay Shore, New York. Several years ago he worked on Wall Street with the hopes of becoming a stockbroker. Unfortunately, an accident left him a quadriplegic and he relies on a tracheostomy to help him breathe and to speak. He requires nurses

or caregivers to clean his tracheostomy and requires 24-hour home care to assist him with activities of daily living.

His physical challenge, however, does not inhibit his ability to be a stockbroker. Years after his tragic accident, he successfully passed the Series 7 test, a grueling 6-hour exam to become a licensed stockbroker. And I would add, Mr. Chairman, with the diversity of technology that is now available, the folks who are challenged with disabilities have even more employment opportunities. He would like to open up his own firm and hire people with disabilities. Nothing is stopping him in pursuing his American dream except us, the Federal Government.

His predicament is replicated all across this country by the millions. According to the report of the National Organization on Disability, 72 percent of Americans with disabilities want to work. Yet, less than .5 percent of disabled Americans are able to move from disability benefits to employment and self-sufficiency. What is the problem? The problem is that Federal benefit programs, such as SSDI and SSI, provide benefits, including healthcare coverage through Medicare and Medicaid. Services that many disabled workers require are often not covered by employer healthcare. So, when a disabled American secures a modest job and earns income, he or she risks losing their Government benefits, including health coverage.

Mr. Chairman, this is very important and not hard to understand. Disabled Americans must choose between working and surviving. The sad reality is that access to healthcare makes all the difference when it comes to people with disabilities moving from the Government roles into the workplace.

This is why together we have introduced the Work Incentives Improvement Act. The Federal Government should remove existing barriers and allow these individuals to work. Like all other Americans, disabled Americans deserve economic opportunity. They deserve the satisfaction that only a paycheck can bring. They deserve to be in control of their lives and have the peace of mind of independence and personal security. They deserve to follow their own American dream.

The Work Incentives Improvement Act takes significant steps toward reforming Federal disability programs, improving access to needed services, and releasing the shackles of dependency. We, in Congress, have an obligation to help people with disabilities make this leap and become more productive citizens.

I know that some members of this committee might have some reservations about the Medicaid and Medicare provisions in the bill, especially at a time when these programs face a looming crisis as the baby-boom generation ages, but we all must keep in mind that these Medicaid expansions are options for the States, not mandates. Our bill will give States maximum flexibility in designing initiatives to promote work for people with disabilities. And more importantly, these options under Medicaid are not freebies. States can require people with disabilities, depending on their income levels, to pay up to 100 percent of premium costs. Likewise the 10-year Medicare demonstration for SSDI recipients would be available only to people who would otherwise be eligible for the pro-

gram. Why not allow them to get the coverage they need and work at the same time?

Last week at our press conference, Angelo Bianco, an Air Force veteran from Jackson Heights, New York, who fought in Operation Desert Storm, spoke for a few minutes. Angelo has a spinal cord injury he suffered during his service in the Persian Gulf. Angelo spoke about how the two most miserable years of his life were the time he spent at home after the war. Fortunately, he is now working for the Eastern Paralyzed Veterans Association and is a productive member of society. I know, Mr. Chairman, how dedicated you are to the veterans community, so I know you can relate to this. We need to pass this bill to enable many more Americans with severe disabilities to follow Angelo's lead and to move into the workforce and the mainstream of American life.

I want to thank you again, Mr. Chairman, and the ranking member, Mr. Brown, and all the members for their supportive comments and for working in the bipartisan fashion for helping to move us one major stride forward to ensuring that we have financial independence for those who have disabilities.

Thank you.

Mr. BILIRAKIS. Thank you, Rick.

The Chair now calls upon our colleague, Mr. Waxman. First, I would say that the mayor of the District of Columbia, Mr. Williams, is scheduled to be here. We are, of course, very pleased to have him testify at his request, but he hasn't arrived yet. So, Henry, take your time.

**STATEMENT OF HON. HENRY A. WAXMAN, A REPRESENTATIVE
IN CONGRESS FROM THE STATE OF CALIFORNIA**

Mr. WAXMAN. Mr. Chairman, and my colleagues, I thank you very much for this chance to speak with you and to join with Congressman Lazio in supporting this legislation. It is clear that, from the opening comments, all the members of this subcommittee understand the importance of this bill, and if not all of you, certainly most of you, are already on as co-sponsors.

This is an important proposal and it is an unusual one. It's unusual because of the extraordinary degree of bipartisan support the bill has. It is, of course, supported by the chairman, the ranking member of the subcommittee, the chairman and ranking member of the full committee. It has the endorsement of the administration. Indeed, it was singled out by the by the President in his State of the Union Address.

It already has passed the Senate Finance Committee, again, with the sponsorship of the chairman and the ranking member of that committee. It has support at the State level, as well as here in Washington. This bill has this degree of support, I believe, because it is such a common-sense piece of legislation. It is moderate in costs. It offers benefits in terms of productiveness and self-respect for people who are determined to work and become taxpaying, contributing members of society.

I want to make just two points about his bill, and if the mayor doesn't come, I'll soon make three or four additional ones.

First, it provide States with options to allow them to use their Medicaid programs to cover people with severe disabilities who can

work if their healthcare coverage is continued. I, myself, would have preferred a mandate, but if we——

I only said that to see your reaction.

But I think it is important, at least, to have options available to the State and I expect the States will respond favorably to that. And the bill provides options and allows States to use their Medicaid program to cover people with severe disabilities who can work if their healthcare coverage is continued. And it authorizes an extremely important demonstration program to allow States to provide Medicaid coverage at a stage that will prevent people from having their disability become so severe that they end up on SSI. Truly, that is one of the most sensible things we can do.

This bill also lets people with disabilities who have been covered by Medicare keep that coverage if they are able to return to work. Again, this is absolutely critical. This provision allows people to work. It makes a great deal of common sense. No one benefits if we bar the door to returning to work by taking away the healthcare support necessary for a person with a disability to be able to work. When you look at how much sense this bill makes, the only real question is, why haven't we done this sooner?

Let's remedy the fact that this is not yet law. Let's move as quickly as possible. Let's do it in a bipartisan way. Let's have an initiative to improve healthcare coverage for Americans. May this be the first of many bills that this committee will author and move forward with bipartisan, overwhelming support, so that we can show the American people that we are willing to, and actively anxious to, address problems that really mean something to them in their lives.

Thank you.

Mr. BILIRAKIS. Well, thank you, Henry. Very well put in most respects.

We have a history over the last few years of working out some pretty tough issues on a bipartisan basis, and I am very hopeful that this is going to continue as far as this legislation is concerned.

And you and I very briefly chatted about managed care, sitting down and try and work that out. I don't know why in the world we can't do that. Of course, it has all come about because everybody has been willing to give and take a little bit because we know that is what it is all about, and because of the great cooperation on the part of my ranking member, Mr. Brown.

Mr. Brown, do you have any questions of this panel? Any questions from any member of the panel?

Ms. ESHOO. I just have a curiosity question. I just can't see how anyone would not support this. There are those that you might not get to co-sponsor, but I can't help but think that this really should go to the House on the suspension calendar. How many co-sponsors are there so far?

Do we know? Forty, and we've just introduced it.

Mr. BILIRAKIS. Yes, we just introduced it.

Ms. ESHOO. I really think this should be our collective goal, and that you turn this subcommittee, since we have the original jurisdiction on this as the whips from both sides of the aisle to go out and get our colleagues. An eloquent statement would be made by

the House of Representatives if we could bring this to the floor, and I think that we can on the suspension calendar.

For those of you that don't know what the term means, it means that there are 218 people that have signed on and that there isn't any controversy. So, that is the majority of the House.

Mr. WAXMAN. This bill is in our committee, but it is also in the Ways and Means Committee, and to give credit where it is due, the Ways and Means Committee did some of the pioneering work on this legislation.

Ms. ESHOO. That is great. So we shouldn't be too self-congratulatory here?

Mr. WAXMAN. No, but I think we need to compliment them for their initiatives and to impress upon them that we have now added on some very important features. The healthcare features are essential, not just the financial assistance to people, but healthcare and Medicaid is in our jurisdiction as well as Medicare, which they share with us. So, I hope that—

Ms. ESHOO. We'll join with them?

Mr. WAXMAN. We will not only work on a bipartisan basis, but that our two committees will move together.

Mr. BILIRAKIS. Sometimes it is more difficult to work with the other committee than it is on a bipartisan basis.

Ms. ESHOO. Not on this one, though. Not on this one. Right.

Mr. WAXMAN. I never experienced that, Mr. Chairman.

Mr. BILIRAKIS. You have never?

All right, Henry.

Barbara, any questions?

The mayor is not here yet. Should he arrive—he was scheduled to be here about 5 minutes to 3—we'll work him in somewhere along the line, if he has the time to wait a while.

Mrs. CUBIN. Mr. Chairman, I do have a bill in Resources Committee that I could educate the committee on, if—Never mind.

Ms. BILIRAKIS. You mean just to take up the time.

Mrs. CUBIN. Sure.

Mr. WAXMAN. I can tell you about the activities in the Government Reform Committee, so you don't think everything is bipartisan or harmonious.

Mr. BROWN. Speaking of bipartisanship.

Mr. WAXMAN. Well, it is appropriate this is the first hearing post-Hershey.

Mr. BILIRAKIS. Well, thanks. Thanks guys. We are going to do this. We are going to do this together.

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

Mr. BILIRAKIS. The second panel.

I tell you, we don't usually see or hear very much applause on this committee. The press conference the other day was, I think, the first that I've experienced in quite a while, and that was really great. So, we appreciate it again today.

The second panel consists of Ms. Sally Richardson, the Director—is she here?

Ms. RICHARDSON. Yes, sir.

Mr. BILIRAKIS. Oh, there she is. Sally, I'm sorry.

Ms. RICHARDSON. That's all right.

Mr. BILIRAKIS. Director of the Center for Medicaid and State Operations with HCFA, Ms. Richardson. We're turning the clock to 10 minutes, but just tell us what it is you want to tell us.

STATEMENT OF SALLY RICHARDSON, DIRECTOR, CENTER FOR MEDICAID AND STATE OPERATIONS, HEALTH CARE FINANCING ADMINISTRATION

Ms. RICHARDSON. Well, the first thing I would like to do, Chairman Bilirakis, and Congressman Brown, and the rest of your distinguished subcommittee members, is to thank you for asking me to discuss the very strong—

Mr. BILIRAKIS. Why don't you pull that closer to you [referring to microphone], if you will please?

Ms. RICHARDSON. [continuing] oh, I'm sorry—to discuss the very strong support of the Clinton administration for the Work Incentives Improvement Act of 1999. We would also like to thank you, Chairman Bilirakis and Congressman Brown, for your leadership in building bipartisan support for this important legislation, along with Chairman Bliley, Congressman Dingell, Lazio, Waxman, and Senators Roth, Moynihan, Jeffords, and Kennedy. It is a wonderful, wonderful example of Congress joining together to fill a real need.

The Health Care Financing Administration and the Clinton administration have been working diligently to improve the lives of people with disabilities. We recognize that they deserve to be treated with dignity. They deserve to be able to contribute their talents and skills to our communities in our society, and they deserve to have broad options for obtaining the care and the services that they need.

The threat of not having health coverage should never allow them or us to be able to discourage capable individuals from returning to work. We believe it is both prudent and fair to extend Medicare and Medicaid benefits to disabled individuals, as you have proposed in the Work Incentives Improvement Act, in order to remove this threat.

The Work Incentives Improvement Act will help people with disabilities take fuller advantage of the technological advances that have opened doors for them to the workplace. Under current law, a person as you know with a disability who takes a job can become ineligible for Medicare and Medicaid because of their income or their ability to work. The private-sector coverage that is available to many employees of private companies is very often unavailable or unaffordable for disabled people, specifically because of their disability. The Work Incentives Improvement Act will help States do something about that. It allows States to lift or relax current eligibility limits on assets and income for this population, building on the provision that you passed in the Balance Budget Act of 1997. It allows States to charge premiums on a sliding scale. It allows States to let the working disabled buy Medicaid coverage when they would otherwise lose eligibility due to medical improvement. It gives States \$150 million for infrastructure grants to help develop programs and systems that can support the working disabled moving into work and also provide assistance supporting home and community-based services for people who are served currently in institutions.

It provides Medicare Part A coverage during the 10 years following the enactment of this bill for those disabled individuals who lose Social Security due to their ability to earn a living. This is a provision that will provide relief for individuals in those States that may not choose the Medicaid expansions in the bill.

And it authorizes a demonstration, a test, so that we can measure the value of providing Medicaid to individuals with conditions like diabetes and HIV that, left untreated, can lead to disability. The bill is included in the President's fiscal year 2000 budget, and it is part of a broader administration agenda for helping disabled individuals return to the workforce.

We are really proud to be among a wide bipartisan array of supporters for this legislation. We look forward to working with you to help pass this bill and to help bring disabled individuals into the workforce. I especially appreciate, as I said when I began, your holding this hearing and your asking us to be part of it. And I am very happy to answer questions that you have.

[The prepared statement of Sally Richardson follows:]

PREPARED STATEMENT OF SALLY RICHARDSON, DIRECTOR, CENTER FOR STATE AND
MEDICAID OPERATIONS, HEALTH CARE FINANCING ADMINISTRATION

Chairman Bilirakis, Congressman Brown, distinguished subcommittee members, thank you for inviting me to discuss the strong support of the Clinton Administration for the Work Incentives Improvement Act of 1999. We would like to thank Chairmen Bilirakis and Bliley, Congressmen Dingell and Waxman, and Senators Roth, Moynihan, Jeffords and Kennedy for their leadership in building bipartisan support for this prudent, fair, and necessary legislation.

The Health Care Financing Administration is working diligently, in concert with the President's goals, to improve the lives of people with disabilities. These individuals deserve to be treated with dignity, to be able to contribute their talents and skills to society, and to have broad options for obtaining the care and services they need. Now, more than ever, given innovations in technology and the historic strength of the economy, people with disabilities can and should be able to work and pay taxes.

One way we are working to meet these goals is by encouraging States to offer more Medicaid home and community-based services. This involves allowing funds for care and services to "follow the person," instead of dictating that services will be funded only in specific settings like nursing homes. And, based on results of a University of California San Francisco study we commissioned, we are changing Medicaid rules to encourage care in home and community-based settings.

However, some policy changes needed to improve the lives of people with disabilities require legislation. The Work Incentives Improvement Act is one such piece of needed legislation.

We need this legislation so people with disabilities can take fuller advantage of technology advances that have opened doors to the workplace for them. We must ensure that people with disabilities can engage in gainful employment without losing public health care coverage that they often cannot replace in the private sector. We must also give young people with disabilities the opportunity to go from education to employment without ever receiving cash assistance in order to gain health care coverage. This bill will do so.

The President, HCFA and a wide, bipartisan array of Congressional leaders strongly support this bill. It is included in the President's fiscal 2000 budget, and is part of a broader Administration agenda for helping disabled individuals return to the workforce.

Currently three out of four people with disabilities are not working. The unemployment rate among disabled people is exacerbated by existing law, which can make a person with a disability who takes a job ineligible for Medicare and Medicaid because of their income or ability to work. Private sector coverage is often unavailable or unaffordable for disabled people specifically because of their disability.

The Balanced Budget Act enables States to provide Medicaid coverage to the working disabled with incomes up to 250 percent of the federal poverty level if they meet the unearned income eligibility criteria and definition of disability for the Supplemental Security Income program. We have encouraged States to take advantage

of this opportunity, and have approved Oregon's plan to do so. Several other States have proposals under consideration, but too few States have taken advantage of this BBA provision.

The Work Incentives Improvement Act will improve upon the Balanced Budget Act in a number of ways. It expands State options for providing Medicaid coverage to the working disabled. It allows States to lift or relax current eligibility limits on assets and income for this population. States would be able to set limits on assets and income, and they would be able to charge premiums on a sliding scale. States could also allow the working disabled to continue to buy Medicaid coverage when they would otherwise lose eligibility due to medical improvement.

The Work Incentives Improvement Act will provide \$150 million over five years in grants to participating States to help them develop programs and systems that support working individuals with disabilities, build the capacity to provide home and community-based services, and conduct outreach campaigns to connect individuals with services. This money should help States facilitate coverage for optional eligibility groups and increase the likelihood that they will choose to provide this coverage.

The Act will also provide Medicare Part A coverage (for inpatient hospital and related acute care needs) to any individual who remains disabled but loses Social Security during the 10 years following enactment of this bill due to their ability to earn a living. This will provide important relief for the working disabled in States that do not choose the Medicaid expansions.

And it provides for a \$300 million demonstration program over five years that would allow participating States to provide Medicaid to individuals with health conditions that have not yet rendered them disabled, but that can be expected to cause the level of disability required to qualify for disability income. This demonstration would test the cost effectiveness of providing coverage and consequent care needed to prevent disability and related costs. And it will provide important data that private insurers can use in crafting new coverage policies for disabled workers.

The bill also includes a series of non-health provisions that target individuals receiving Social Security disability benefits, including:

- a "Ticket to Work" public-private partnership program that would allow beneficiaries to go to either a public or private participating provider for employment-related services, with payment to providers based on employment outcomes;
- restrictions on employment as the sole basis for continuing disability reviews;
- expedited eligibility determinations for beneficiaries who have left disability rolls to return to work but then must reduce or stop work due to their impairments; and
- outreach and assistance programs to provide information on work incentives.

The President has proposed to broaden the outreach and assistance grant programs in the bill to include "one-stop shopping" assistance for people who need help navigating the bureaucracies involved in returning to work. The proposal would provide grants to ensure that one-stop centers, established by the Workforce Investment Act of 1998, are focused on integrating services that are essential for people with disabilities. We hope that you will consider this broader grant program in this bill or other legislative proposals.

The threat of no health coverage should not be allowed to discourage capable individuals from returning to work. It is both prudent and fair to extend Medicare and Medicaid benefits to disabled individuals under the Work Incentives Improvement Act in order to remove this threat.

ADMINISTRATION SUPPORT FOR THE WORKING DISABLED

As mentioned above, support for the Work Incentives Improvement Act is part of broad Clinton Administration support for efforts to improve the lives of people with disabilities and facilitate their employment. President Clinton established the President's Task Force on Employment of Adults with Disabilities by executive order on March 13, 1998. This task force is working to coordinate national policy to bring adults with disabilities into the workforce at a rate that is closer to the general population.

The President's fiscal 2000 budget includes a three-part initiative that will invest more than \$2 billion over five years to encourage employment among disabled individuals. The first part of that initiative is enactment of the Work Incentives Improvement Act. On January 13, 1999, the President announced his support for this legislation as part of his larger initiative to improve economic opportunities for Americans with disabilities.

The President's fiscal 2000 budget's working disabled initiative also includes a proposed \$1,000 annual tax credit for workers with disabilities to help defray the costs of transportation, adaptive equipment or other job assistance. It also includes a \$15 million or 50 percent increase for assistive technology activities authorized under the Assistive Technology Act of 1998, and expanded access to information and communication technological advances that help disabled individuals function on the job. Workers with disabilities also will benefit from the President's multi-faceted long-term care initiative that includes a number of provisions targeted toward adults with disabilities.

Also, to further provide States flexibility to offer more home and community-based services, the Vice President recently unveiled a new proposal to allow States to expand home and community-based care to individuals with incomes up to 300 percent of the Social Security Income limit. That is the same income limit for providing care in nursing homes. This would provide another State option to enable families with long term care needs to stay in the community. The initiative would cost \$110 million over five years, and is paid for in the Administration's balanced budget.

CONCLUSION

The Work Incentives Improvement Act is prudent, fair, and necessary to ensure that disabled individuals can participate fully in the job market without fear of losing health care coverage. We are proud to be among a wide, bipartisan array of supporters for this legislation. We look forward to working with you to secure passage of this bill and other Administration proposals to help bring disabled individuals into the workforce and to increase the availability of Medicaid services in home and community-based settings. I thank you for holding this hearing, and I am happy to answer your questions.

Mr. BILIRAKIS. Thank you very much, Ms. Richardson, and we are very pleased that you were willing to come here because, again, when we talk bipartisanship, we should mean including the other portions of government in the process.

Let me ask you, and I guess this is more curiosity on my part, but I think it is also pretty significant. BBA 1997 allowed States to increase the Medicaid buy-in for workers with disabilities up to 250 percent of the poverty level. Yet, as I understand it, only one State, Oregon, has exercised this option. Why do think this is?

Ms. RICHARDSON. With all due respect, Mr. Chairman, BBA gave the States a good deal to think about and to work for that they hadn't expected, so to speak. And I think the Children's Health Insurance Program which expanded healthcare coverage to 5 million additional children in this country, changes in the Medicaid Managed Care Program which, obviously, concerns all the States since most of them have some form of managed care now operating in their State—I think these were all things that they felt had to be addressed. I think that these were more immediate concerns, as you know. CHIP was initiated or had to be implemented by the first of the fiscal year, and Medicaid Managed Care, as I said, has been very much on their plates. We now have another 11 States that are talking to us about the provision in BBA 1997—

Mr. BILIRAKIS. Good.

Ms. RICHARDSON. [continuing] and looking toward submitting plans to us to be able to implement it. Sometimes because this is a very complex area and this is a very complex policy for States, it takes longer to put it together than States might imagine at the beginning.

And you're going to hear from Mr. Auerbach today, who has implemented this provision or is implementing this provision in the State of Oregon, and he will be able to either confirm or expand

on what I think are the reasons why States have not immediately taken this up.

Mr. BILIRAKIS. Right, well, let me ask you, then, a thought in that same vein. I was very curious why more States hadn't taken advantage of it and your answers are very good. I just wonder, though, is the language in BBA 1997 a problem in terms of interpretations, definitions? Since I think we all intended to give the States this authority and we all think it was a good idea, is there something that we can do regarding the language of BBA 1997 to maybe spur this on somewhat?

Ms. RICHARDSON. Well, I think—

Mr. BILIRAKIS. In your opinion?

Ms. RICHARDSON. I think that you have done that in this legislation by lifting the 250-percent cap and also by giving States the explicit authority to set income and assets levels, also to set premium levels on sliding scales. We have had some concerns, and I think Mr. Auerbach will talk to you about those, about the fact that there are concerns about statewideness. There are some of the concerns that States have about the definition of working in this population.

Mr. BILIRAKIS. Good. Well, we need to know more about that because we might be able to be very helpful, and should be able to be very helpful in that regard.

Thank you very much.

Mr. Brown.

Mr. BROWN. Thank you, Mr. Chairman.

Ms. Richardson, welcome back to our subcommittee. Understanding your expertise is specifically—"especially," I should say, rather than specifically—Medicaid, I wanted to ask you a couple of questions. You've always been able to go further than that in answering questions. I wanted to ask you a couple of questions about Part A Medicare.

As you know, we've talked during the meetings of the Medicare Commission, and much of that is centered around solvency, the Part A trust fund, and we got good news last week when CBO extended the period to 2010, two more years, rather than 2008. Critics of the bill argue, however, that we should not be extending or this whole idea, critics say, we should not be extending Medicare coverage to anyone. What is your response to people who say that doing this and extending Medicare to more people will unduly drain the trust fund?

Ms. RICHARDSON. I think that the estimates are, for this particular bill, that it would have negligible impact on the trust fund. It is something we could do now. It is in the President's 2000 budget, and as I said, it is an insignificant, very negligible—

Mr. BROWN. Negligible means how much?

Ms. RICHARDSON. I think it's less than a percent, maybe two. They told me to give you a graphic example and I forgot.

It is basically less—certainly way less than a month's expenditures in the trust fund is what it would have on the solvency of the trust fund over the long run.

Mr. BROWN. So, if the solvency is 2010, then this would be 2009 and 11-plus months. It is that insignificant in terms of solvency of the trust fund?

Ms. RICHARDSON. Yes, that's right.

Mr. BILIRAKIS. Okay. The bill makes SSDI recipients who return to work permanently eligible for Medicare Part A without having to pay Part A premiums. My understanding is, under present law, there is some trial period that people in SSDI may receive Medicare for up to, I believe, 4 years——

Ms. RICHARDSON. It is 4 years.

Mr. BROWN. [continuing] if they sort of pass the hurdles, without paying Part A premiums. Why do we need this then? What is the real difference?

Ms. RICHARDSON. Most people who enter into that program, basically, don't ever finish it. Our figures show that only about 7,500 a year actually successfully complete that extended period of eligibility, and our figures also show that we have only about 170 people who have actually bought into Medicare following their extended period of eligibility.

The thought for most people of losing their Medicaid eligibility even at the end of 4 years is, particularly, because it takes so long for them to get back into Medicaid—I'm talking Medicaid; I should be saying Medicare—because it takes them so long to get back into Medicare. Basically, it is an enormous threat after what, basically, is their physical liability.

Mr. BROWN. So making that permanent would sort of change—it would mean those people, rather than falling short on 4 years, might be able to with some permanence, without having to pay Part A premiums, with some permanence, would be able to stay with it and keep getting the benefit?

Ms. RICHARDSON. To stay with it, and to not have the fear that they are going to at any point have to sit out 2 years without any Medicare insurance.

Mr. BROWN. Okay, thank you, Ms. Richardson. Thank you, Mr. Chairman.

Mr. BILIRAKIS. I thank the gentleman. Mr. Lazio.

Mr. LAZIO. Thank you very much. I appreciate very much your supportive comments on behalf of the administration.

I have two questions I want to ask. First of all, some people who have disabilities do go back to work. They may have employer-paid healthcare, but there is a concern that many of those benefit options, that coverage, does not provide the type of coverage that folks need who have disabilities.

Could you speak to that issue and why is it that it is just not good enough to rely on employer-paid healthcare premiums for folks that have disabilities?

Ms. RICHARDSON. With the new assistive technologies that are available to individuals, a much broader array of individuals are able to go back to work if they would have the kind of coverage that could pay for things that they particularly need. I think probably the most frequent need that they have that Medicaid covers, but that private insurance doesn't, is personal-assistant services. There are a number of services of that same nature that, basically, private insurance doesn't cover. In addition to that, many of the assistive devices that they actually need to be able to work are not covered by private insurance, but are covered by the Medicaid program.

Mr. LAZIO. And so on top of the actual coverage, this bill does include infrastructure money, \$150 million?

Ms. RICHARDSON. It includes infrastructure, \$150 million, and then an increasing amount in the out 5 years based on the CPI.

Mr. LAZIO. Let me ask you in terms of scoring because we are so cost-sensitive: You were involved, as I understand it, in working with CBO to come up with a score on this and—am I right?

Ms. RICHARDSON. Well, our agency was.

Mr. LAZIO. We can change that. One of the concerns that I have, though, in achieving this scoring or the estimate of costs for this bill, is that it appears as though the costs associated with staying on a public subsidy, on SSI or SSDI, indefinitely, including reliance on perhaps housing assistance, section 8 housing assistance or food stamps or other issues, was not really taken into account in terms of developing a cost estimate. Nor, I might add, was the sort of sense of what type of Federal dollars would be created by people going back to work and paying taxes and contributing to the economy. I know some of this is very difficult to calculate, but even on the example that I used with a stockbroker that technology is now opening up huge vistas to people with disabilities that even a few years ago would not have been possible. And I can't help but thinking about people like Steven Hawking and others with enormous genius and brilliance who are challenged with disabilities, but their potential for income is enormous.

Could you speak to why you think that came out that way, and do you think that those ailments need to be included in an understanding of what the costs might be?

Ms. RICHARDSON. Basically, I think it has not been the practice at the Federal level to estimate costs in relationship across components and across programs. It is a very, as you said, quite difficult thing to do, and I think it just has not been the practice to do. We certainly have discussed it within our own agency in talking about programs for the duly eligible, for instance. But it has not been something that anyone has been willing to take on as a new concept for consideration.

Mr. LAZIO. In your experience, though, would you say that common sense would dictate that there would be a savings as people with disabilities go back to work.

Ms. RICHARDSON. Well, there certainly are going to be additional costs, and there are going to be additional savings that would be put into the successful, particularly if you really want to reach out and enable all of the people who could go to work through the Work Improvement Act. There will be other costs—

Mr. BILIRAKIS. The gentleman's time has expired. I also want to announce—what is our yearly budget here in the United States of America and in the Congress? But this machine is not working and the clock is not working.

So I am going to have to just estimate.

Ms. RICHARDSON. Are you Y2K compliant?

Mr. BILIRAKIS. I did want to announce that his honor the mayor is here. I understand there will be a series of votes when they finally finish up with the suspension that is on the floor right now. I would ask for brevity from the committee in terms of questioning Mrs. Richardson, because I think it would be a good idea if we

could hear the mayor's testimony before we break for the series of votes; otherwise, he is going to be cooling his heels for quite some time.

Ms. ESHOO. Mr. Chairman, can I just make a suggestion that, if any of us do have questions, that we have unanimous consent to submit them to Ms. Richardson?

Mr. BILIRAKIS. Well, I like that suggestion. Is there any objection to that?

Ms. ESHOO. Well, I'm asking for unanimous consent for that.

Mr. UPTON. May I get my tickets?

Mr. BILIRAKIS. Unanimous consent has been asked that all of the questions be forwarded to Mrs. Richardson in writing, and, of course, there will be other questions that may arise or we would ask at this point in time. The questions asked by Mr. Lazio are obviously very pertinent and very significant, and there will be others. Basically, what we are saying is, help us to be able to get this bill through as quickly as we can.

Ms. RICHARDSON. We are really—at HCFA, we are really, and the administration—really committed to getting this bill done. As much help as we can give you, we will.

Mr. BILIRAKIS. Great. Well, we are all looking forward to it. Thanks again so very much, Ms. Richardson, for being here today.

The Chair now will call upon Mayor Anthony Williams to come forward.

Mayor Williams served as the Chief Financial Officer for the District of Columbia from October 1995 to June 1998. He was appointed by former Mayor Marion Barry to assist the agencies and balance the city's budget. This put the District on a track for the return to self-government 2 years earlier than projected, and delivered a surplus of \$185 million in fiscal year 1997. Having stabilized the city's financial management, Mr. Williams resigned as CFO in June to run for mayor. As we know, he was most successful.

Mr. Williams brought extensive experience in management and strategic planning to his role as the District's independent CFO, and, of course, to his work now as mayor. Under his leadership, the District achieved significant improvement in case management, budget execution, and revenue collections.

He has a very impressive resume. He served in the United States Air Force. I, too, am an alumnus of the Air Force, sir. He holds a bachelor of arts degree in political science from Yale, where he graduated magna cum laude, a juris doctorate from Harvard Law School, and a master's degree in public policy from the Kennedy School of Government.

Mayor Williams, thank you so much for gracing this subcommittee with your presence. Please proceed to talk about the need for this legislation in your own words.

STATEMENT OF HON. ANTHONY A. WILLIAMS, MAYOR, DISTRICT OF COLUMBIA

Mr. WILLIAMS. Well, Mr. Chairman, and I also thank Chairman Bliley, and thank the members of the committee for allowing me to come up to the Hill and testify in support of H.R. 1180. I believe that this bill very much complements what we are trying to do in our city, which is to promote work and preserve the family, to build

community, and to show that by building community and supporting all in our city, and giving them a hand-up into fulfillment, we show that democracy can work in our city. And I do believe that the Work Incentives Improvement Act will serve as a major step forward for those members of our society and city who want to participate fully in the workforce, but simply need support to do so.

We face a challenge not like that of other jurisdictions. Although we've entered into a period of economic and financial recovery, too many of our citizens are being left behind. We believe that we will not have true economic recovery until we have extended the benefits of economic prosperity to all of our citizens, black and white, rich and poor, young and old, sick and healthy. One group that has fared worse than others are our disabled citizens, the overwhelming majority of whom want to join the workforce, but have, until this point, been faced with many disincentives. We have to do better by these citizens.

I believe that this legislation is in keeping with what we are trying to do here in the District, our Nation's capital. I want to get this city moving again, and to do that, we need to have all of our citizens onboard. As I have said many times, to really get our city moving, everyone has to be at work, out of the stands, doing color commentary, and down on the field. I think this legislation helps get everyone on the field, and helps everyone become a vital and active part of our economy. I also believe that it promotes work and helps people realize their true potential. It is about not giving up on people just because they have a disability. It is recognizing the contributions that every citizen can make.

I believe that it complements an initiative that we are undertaking in our city to provide healthcare insurance to 39,000 of our citizens who currently go without coverage. Much like those who will be positively affected by this act, these individuals, members of the working poor, are struggling to survive under difficult economic circumstances. They are working; they are often supporting families, but if they get sick, they face personal and financial ruin. By providing insurance and, very importantly, giving our citizens a choice of where they get their healthcare, we help them to attain financial security and personal fulfillment. Most importantly, we help them find true independence.

The District, like other jurisdictions across the country, is in the process of moving thousands of people off the welfare rolls. But simply moving someone off the welfare rolls is not an accomplishment if we have not put the infrastructure in place to move these citizens meaningfully and fully into the world of work. This means investing in job training, child care, and, yes, healthcare for disabled and working poor.

Now, I have often said that I am the product of the civil rights movement, the product of activist government, in a useful way, and the product of loving parents. I have been fortunate in life, but I would not be here today without the support of government programs that serve essentially as a hand-up in our climb toward personal fulfillment. I think this legislation is legislation that all Members of Congress can and should support. I thank the chairman for holding these hearings and taking the first step toward helping a segment of society that has been, for too long, overlooked,

and must not be ignored. So thank you, Mr. Chairman, and members of the committee, for offering this testimony to you.

[The prepared statement of Hon. Anthony A. Williams follows:]

PREPARED STATEMENT OF HON. ANTHONY WILLIAMS, MAYOR, DISTRICT OF COLUMBIA

Chairman Bliley, Subcommittee Chairman Bilirakis, Members of the Committee, thank you for the opportunity to testify before you today in support of HR 1180—The Work Incentives Improvement Act. This important legislation will serve as a major step forward for those members of our society who want to participate fully in the workforce but simply need support.

The District of Columbia faces a challenge not unlike that of other jurisdictions: although we have entered into a period of economic and financial recovery, too many of our citizens are being left behind. We will not have true economic recovery until we have extended the benefits of economic prosperity to all of our citizens—black and white, rich and poor, old and young, sick or healthy.

One group that has fared far worse than others are our disabled citizens, the overwhelming majority of whom want to join the workforce, but have until this point been faced with disincentives. We must do better by these citizens.

This legislation is in keeping with what we are trying to do here in the District of Columbia, our Nation's capitol. I want to get this city moving again. To do that, we need to have all of our citizens on board. We cannot afford to leave anyone on the sidelines.

This legislation promotes work and helps people realize their true potential. This legislation is about not giving up on people just because they have a disability. It is about recognizing the contributions each citizen can make.

This legislation will complement an initiative I am undertaking here in the District to provide insurance to 39,000 of our citizens who currently go without coverage. Much like those who will be positively affected by this act, these individuals, members of the working poor, are struggling to survive under difficult economic circumstances. They are working, often supporting families, but if they get sick, they face personal and financial ruin. By providing insurance, we help them to attain financial security and personal fulfillment. Most importantly, we help them find true independence.

The District, like other jurisdictions across the country, is in the process of moving thousands of people off the welfare rolls. But simply moving someone off the welfare rolls is not an accomplishment if we have not put the infrastructure in place to move these citizens into the world of work. That means investing in job training, child-care, and yes—health coverage for the disabled and working poor.

I have been fortunate in life, but I would not be where I am today without the support of government programs, such as this, that serve as essentially a hand-up in our climb toward personal fulfillment.

I think this is legislation all Members of Congress can support. I thank the Chairman for holding these hearings, and taking the first step toward helping a segment of our society that has been too long overlooked.

Mr. BILIRAKIS. Well, thank you, thank you so much. Your honor, I think that you probably have said it better than any of us could, in terms of proper philosophy—a Republican philosophy, a Democratic philosophy, really an American philosophy. We appreciate very much you being here, and it is going to be a big factor in our moving this legislation forth.

Mr. WILLIAMS. And I thank the chairman, and if the chairman or any members of the committee would like to submit written questions, or anything you would like to know about what we are doing in our city and how this legislation would be supported, we would be more than happy to provide—

Mr. BILIRAKIS. Well, without objection, questions might be afforded to you for response, which would be very helpful in the continuation of this legislation. I don't really want to cut anyone off, as far as asking any questions at this point in time.

Ms. ESHOO. You just did.

Mr. BILIRAKIS. But I did. Do you want to make your comment?

Ms. ESHOO. Just very quickly. Thank you for coming up to the Hill in support of this. You spoke eloquently to it, and we appreciate it. I just wanted to say, as a during-the-week resident in the District, I think you have passed your first major test. The roads were cleared when the snow fell. Thank you.

Mr. WILLIAMS. Thank you very much. I appreciate that, Congresswoman.

Mr. BILIRAKIS. Mayor, I was up here back in the early 1960's, as an engineer before my current life. I remember when it snowed then, everything froze, everything just died. I'm not sure that has changed very much. But I think there has been some improvement over the last couple years.

Mr. WILLIAMS. Thank you very much. Thank you all very much.

Mr. BILIRAKIS. Thank you very much for coming. Well, I guess I will introduce the next panel. It might be a good idea in the interest of time, and then we'll break. We have, as far as I know, three votes coming up; there may be four. So, you know, we're probably talking a good 40-45 minutes before all of those are disposed of. But, I'm going to introduce the next panel, although they are free, of course, after we recess, to walk around.

The next panel will consist of Mr. Jeff Bangsberg, Interim Public Policy Director for the Courage Center. Jeff is here from Minnesota. We heard him speak the other day, he is very eloquent, and we look forward to hearing from you again, Jeff. Mr. Tom Deeley, the CEO of Mark Hall, Vice President of Business Development, Fairfax Opportunities Unlimited, accompanied by Harold Deeley. Mary Gennaro, Director of Federal-State Relations, National Association of Developmental Disabilities Councils here in DC; Alan Bergman, President and CEO of the Brain Injury Association, here from Alexandria; Steven R. Cooley, Fellow with the American Board of Disability Analysts, from my area of Clearwater, Florida; Roger Auerbach, Administrator, Oregon Senior and Disabled Services Division. I know Roger is expecting us to inquire a little more in terms of why Oregon is the only State that seems to have taken advantage of the BBA 1997 language. And Mr. Craig Gray, Director of Services for Independent Living, UNUM Life Insurance, from Portland, Maine.

Ladies and gentleman, I would ask you—you now are officially the third panel, but we are going to recess until we finish up with those three, possibly four votes. Well, 4:15 or earlier, I'm going to ask members to get here right after those four votes. They're not voting until 4:15? See how things change up here?

I would ask the third panel to come forward at this time.

Mr. BRYANT. Mr. Chairman?

Mr. BILIRAKIS. Yes?

Mr. BRYANT. Do we have unanimous consent to submit—

Mr. BILIRAKIS. Yes, we've already done that, by all means.

Mr. BRYANT. Thank you.

Mr. LAZIO [presiding]. Again, good afternoon. Let me again thank the third panel for coming forward and for submitting and preparing testimony. All of that testimony will be included in the record by unanimous consent requested. Without objection, that is so ordered.

We're going to move first to hearing the testimony of Jeff Bangsberg. I want to welcome you, Jeff, and thank you again for your appearance and your eloquence at the press announcement. Without further delay, let me recognize you for your statement. You can summarize it, because, as I say, the rest of the written comments will be included in the record.

STATEMENTS OF T. JEFF BANGSBERG, INTERIM PUBLIC POLICY DIRECTOR, COURAGE CENTER; TOM DEELEY; HAROLD DEELEY, FATHER OF TOM DEELEY; MARY GENNARO, DIRECTOR OF FEDERAL-STATE RELATIONS, NATIONAL ASSOCIATION OF DEVELOPMENTAL DISABILITIES COUNCILS; ALLAN I. BERGMAN, PRESIDENT AND CEO, BRAIN INJURY ASSOCIATION; STEVEN R. COOLEY, FELLOW, AMERICAN BOARD OF DISABILITY ANALYSTS; ROGER AUERBACH, ADMINISTRATOR, OREGON SENIORS AND DISABLED SERVICES DIVISION; AND CRAIG E. GRAY, DIRECTOR, SERVICES FOR INDEPENDENT LIVING

Mr. BANGSBERG. Thank you, Mr. Chairman. It is my honor to be here today, and thank you for heading up this effort. Mr. Chairman, and members of the committee, my name is Jeff Bangsberg, and I am here on behalf of Minnesotans with disabilities, which includes the great Governor, Jesse Ventura.

It is no exaggeration that the Work Incentive Improvement Act of 1999 is as significant as the Americans with Disabilities Act. Thanks to the ADA, many people with disabilities are being offered jobs, but they cannot take advantage of those jobs, because barriers remain in the way. First and foremost is the loss of health coverage. Although employer-based insurance pays for acute and primary care, it generally does not cover specialized medications, personal assistant services, and other long-term care health needs.

Last spring, we conducted a survey on healthcare barriers to employment for people with disabilities in Minnesota. Almost 1,200 persons with disabilities completed this survey, and this survey is attached in the testimony that I have before you. The majority of the respondents indicated that they would go to work or increase their employment if their healthcare benefits were not affected.

Mr. LAZIO. Could you suspend for a minute? May I have some order, please, for Mr. Bangsberg? Thank you. You can continue.

Mr. BANGSBERG. In addition to worrying about healthcare, people with disabilities often face the prospect of losing cash assistance before they can earn enough to make up for the benefits they lose. In particular, the SSDI program's all-or-nothing approach leaves many people who go to work with less money than when they were unemployed.

Now let's talk about the complexity of the system as it exists today. People with disabilities who want to work are faced with a maze of complex, complicated government rules and regulations. Many people have college degrees, some of them are even rocket scientists, but nothing can prepare them to find their way through this particular bureaucracy. The beauty of the Work Incentives Act is that it takes a comprehensive approach in addressing all of these programs.

I would like to tell you about a few people in Minnesota who are being helped by this legislation. Tom is a young man in his early 30's who is paralyzed from the chest down, like I am. Tom was a pipefitter prior to his accident, and his employer is willing to retrain him. Tom cannot accept this offer because he needs costly personal care services that are available through the Medicaid program. Current regulations require him to impoverish himself to retain Medicaid. Tom lives in an apartment with the elderly, and hates being on public assistance, but he has no choice under the current system. According to Tom, being able to go back to work and make a living, as he was before his injury, would be the best medicine ever out there.

A woman named Deb is faced with some of the similar issues. Deb works and has been offered raises, but has been unable to take them. If her wages increased, her Medicaid would increase. Her rent, which is based on gross income, would also increase. After taxes, she ends up with less to live on than before her raise. She lives in subsidized housing because she can't afford market rate rent. She drives a 1979 van and cannot afford to replace it. Because of her Medicaid and the \$3,000 asset limit, she cannot participate in the matched savings retirement plan available through her employer.

Then there is Charles, a man with severe cerebral palsy, who developed an accounting partnership with another disabled individual. He would be more than happy to pay his fair share, if it was affordable to him, or as long as it is affordable to him.

On a personal level, I was only able to work my way off of Medicaid because I married a woman who was able to provide the personal care assistance that I need. Not everybody is that fortunate. Paying out of pocket for caregiving would cost me over \$30,000 a year. If my wife hurts her back doing transfers, or becomes ill, we would have to divorce, and I would once again have to impoverish myself to qualify for Medicaid.

Passage of the Work Incentives Act is both the right thing to do, and the fiscally responsible thing to do. It is important to remember that most people with severe disabilities who want to work already receive Medicare and Medicaid, so these costs are already incurred today.

There are a few other examples to the government if more people with disabilities are able to work. Acute and primary costs would be reduced for individuals on Medicaid and Medicare who get employer-based insurance. Social Security cash payments to people with disabilities would also decrease as they work their way off the benefits. Other programs, such as HUD and food stamps, would be reduced as well. Everybody benefits from removing policy barriers to employment. Employers also benefit from an extended pool of employees in a shrinking labor market. And under the Work Incentives Improvement Act, employers would not be expected to pick up more healthcare costs than they do for non-disabled employees.

Finally, taxpayers benefit as people with disabilities reduce their dependence on government programs. More people with disabilities will become taxpayers themselves. People with disabilities across the country are anxiously awaiting passage of the Work Incentives Act of 1999, so they can go back to work. Thank you very much.

[The prepared statement of T. Jeff Bangsberg follows:]

PREPARED STATEMENT OF T. JEFF BANGSBERG, MINNESOTA

My name is Jeff Bangsberg and I'm here on behalf of Minnesotans with disabilities. I represent Courage Center, a rehabilitation center headquartered in Minneapolis. I also serve as co-chair of the Work Incentives Committee of the Minnesota Consortium for Citizens with Disabilities (known as Minnesota CCD).

It is no exaggeration to say that the Work Incentives Improvement Act of 1999 is as significant as the Americans with Disabilities Act (ADA). Thanks to the ADA, many people with disabilities are being offered jobs, but they cannot take advantage of those jobs because barriers remain in their way.

First and foremost is the loss of health coverage. For some, employer-based coverage is unavailable because they are self-employed or because their disabilities prevent them from working full-time. For others, coverage may be unaffordable due to co-pays or co-insurance for repeated, ongoing treatments. For those who have affordable employer insurance, coverage is often inadequate. Although employer-based insurance pays for acute and primary care, it generally does not cover specialized medications, equipment and supplies, personal assistance services and other long term health needs.

Last spring, Minnesota CCD and the Minnesota Work Incentives Coalition conducted a survey on health care barriers to employment of people with disabilities. Almost twelve hundred persons with disabilities completed the survey. The majority of respondents indicated they would go to work or increase their employment if their health care benefits would not be affected.

In addition to worrying about health care, people with disabilities often face the prospect of losing cash assistance before they can earn enough to make up for the benefits they lose. In particular, the SSDI program's "all or nothing" approach leaves many people who go to work with less money than when they were unemployed. After a nine-month trial work period, someone who has an \$800 SSDI check will lose their whole check as soon as they earn \$501 dollars per month. The ability to deduct work-related expenses may cushion the blow, but for many, the figures simply don't compute.

Now let's talk about the complexity of the system as it exists today. People with disabilities who want to work are faced with a maze of complicated, government rules and regulations, as well as a barrage of acronyms and incomprehensible terms. You've got your TWP, your EPE, your SGA, your FBR and your IRWE's. Then, you've got your MA spenddowns, your 1619(b) thresholds, your Pickles and your Iamarino's. Many people with disabilities have college degrees—some of them are even rocket scientists—but nothing can prepare them for trying to find their way through the bureaucracy.

The beauty of the Work Incentives Improvement Act is that it takes a comprehensive approach in addressing all of these problems. I'd like to tell you about a few of the people in Minnesota who would be helped by this legislation:

Tom is a young man in his early thirties who is paralyzed from the chest down like I am. Tom was a pipefitter prior to his accident. His employer is willing to re-train him to do computer-aided drafting or dispatching. Tom cannot accept this offer because he needs costly personal assistance services that are only available through the Medicaid program. Current regulations require him to impoverish himself to retain Medicaid. The more he earns, the more he has to give back to the government. Tom lives in an apartment building for the elderly and hates being on public assistance, but he has no choice under the current system. According to Tom: "Being able to go back to work and make a living as I was before my injury would be the best medicine ever out there."

A woman named Deb is faced with the same issues. Deb works and has been offered raises, but is unable to accept them. In Deb's words: "If my wages increased, my Medicaid spenddown, which is based on gross income, would increase. My rent which is also based on gross income, would increase. After taxes, you end up with less to live on than before your raise... I had been taught growing up that the American Dream was to work hard, get ahead, and make a better life for yourself. But the financial disincentives for working people with disabilities make that impossible. I cannot strive for what everyone else wants out of life. I cannot afford to have a house of my own. I live in subsidized housing because I cannot afford market rate rent. I drive a 1979 van that I cannot afford to replace. I couldn't afford car payments or an increase in automobile insurance. Because of my Medicaid spenddown and the \$3000 asset limit, I cannot participate in the matched savings retirement plan available through my employer. I want financial security for my retirement years."

Then, there's Charles, a man with severe cerebral palsy who developed an accounting partnership with another disabled individual. They landed a significant contract with a local school district, but can't keep much of what they earn. Charles asks: "I was under the impression that the state wanted everyone to work their way off of assistance. But, how can one do so, when the laws are this way, and by the time all of the bills are paid, we are so broke we barely have enough to buy groceries? I would be more than happy to pay my share as long as it remains a reasonable and livable amount a month."

On a personal level, I was only able to work my way off of Medicaid because I married a woman who is able to provide most of the personal care assistance I need. Not everybody is that fortunate. Paying out of pocket for my caregiving would cost over \$30,000 per year. If my wife hurts her back or becomes ill, we would have to divorce and I would once again have to impoverish myself to qualify for Medicaid.

Passage of the Work Incentives Improvement Act is both the right thing to do and the fiscally responsible thing to do. It is important to remember that most people with severe disabilities who want to return to work already receive Medicaid and Medicare, so these costs are already being incurred.

Here are a few examples of potential savings to the government if more people with disabilities are able to work:

- Acute and primary care costs will be reduced for every individual on Medicaid or Medicare who gains employer-based insurance.
- Social Security cash payments to persons with disabilities will also decrease, as individuals work their way off those benefits.
- Other federal expenditures will decline as people with disabilities move off of programs such as Food Stamps and HUD-subsidized housing.

Everyone benefits from removing policy barriers to employment. People with disabilities will no longer be forced into poverty to secure the long term health coverage they need. Employers also benefit from an expanded pool of employees in a shrinking labor market. Under the Work Incentives Improvement Act, employers would not be expected to pick up more health care costs than they do for non-disabled employees.

Finally, taxpayers benefit as people with disabilities reduce their dependence on government programs. More people with disabilities will become taxpayers themselves.

People with disabilities across the country are anxiously awaiting the passage of the Work Incentives Improvement Act of 1999 so they can go to work. Congress can't afford not to pass the Work Incentives Improvement Act this year. Thank you.

Mr. LAZIO. Thank you very much, Jeff. And a special thanks also to your Congressman, Jeff Ramstad, for his hard work in moving this bill forward.

Mr. BROWN. Mr, Chairman, for a moment?

Mr. LAZIO. Yes?

Mr. BROWN. Can I ask unanimous consent for—because these two panels were combined—that we would get two rounds of questions if we break for a vote? So people know when they come back, that we would, if there was unanimous consent, that we would get a second round of questions?

Mr. LAZIO. Yes, I think, without objection, as long as members wish to ask additional questions, and unless anybody's got a particular time problem, we will try to accommodate that—if one of the witnesses' have a time problem—but barring that, that is so ordered.

Let me now turn to Tom Deeley, who is accompanied by his father, Harold Deeley, and thank them very much for their commitment in being here. Without any further delay, let me recognize both Mr. Deeleys.

STATEMENT OF HAROLD DEELEY

Mr. HAROLD DEELEY. Thank you, Mr. Chairman, and the other members of the committee. My name is Hal Deeley. I am 73 years old, and I am a former United States naval officer and a former

government patent attorney. I live in Annandale, Virginia, with my wife, Sally, and our two sons, Tom, age 39, who is seated here besides me, and Joe, age 34. Tom and I are here today as a team, to express our support for H.R. 1180, the Work Incentives Improvement Act, that is now being considered by this committee. Our goal is to briefly tell you that, based on our own life experience, working within the Social Security Disability Income, SSDI, system, we believe that this Act contains many needed improvements and deserves passage in the 106th Congress.

We are here today to urge you to support this legislation, which will enable individuals with disabilities to improve their employment status while maintaining needed healthcare benefits that are not otherwise available. How will Tom be impacted by the passage of the Work Incentives Act? First, Tom is developmentally disabled, which is a more appropriate term for those who, in the past, have been characterized as mentally retarded. Today, if an individual with a developmental disability works and earns enough to reach the "gainful employment" income level, that worker will lose eligibility for SSDI health benefits. That level is now set at only \$500 per month. Because of the low income restrictions that are now in place, most recipients of SSDI benefits are forced to work part-time and remain underemployed. This is certainly true for my son. Under the current SSDI system, the benefits of working full-time, earning full-time wages, and becoming fully productive members of society are lost to many with developmental disabilities, because of the potential to lose needed healthcare benefits.

The country also loses the benefit of including many individuals into the full-time workforce that could become productive taxpayers as well. Loss of healthcare benefits could cause catastrophic consequences for many individuals with developmental disabilities, and their families across America. This is the case with my son. Tom now holds a part-time job working at a Javits-Wagner-O'Day program performing custodial services at the Defense Logistics Agency at Fort Belvoir, Virginia. Tom is limited to working 2 days a week because of the income limitations under SSDI, that, if violated, will have an adverse impact on his health benefits. While working at the DLA, Tom is fortunate to receive job supports from Fairfax Opportunities Unlimited, a community rehabilitation service provider, headquartered in Alexandria. I am also affiliated with Fairfax Opportunities as a volunteer member of the company's board of directors.

Many who know Tom will tell you that he is a hard worker who is very eager to work full-time. Tom has been the recipient of his company's employee of the year award for his work at the DLA. When Tom was recently offered a cash award of \$200 for his work performance, he was forced to consider an alternative award because of the impact of additional earnings. Of course, Tom cannot accept a pay raise, because it would place him over the income threshold to retain his current health benefits. I hope that you will agree with me that this would be a tremendous disincentive for any American in similar circumstances who wants to work to better himself. I think it is also important to note that his supervisor at the Defense Logistics Agency is also very eager for Tom to come to

work full-time, and is disappointed that he can't because of the limitations of the current system.

As a family, we are concerned that if Tom lost his SSDI benefits, and then were to face a job reduction or loss, he would face great difficulty in recovering the needed long-term healthcare benefits that can be provided through Medicare, supplemental income, and necessary job supports.

A developmental disability is a life-long condition. A person does not recover, get better, or get over it. Unfortunately, the SSDI system often assumes that they will. The threat of the loss in healthcare benefits is a major risk that we cannot ignore. Over the long-term, our family cannot afford to place Tom's employment needs at a higher premium than his healthcare needs.

Earlier I mentioned my age, because, like me, many parents of the developmentally disabled are senior citizens, and their adult children are often heavily dependent on their parents for assistance and support. Most, if not all of us, continue to worry about the long-term outcomes for our children as long as we live. The provisions for Medicare coverage that are included in this legislation will help provide my wife and me with an improved peace of mind, and Tom with the benefits of increased work incentives, and the opportunity for improving his employment status.

Finally, in my role as a board member of Fairfax Opportunities Unlimited, I am aware of a recent survey that FOU conducted of 79 individuals who receive similar benefits to my son, and are employed by the company part-time. Of that group, 63 percent expressed interest in working full-time if their eligibility for healthcare and job support benefits could be maintained. I think that this sample does help to illustrate that this bill, which is now under your consideration, will positively impact many that want to work, and want to work full-time.

Now, as the second part of our team presentation, I would like to ask Tom to say just a few words about what it means to him to work as a productive American citizen.

[The prepared statement of Harold Deeley follows:]

PREPARED STATEMENT OF HAROLD AND TOM DEELEY

Thank you Mr. Chairman and the other members of the Committee.

My name is Hal Deeley. I am 73 years old and I am a former United States Navy officer and retired federal government patent attorney. I live in Annandale, Virginia, with my wife, Sally, and our two sons—Tom, age 39, who is seated beside me, and Joe, age 34.

Tom and I are here today as a team to express our support for H.R. 1180, the Work Incentives Improvement Act that is now being considered by this Committee. Our goal is to briefly tell you that based on our own life experience working within the Social Security Disability Income (SSDI) system, we believe that this Act contains many needed improvements and deserves passage in the 106th Congress. We are here today to urge you to support this legislation which will enable individuals with disabilities to improve their employment status while maintaining needed health care benefits that are not otherwise available.

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Because of the low-income restrictions that are now in place, most recipients of SSDI benefits are forced to work part-time and remain under-employed. This is cer-

tainly true for my son. Under the current SSDI system, the benefits of working full-time, earning full-time wages and becoming fully productive members of society are lost to many with developmental disabilities because of the potential to lose needed health care benefits. The country also loses the benefit of including many individuals into the full-time work force that could become productive taxpayers as well. Loss of health care benefits could cause catastrophic consequences for many individuals with developmental disabilities and their families across America.

This is the case with my son. Tom now holds a part-time job working on a Javits-Wagner-O'Day program performing custodial services at the Defense Logistics Agency at Fort Belvoir, Virginia. Tom is limited to working two days a week because of the income limitations under SSDI that if violated, will have an adverse impact on his health benefits. While working at the DLA, Tom is fortunate to receive job supports from Fairfax Opportunities Unlimited, a community rehabilitation service provider headquartered in Alexandria. I am also affiliated with Fairfax Opportunities as a volunteer member of the company's Board of Directors.

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As a family, we are concerned that if Tom lost his SSDI benefits and then were to face a job reduction or loss, he would face great difficulty in recovering the needed long-term health care benefits that can be provided through Medicare, supplemental income and necessary job supports. A developmental disability is a life-long condition; a person does not "recover," "get better," or "get-over-it." Unfortunately the SSDI system often assumes that they will. The threat of a loss in health care benefits is a major risk that we cannot ignore. Over the long-term, our family cannot afford to place Tom's employment needs at a higher premium than his health care needs.

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Now, as the second part of our team presentation, I would like to ask Tom to say just a few words about what it means to him to work as a productive American citizen. Thank you.

STATEMENT OF TOM DEELEY

Mr. TOM DEELEY. I would like to work 5 days a week.

Mr. HAROLD DEELEY. Short, but sweet.

Mr. LAZIO. I want to thank you both very much. Tom, you must be a terrific employee and a real star.

Mr. HAROLD DEELEY. He is, believe me.

Mr. LAZIO. And now I'd like to turn now to Mary Gennaro, who is the Director of Federal-State Relations at the National Association of Developmental Disabilities Councils. I want to thank you for your attendance and your preparation of testimony, and now I'll turn and recognize you. Good to see you.

STATEMENT OF MARY GENNARO

Ms. GENNARO. Thank you, Representative Lazio, and members of the subcommittee, for the opportunity to testify. I have had cerebral palsy since birth. I once received SSI benefits, and I am now employed. I am anxious for enactment of the Work Incentives Improvement Act, because I believe it will help more people with disabilities to work. With about 75 percent of people with disabilities not employed, one of the Nation's largest minorities without jobs, we are needlessly wasting vital, irreplaceable human potential.

Major barriers stand in the way of people with disabilities who want to work. Some of these are: lack of access to vocation and rehabilitation and employment services and supports, and lack of choice regarding these services and providers; lack of access to healthcare coverage; financial disincentives, and complex rules regarding what happens to beneficiaries who work. By giving people with disabilities choice, the ticket program included in H.R. 1180 will increase access to VR and employment services and supports. It will help more people with disabilities to work. It moves us a step closer, but unless it removes the fear that people will continue to have regarding loss of healthcare benefits, it will not do what it promises to do.

Healthcare coverage is the key. Current policies must change so that people with disabilities are no longer forced to choose between healthcare and work. People with developmental and other disabilities may have part-time work, or low-wage work, where private insurance is not available. If it is, it may be too costly given their earnings, or maybe simply inadequate to meet the needs that they have for healthcare. I have seen people struggle with the difficult choices in the current system. I have seen people held back, unable to fulfill their potential. Government policies intended to help people have too often served as traps, rather than tools, for empowerment, and we are anxious to see that change.

The Work Incentives Improvement Act would address that in a variety of ways. It provides for continued Medicare coverage for DI beneficiaries who work, and this is not a matter of adding new people to the program, which has been already pointed out, but of continuing benefits, continuing coverage for people who have been able to work their way off of cash benefits. It allows people to make the choice for work. By giving States the option to offer Medicaid buy-ins to people with disabilities who earn over 250 percent of poverty, and allowing States to increase the assets and resource limits, H.R. 1180 will help people to work to their potential. People with disabilities need to be assured that they will not lose access to the critical therapies they need, personal care, prescription drugs, and other supports and services that are often vital to their ability to work in the first place. The State options contained in the bill will assist and encourage States to address this need. States will be able to help people with disabilities who are employed to stay employed. And the State and infrastructure grants will be able to assist and encourage States to offer personal assistant services. Lack of these services is often the major barrier to employment for people with disabilities, particularly people with developmental disabilities.

As you know, the bill also provides important beneficiary protections, work incentives, planning and assistance in outreach provisions, and demonstration projects that will address other major barriers to work. It does not address all the issues, no bill could, but it addresses the critical, essential elements necessary to bring us a step closer in positively changing the current environment. It is an important step in removing barriers to work for people with disabilities. And what it can do is help to erase prejudice and shatter myth about our abilities to contribute in the workplace, and in every area of life. People with disabilities are encouraged by your support and are looking forward to swift, bipartisan passage of this bill.

[The prepared statement of Mary Gennaro follows:]

PREPARED STATEMENT OF MARY GENNARO, DIRECTOR OF FEDERAL-STATE RELATIONS,
NATIONAL ASSOCIATION OF DEVELOPMENTAL DISABILITIES COUNCILS

Chairman Bilirakis, Members of the Subcommittee on Health and Environment, thank you for the opportunity to testify on the Work Incentives Improvement Act of 1999. I am Mary Gennaro, Director of Federal-State Relations of the National Association of Developmental Disabilities Councils. I am also a person with a disability, namely cerebral palsy, which limits my mobility and therefore, my employment options.

NADDCC is a national organization representing Developmental Disabilities Councils that work for change on behalf of people with developmental disabilities and their families. It promotes a national policy to enhance the quality of life for all people with developmental disabilities. A developmental disability is generally, defined as a severe, chronic disability which occurs in an individual before the age of 22 and results in substantial functional limitation in three or more of the following areas of major life activity: self-care; receptive and expressive language; learning; mobility; self-direction; capacity for independent living; and economic self-sufficiency.

Developmental Disabilities Councils exist in every State as well as in the District of Columbia, and the territories of America Samoa, the Commonwealth of the Northern Mariana Islands, Guam and Puerto Rico. Councils have been established pursuant to "The Developmental Disabilities Assistance and Bill of Rights Act." The purpose of the Councils in each State is "to promote, through systemic change, capacity building, and advocacy activities—the development of a consumer and family-centered, comprehensive system and a coordinated array of culturally competent services, supports and other assistance designed to achieve independence, productivity, and integration and inclusion into the community for individuals with developmental disabilities." In recognition of a great need for improvement and change the only federal priority area "The Developmental Disabilities Assistance and Bill of Rights Act" requires the Councils must focus their work on is employment.

The Problem

The Presidential Task Force on Employment of Adults with Disabilities indicates in its first report "Re-charting the Course," that about 70% of adults with severe disabilities are not employed—one of the largest minorities in the nation without jobs.¹ The time to take action to address this problem is now. When our nation's economy is flourishing and unemployment rates are at all time lows we must take serious steps to begin to break down the barriers preventing people with disabilities from working. This would save taxpayers money, but more importantly it would begin to allow people with disabilities to more fully contribute their talents to the community.

People with disabilities want to work. A 1998 Harris poll found that seven out of ten (72%) of people with disabilities age 16—64 who are not employed say they would prefer to be working.² Disability benefits provide a critical safety net to millions of people with disabilities. The latest figures from SSA indicate there are 4.7 million individuals receiving Social Security disability benefits as disabled workers, 700,000 as disabled adult children, 200,000 as disabled widows and widowers; and

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

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

there are 3.7 million individuals with disabilities, aged 18-64 receiving Supplemental Security Income benefits (SSI). Some Social Security Disability Insurance (SSDI) beneficiaries and SSI beneficiaries are simply unable to work because of their impairments. Some are very seriously ill, others have terminal illness. Other people receiving benefits have work potential and want to work to the maximum extent of their abilities, but barriers prevent all but a few from working. If enacted the "Work Incentives Improvement Act of 1999" will take a significant step forward in removing some of these barriers.

Barriers to Employment for People with Disabilities

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

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

Removing these barriers will assist many people with disabilities who can work to work. Some will be able to achieve economic self-sufficiency; others will earn enough to move off of benefits, but will require some ongoing support such as health care, personal assistance, and housing subsidies. Still others will work to their maximum potential and continue to need both some cash assistance as well as other supports. For instance, over 150,000 people with very significant disabilities have gone to work since supported employment was added to the Rehabilitation Act in 1986, those with the most significant disabilities are unable to move completely off benefits, but they are given a chance to work to their potential. Many other people with disabilities would benefit from removal of barriers to employment.

Barrier: Lack of Consumer Access to and Choice of Vocational Rehabilitation and Employment Services and Providers

The "Work Incentives Improvement Act of 1999" recognizes the need to improve access to vocational rehabilitation and employment services and to allow consumers to choose their own providers and services as they attempt to return to work or work for the first time. Few beneficiaries of SSDI/SSI are referred for vocational rehabilitation, and fewer return to work because of these services. The Congressional Budget Office (CBO) has estimated that about 10 to 15 percent of new SSDI and SSI beneficiaries are referred to State Vocational Rehabilitation (VR) agencies, and about 10 percent of those referred are accepted for services. 1998 data from the Social Security Administration (SSA) indicates that last year 9,950 SSDI or SSI beneficiaries moved off of disability benefits into employment due to SSA funded VR services. During that time about 4.8 million disabled workers received monthly SSDI benefits, and about 3.6 million individuals with disabilities, aged 18-64 received SSI benefits. Providing beneficiaries with a "ticket" and allowing them to choose their own provider and services will enable more people to get the services and supports they need to work.

Establishment of a "Ticket" Program

NADDC believes that by establishing a Ticket to Work and Self-Sufficiency Program the "Work Incentives Improvement Act of 1999" will improve access to services, improve the services and supports people with disabilities receive and improve the results of those services and supports—helping more people with disabilities to work. In overwhelmingly passing H.R. 3433, the "Ticket to Work and Self-Sufficiency Act," by a vote of 410 to 1 in the 105th Congress, members of the House have shown they understand the need for and benefits of expanded access to and choice of services and providers. Giving beneficiaries control over the rehabilitation process will assist them in their efforts to succeed and will spur providers to improve services. Beneficiaries must have the choice to obtain the services they need whether provided by VR, private providers, or a combination of both. Choice is important for all people with disabilities, some may need assistance in exercising choice and such assistance must be easily available through out the rehabilitation process.

H.R. 1180 will improve outcomes. Inclusion of milestone payments as well as outcome payments is critical. Milestone payments will allow more qualified providers to participate in the ticket program and assist providers in providing services to people who may be harder to serve. Extending payments over a 60-month period will also allow providers to offer continued supports and services beyond initial employment. People with disabilities often need vocational and employment services and supports to assist them in maintaining employment and dealing with changed circumstances on the job or related to their disability. The ticket should encourage work by all SSDI/SSI beneficiaries, regardless of their ultimate work capacity. In-

stead of rewarding providers only for removing people from the rolls, it should reward providers for assisting people to minimize their dependency on cash assistance programs. Paying providers a portion of the savings realized by the federal government will enable many more people to work to their full capacity resulting in greater savings than only paying for those attaining SGA. Payments should be made on a milestone/outcome approach. Finally, an Advisory Commission will be important to the success of the "ticket" program as well as the other work incentive provisions of the "Work Incentives Improvement Act of 1999."

Barrier: Access to Health Care Coverage

Access to health coverage is increasingly cited as the key obstacle to employment. People fear losing medical benefits that can mean the difference between life and death. A "ticket to work" program will go a long way in addressing some of the major barriers to employment, but if lack of access to health care benefits is not addressed, the "ticket" program will fail. Until they can be assured that working will not threaten their ability to receive necessary health care services, SSDI/SSI beneficiaries will not be able to take advantage of what a "ticket" program could offer. Without provisions that will allow sufficient access to health coverage, a ticket program will only create the illusion of adequately addressing barriers to employment for people with disabilities.

Medicare—SSDI beneficiaries who become employed need to know that in doing so they will not lose Medicare coverage. Currently SSDI beneficiaries are eligible for Medicare benefits 24 months after becoming eligible for cash benefits. They receive Hospital Insurance (Part A) and Supplementary Medical Insurance (Part B). (Part B is voluntary, but virtually all Part A beneficiaries enroll in Part B.) The Part B premium of \$45.50 is deducted from the individual's benefit check. The average monthly cash benefit is \$733. Many people with developmental disabilities receive Social Security benefits as adult dependents of their parents, who have retired, become disabled, or died. To qualify based upon a parent's work history, the adult "child" must have become disabled prior to the age of 22. In addition, many people with developmental disabilities have, through years of sheltered, supported, or competitive work, earn their own disabled worker's insurance coverage. (Note: Since the eligibility criteria and work incentive provisions of the disability insurance program are applied to all of these categories of adults, the term SSDI (Social Security Disability Insurance) is often used, and is used here, to encompass all of the Title II disability programs, even though it is technically incorrect to use it as a term encompassing all categories of adults who may be receiving disability insurance benefits.)

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

People with developmental and other disabilities lose Medicare when they may be earning as little as \$500 a month. Yet their need for health care coverage continues unchanged. People may be working to their fullest potential at a part-time job, or at a full-time job with limited earnings in which health care coverage is not offered or if offered is too costly given their income. Or private insurance is not available or adequate. These circumstances force beneficiaries to choose between critical health care and a job. Only one choice is possible and they, by consequence, remain trapped on benefits.

Many SSDI beneficiaries find they need Medicaid to supplement their Medicare coverage and to cover the cost of Medicare premiums, deductibles, and cost sharing requirements. Medicare does not cover prescription drugs, non-medical personal care or personal assistance services. Many people with disabilities need these critical and

sometimes commercially unavailable benefits. The personal care received by a person with severe cerebral palsy, enabling them to bathe, eat, dress and accomplish other activities of daily living can be the very thing which makes employment possible. Medicaid covers personal care services, which is not available through Medicare or private insurance, but needing to meet the income and asset limits of Medicaid buy-ins acts as another disincentive to work.

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

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

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

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

Private Insurance—For many reasons employer based or private insurance will not adequately meet the needs of people with disabilities. Employers may not offer a group plan, or the cost of the group plan offered may be too expensive given the person's income. This is especially true in part-time or low-income jobs in which many SSDI beneficiaries and SSI recipients are likely to be employed. Furthermore, if insurance is offered, the benefit package may be limited, failing to cover many of the items, services and supports needed by many people with disabilities, such as coverage of prescription drugs, mental health services, durable medical equipment, assistive technology, physical, occupational and speech/hearing/ language therapies and personal assistance services. Additionally, people with severe disabilities may have difficulty accessing covered services because the insurer uses a narrow definition of medical necessity, limiting services to those which restore health, and not covering services which maintain function and/or prevent deterioration or loss of function. Also of concern is a recent Harris Poll finding that: "Among adults with disabilities who are not covered by health insurance, one in five (18%) were not able to get insurance because of a disability or preexisting health condition."³

Private insurance also does not offer personal assistance services, a critical need for many people with developmental and other disabilities. Personal assistance services refer to a range of services, provided by one or more persons or devices, to assist an individual with a disability to perform daily activities on or off the job, which

³National Organization on Disability/Louis Harris Survey, conducted April and May of 1998.

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

Providing Access to Health Care Coverage

H.R. 1180 addresses the very real concerns SSDI beneficiaries have regarding loss of Medicare coverage when they work. For a ten-year trial period it would allow SSDI beneficiaries who work to continue to receive Part A coverage. It recognizes that the current extended eligibility for Medicare and the Medicare buy-in are simply insufficient to address the needs of beneficiaries. Coverage for Medicare must be extended without an arbitrary cut off after a certain number of years. This continuation of Medicare does not add new people to the program; rather it maintains benefits for beneficiaries who have been able to move off cash benefits. It saves the government money, and frees people with disabilities to work secure in the knowledge that doing so will not jeopardizing their life or health.

By giving states the option to offer a Medicaid buy-in to people with disabilities who earn above 250 percent of poverty and allowing states to increase the assets and resource limits under which people can receive Medicaid, H.R. 1180 will remove a significant barrier to employment. People with developmental and other disabilities will not have to worry that increased earnings will mean the loss of health care, personal care, prescription drugs or other necessary items or services covered by Medicaid.

The "Work Incentives Improvement Act of 1999" will help people with disabilities who are employed to stay employed by giving states the option to continue Medicaid coverage for individuals whom SSA has found to have medically improved. This would allow people who continue to have a disability and are employed and have lost benefits due to medical improvement, to continue to receive coverage. Critical health care, such as prescription drugs, personal care, and other supports and services that enabled their medical improvement and thus their employment could continue. If these individuals are not able to obtain coverage for these services and supports they will not be able to work and therefore, need cash assistance as well as Medicaid. H.R. 1180 also includes an important demonstration program which would allow states to provide medical assistance to workers who have a disability and who without health care and the services and supports covered by Medicaid would likely become eligible for SSDI and/or SSI. This will help prevent the need for cash assistance.

H.R. 1180 will support and encourage states to develop systems to provide the items, services and supports people with disabilities need in order to work. Infrastructure grants will assist people with disabilities to work by encouraging states to cover personal assistance services under Medicaid. Lack of personal assistance services often is major barrier to employment for people developmental and other disabilities. Yet the availability of these services is limited. Currently, only 31 states offer the more limited personal care option through Medicaid.

Barrier: Financial Disincentives

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

Beginning to Address the Financial Disincentive Faced by SSDI Beneficiaries

The SSDI program should allow for a gradual reduction of benefits as earnings increase, similar to the SSI program. This would help alleviate the financial disincentive currently faced by SSDI beneficiaries who want to work. The "Work Incentives Improvement Act of 1999" begins to address this by requiring SSA to conduct a demonstration project under which SSDI benefits would be reduced by \$1 for every \$2 earned above a certain level. This demonstration would also allow informa-

tion to be gathered regarding payment for reduction of benefits in the “ticket” program.

NADDC also supports language in H.R. 1180 calling for the General Accounting Office to evaluate the coordination of work incentives for individuals eligible for both SSDI and SSI. Disabled adult children who receive both SSDI and SSI can experience great difficulties due to the different work incentives in these programs. When they become eligible for SSDI due to their parent’s retirement, disability or death, this increase in unearned income can lead to the loss of SSI and Medicaid and act as a disincentive to work. A person with a severe disability who needs some level of life-long support can’t afford to work or continue to work unless potential income is high enough to skip over the “income cliff” in the SSDI program.

Barrier: Work Incentives are Complex and Can Hinder Work Attempts

Work incentives are often complex and difficult to understand and it can be very difficult to get dependable, accurate information regarding them. Given the risks that people with disabilities face (loss of health benefits, loss of cash assistance, loss of other income based assistance) when attempting to work, SSDI/SSI beneficiaries often fear using work incentives. They fear overpayments, knowing that others with disabilities have been surprised by overpayments of thousands to tens of thousands of dollars, even when they had reported their earnings to SSA. They fear that a work attempt will lead to a review of their disability and put their eligibility for benefits in jeopardy. They fear that if they fail at their attempt, or if they become unable to work, but continue to have a disability they won’t be able to reestablish their eligibility for benefits. Individuals need information, advice, advocacy and other supports and services in order to benefit from work incentives and other programs designed to assist them in securing or reentering employment.

Protecting Beneficiaries and Helping Them to Use Work Incentives

It is critical that beneficiaries be able to use work incentives without fear of losing necessary support. They must be able to risk the failure that often occurs before success. They must be able to try in order to succeed. The “Work Incentives Improvement Act of 1999” assures that continuing disability reviews will not be scheduled solely because of work activity. It also provides that work activity by a person with a disability will not be used as evidence that he/she no longer has a disability. Further, it provides for expedited reinstatement of benefits when a person who continues to meet SSA’s standards for disability, finds him or herself unable to work.

The work incentives planning, assistance and outreach provisions of H.R. 1180 are necessary elements in a comprehensive plan to remove barriers to employment for people with disabilities. Community based outreach will help assure that people with disabilities receive the information and assistance they need to make the informed choices necessary to prepare for, secure, maintain and advance in employment, while at the same time accessing or maintaining access to necessary health care and other supports and services. Requiring SSA to make a greater commitment within its own program to have trained, knowledgeable and accessible work incentive specialists will also help beneficiaries to successfully use work incentives. It will enable SSDI/SSI beneficiaries as well as community-based planners to obtain reliable information and assistance. H.R. 1180 recognizes the importance of giving SSDI/SSI beneficiaries access to protection and advocacy services. This will assist people with a variety of issues and difficulties, which can arise as they navigate through a new way of assisting people with severe disabilities to work. If such assistance is not available people with disabilities will not be able to fully take advantage of the “ticket” and work incentives.

An Opportunity for Change

The “Work Incentives Improvement Act of 1999” would be a great step forward in assisting people with disabilities to move into employment and reduce their dependence on benefits and other assistance. It does not address all issues, no bill could. It addresses critical elements necessary to bring positive change, while balancing the concerns of key stakeholders, taking an important step forward to remove barriers to employment for people with disabilities.

NADDC believes that as we move forward and break down barriers to employment for people with disabilities we will also promote the independence, productivity, and integration and inclusion into the community of people with developmental disabilities and other disabilities. Enacting the “Work Incentives Improvement Act of 1999” will assist in continuing efforts to erase prejudice and shatter myths about the ability of people with disabilities to contribute in the workforce and in every area of life. Thank you for introducing this important legislation, we encourage it

enactment. We must not pass up the tremendous opportunity we have to begin breaking down barriers and changing lives for the better.

Mr. LAZIO. Thank you very much.

The next individual to testify is Allan Bergman, and I welcome you to the committee. Mr. Bergman is the President and CEO of the Brain Injury Association. I now recognize you for your statement. Thank you for being here.

STATEMENT OF ALLAN I. BERGMAN

Mr. BERGMAN. Thank you, Mr. Chairman. Members of the committee, I am Alan Bergman, President and CEO of the Brain Injury Association. I am also Deanna Bergman's father, a daughter with disabilities of 34 years, and Mindy Pearlman's stepdad, a young woman of 27 years with disabilities. So I've sort of walked all sides of this system, professionally and personally, for a number of years. In the world of traumatic brain injury.

I'm sorry to report to you, we are adding to the long-term disabilities rolls at about 90,000 individuals per year. There are now about 5.1 million children and adults with long-term severe disability from traumatic brain injury, and we all are potentially members of that club at any given moment, as a newspaper reporter mentioned to me very recently, potentially a car crash or a banana peel slip away, and many of these folks do end up on the SSI or the SSDI rolls.

What I'd like to do in the few minutes in the oral testimony is look globally at what we've been discussing here today, which is the major disconnect between national disability civil rights policy, as referred to in the Americans with Disabilities Act, and our Federal disability employment policy, which is nested in SSI and SSDI, going back to 1956 and 1972 when people like Jeff and Mary were seen in a very different light and were, very frankly, looked at by the Federal Government as eternally dependent.

I think you have a flavor for what is going on here. We have a revolution in the world of disability in terms of what the opportunities now really can be, not in theory, but in practical life. People with disabilities do want to work. They are capable of working. You've heard about the technology; there is also job accommodation, job restructuring, job sharing. We have all kinds of techniques, but the real issue, as my colleague, Tony Young, said a couple of years ago, is we need a Federal policy that makes work pay for people with disabilities and stops punishing people with disabilities for wanting to contribute to American society.

That is what this piece of legislation begins to do, and we move from paternalism and maternalism and dependency to a policy that talks about economics, empowerment, contribution, and independence. Yet, with the best of intentions, over 8 million working-age adults with severe disabilities are not benefiting from the booming economy or the lowest unemployment rates in our history. Something is clearly wrong, and this bill begins to address it.

You have heard of the Harris Poll, referred to by several members earlier. Let me give you the healthcare data within that same Harris Poll. Among those people with disabilities who are insured, 32 percent say they have special needs because of their disability, such as therapies, equipment, or prescription drugs, not covered by

the employer-based health insurance. These are folks who are working, who are paying a price in order to stay employed. Among adults with disabilities not covered by health insurance, 18 percent were not able to get insurance because of a disability or pre-existing health condition, in spite of the enactment of the Health Insurance Portability and Accountability Act, another disconnect with a well-intended policy to break down the barriers. So, we've still got lots of things to deal with.

Most people with disabilities are not going to be employed by Fortune 500 companies or the government. They are going to be employed, as you know, by the engines of this economy, small business, medium-size business, where most of the jobs are being created. And in those situations, as you've heard, the employer doesn't offer a group plan; the premium is very high in relation to the person's salary; the benefit package is very restricted or limited, and certainly doesn't offer personal assistant services, because none of them do, and, in addition, we often face a rigid definition of medical necessity, having to do with only restoration and not maintenance of function. So, those things continue to be barriers in the commercial market.

So, continuous, affordable access to Medicare or Medicaid is absolutely essential if we want to assure equal opportunity for people with disabilities to join the workforce using Medicaid and/or Medicare as a wrap-around to the benefits, if they are provided. So, the time is now, and we have to move from the 1960's when severe disabilities was a synonym for helpless, hopeless, homebound, and eternally dependent. I think the moral and economic imperatives of 1999, and the new millennium we are approaching, demand that we shift our economic support and health insurance public policies for people with disabilities to one consistent with the wishes, needs, and increased expectation of people with disabilities and the tenets of the ADA.

As a society, we cannot afford to waste a human life and we can't afford to wait any longer. H.R. 1180 moves us toward a 21st century policy, making severe disability a new synonym with personal responsibility, choice, empowerment, interdependence, contribution, and economic self-sufficiency. With this as a first step, we can begin to reframe disability policy as a social and economic investment with a valued performance outcome. Very simply stated, as economic and productivity and contribution and value, and a better society for all of us.

[The prepared statement of Allan I. Bergman follows:]

PREPARED STATEMENT OF ALLAN I. BERGMAN, PRESIDENT AND CEO, BRAIN INJURY ASSOCIATION, INC.

INTRODUCTION

My name is Allan Bergman. I am the President and Chief Executive Officer of the Brain Injury Association (BIA). Founded in 1980, BIA is the only national non-profit association dedicated to the full range of issues related to traumatic brain injury: from trauma care to community integration and appropriate supports for persons with brain injury, their families and caregivers. BIA's mission is to create a better future through prevention, education, research and advocacy. 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 to lend our support to H.R.1180, the “Work Incentives Improvement Act of 1999,” and commend its lead sponsors, particularly Congressman Rick Lazio, Commerce Committee Chairman Thomas Bliley, Health Subcommittee Chairman Mike Bilirakis and Ranking Member Sherrod Brown, as well as Congressmen Henry Waxman, Nancy Johnson, Jim Ramstad, Mark Foley and Bob Matsui. We also appreciate the many other 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, as well as with many members of the Senate who cosponsored S. 331, 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.

In compliance with Commerce Committee Rules, attached is a copy of my resume along with a statement regarding BIA’s federal funding last year.

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.

TBI is the leading cause of death and disability of young people in the United States. Almost one half of all TBIs result from transportation-related incidents. Most of the remainder result from falls, assaults, sports and recreation and firearm-related injuries. *Each one of us, the members of our families, 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 person—without warning, and often with significant and life long consequences. TBI 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 TBI. Thus, daily a growing pool of persons with disabilities and their families must deal with the social consequences and medical challenges of 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 TBI Rehabilitation prepared by the Oregon Health Sciences University for the NIH Consensus Conference on TBI in October 1998, states that “Class II evidence indicates that *supported employment can improve the vocational outcomes of TBI survivors.* (Studies rated as Class II are randomized controlled trials [RCTs] with design flaws, well done, prospective, quasi-experimental or longitudinal studies, and case control studies).

Many persons with long term disability as a result of TBI want to work and are capable of remunerative employment with appropriate supports. *In order to remain employed, however, persons with TBI, like most people with disabilities, need consist-*

ency and continuity of health care services and long term supports. The need for these services is documented in a February 27, 1998, U.S. General Accounting Office Report 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). The report states that “both the private and public sectors finance acute care services to adults with TBI. 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 TBI access public benefits only after their health insurance policy lifetime cap of \$500,000 or \$1 million is met within 3-5 years after the injury.

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 a social insurance program as an amendment to the Social Security Act in 1956, for workers ages 50-64 who become “disabled.” In 1960, it 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” (SGA) by reason of a physical or mental impairment.* The impairment must be medically determinable and expected to last for not less than 12 months, or to result in death. Applicants may be determined to be disabled only if, due to such an impairment, they are unable to engage in any kind of substantial gainful work, considering their age, education, and work experience.

The first step in the disability determination process for a worker is to determine if the individual is engaging in SGA which for most people is defined as more than \$500 per month—nearly \$2,000 per year less than the federal poverty level. (In February 1999, the Social Security Administration (SSA) proposed a regulatory change to increase the SGA level for non-blind individuals from \$500 to \$700 per month, the first increase since 1990 and the second since 1980.) 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 1998, there were 4.698 million persons receiving SSDI with an average monthly benefit of \$733.* 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 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
40-54	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

Table 1-31.—Percent Distribution by Age, Sex and Education of Title II Disabled Beneficiaries Granted Benefits In Selected Calendar Years 1970-96, Compared With Adult U.S. Population in 1990—Continued

Characteristics	Year granted benefits															Adult U.S. population ¹
	1970	1975	1979	1982	1985	1988	1989	1990	1991	1992	1993	1994	1995	1996		
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 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 personal- ity 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 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 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. In addition as a result of amendments included in the Balanced Budget Act of 1997 (BBA), coverage for therapies (physical occupational and speech/language) is capped at \$1,500 per year, which is detrimental to many persons with disabilities.

C. Supplemental Security Income (SSI)

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 as 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. (SSA's February 1999 proposed regulatory change in SGA noted on page 3 would also apply to SSI.)

At the end of 1998 there were 3,518,000 SSI recipients between the ages of 18 and 64. In addition, there were 885,000 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) ¹		
	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; and Nurse-Midwife services

The optional benefits are: (*denotes benefits often needed by persons with disabilities) Podiatrists' services; Optometrists' services; Chiropractors' services; Psychologists' services*; Medical Social Workers' services; Nurse Anesthetists' services; Private Duty Nursing; Clinic services; Dental services; Physical therapy*; Occupational therapy*; Speech, hearing and language disorders*; Prescribed drugs*; Dentures; Prosthetic devices*; Eyeglasses*; Diagnostic services; Screening services; Preventative services; Rehabilitative services*; Age 65 or older in IMDs; Inpatient psychiatric services for under age 21; Christian Science nurses; Christian Science sanatoriums; NF services for under age 21; Emergency hospital services; Personal care services*; Home and Community-based waiver services*; Transportation services; Case management services*; Hospice care services; Respiratory care services*; and 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, and Wisconsin.

The passage of the Home and Community Based Services Waiver Option (H-CB) in 1981, has permitted many persons with disabilities to leave institutions and live in the community. In 1986, amendments to the H-CB waiver authority added supported employment as a habilitation service for persons previously institutionalized. The BBA of 1997 included an amendment to allow H-CB waiver supported employment services to anyone receiving 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 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 21st 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 it must re-craft 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 time lows and 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 penalty that makes the marriage penalty under the IRS code look like kindergarten. As a nation we can do better. H.R.1180 affords us the opportunity to change the disincentives and to disconnect the current link between income support and health insurance. All of the surveys 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 (in spite of the enactment of the Health Insurance Portability and Accountability in 1996).*

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 that H.R. 1180 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 small or medium sized businesses, 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. 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 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 eternally dependent*. The moral and economic imperatives of 1999 demand that we shift our income support and health insurance public policies for people with disabilities to one consistent with the wishes, needs and increased expectations of people with disabilities and the tenets of the ADA. 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. H.R.1180 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 of H.R.1180 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 re-frame 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."

Mr. BILIRAKIS. Thank you, Mr. Bergman, for your very powerful statement.

Next, Mr. Steven Cooley. Steve is from my home area of Clearwater, Florida. He is a Fellow, as I've already indicated, on the American Board of Disability Analysts. Steve, before you even start, I want to personally thank you for all the great work that you are doing for many individuals with disabilities down there. I know you are really strong in the rehabilitation area. Please proceed, sir.

STATEMENT OF STEVEN R. COOLEY

Mr. COOLEY. Chairman Bilirakis, ranking member Brown, and members of the subcommittee, thank you for inviting me here today to testify about the Work Incentives Improvement Act. My name is Steven Cooley, and I am the legislative section chair for the Florida chapter of the National Association of Rehabilitation Providers in the Private Sector, known as NARPPS. More importantly, I am a vocational rehabilitation provider with firsthand experience and knowledge of the barriers that Social Security beneficiaries with disabilities face in their efforts to secure and maintain suitable gainful employment.

In my experience, one of the most fundamental barriers is the loss of access to affordable healthcare coverage. I believe that this legislation will probably address that issue with the proposed Medicaid buy-in, and the continuation of Medicare coverage.

I am not an academian. I come before you with firsthand experience, and not theory. I am out there on the front lines, in the trenches so to speak, working with persons with disabilities, assisting in their transition back to gainful activity, and a productive lifestyle. I go into my clients' homes, I sit down with them, identify barriers to employment, and we develop strategies to overcome those barriers. We set up job-seeking skills counseling, and I develop placement plans, and actually put clients into my car and transport them to interviews that I have arranged with prospective employers. It is this perspective that I bring before you today.

Regardless of the disability status, the nature of their impairment, or their vocational attributes, one of the most common and significant barriers that I encounter in vocational rehabilitation is the concerns of the individuals about he or she's loss of access to affordable medical care. When conducting a vocational evaluation, and providing rehabilitation services to individuals receiving Social Security disability benefits, whenever vocational alternatives are discussed, or actually the process of returning to work, some of the most common questions I am asked are, "Are medical benefits provided with this job? If medical benefits are provided, how much will it cost me? Will I be accepted for medical benefits with my pre-existing medical condition? If I am accepted for medical benefits, will my pre-existing medical condition be covered?"

Surprisingly, these types of questions are often asked before my client asks about the nature of the employment opportunity or even the wages for the job. Fear of losing these benefits represents one of the biggest disincentives against returning to work encountered in the field of vocational rehabilitation. Not just for individuals receiving Social Security, it is a universal concern. Concern regarding continuity of medical benefits is an extremely difficult barrier to overcome.

Upon returning to the workforce, many of the Social Security disability clients that I work with are not likely to secure high-paying jobs, and most of them know that. Most of these individuals have ongoing medical concerns, and anticipate future medical needs. When an individual is earning entry-level wages, the cost of the very treatment or medication that are necessary to enable them to return to the world of work are often financially devastating. Even when employers provide medical benefits within their setting, the cost to the worker is often prohibitive. Many individuals in returning to work actually experience less net income into their home than the benefits they receive through Social Security disability income. From the perspective of the SSDI recipient, they have very little to gain, and much to lose, by returning to work.

The specific impact of healthcare benefits coverage became very apparent to me in 1994 when I participated in the Social Security Administration's Project Network, which was a pilot program that attempted to address some of these barriers we have discussed. And at least temporarily they helped, as they allowed access of SSDI recipients to private rehabilitation providers. I do not know the final statistics of this Project Network, but I do know that all of the clients I worked with were highly motivated to return to work, and I think part of their positive attitude was knowing that their healthcare coverage was intact for a protected period of time while they attempted to re-establish themselves in the workforce.

There is an old rehabilitation joke that goes something like, "How many rehabilitation providers does it take to change a light bulb?" Well, the answer is only one, but the light must want to change. There is a kernel of truth to the joke.

Most of the individuals with disabilities that I see are motivated to return to work, but that light grows dimmer with every barrier they must face, and it has been my experience that the fear or concerns about losing healthcare coverage or access to affordable coverage all but puts that light out.

On behalf of NARPS and all my fellow rehabilitation professors out there in the trenches working with people with disabilities and myself, I thank you for the opportunity to come testify before you and share my feelings regarding this act, and I will be available to answer questions at the appropriate time.

[The prepared statement of Steven R. Cooley follows:]

PREPARED STATEMENT OF STEVEN R. COOLEY, NATIONAL ASSOCIATION OF
REHABILITATION PROFESSIONALS IN THE PRIVATE SECTOR

Chairman Bilirakis, Ranking Minority Member Brown and members of the Subcommittee, thank you for inviting me to testify on the Work Incentives Improvement Act (H.R. 1180). My name is Steven Cooley, and I am the legislative section chair of the Florida Chapter of the National Association of Rehabilitation Professionals in the Private Sector (NARPPS). More importantly, I am a vocational rehabilitation provider who has firsthand knowledge of the barriers that Social Security beneficiaries with disabilities face in their efforts to find and maintain gainful employment. In my experience, one of the most fundamental barriers is the loss of access to affordable health care coverage. I believe that this legislation will properly address that issue with the proposed Medicaid buy-in and the continuation of Medicare coverage provisions.

As for my background, I am a Nationally Certified Rehabilitation Counselor (CRC), Certified Vocational Evaluator (CVE), Certified Case Manager (CCM), a Fellow of the American Board of Disability Analysts (F-ABDA) and I am licensed as a primary rehabilitation and vocational service provider in Florida, Georgia and Tennessee. I have been in private practice as a rehabilitation provider for approximately fifteen years. I conduct vocational evaluations, develop and implement rehabilitation plans, develop and coordinate life care plans and provide overall case management for individuals who have physical, economic, educational, emotional, psychological or situational impairments to help them return to functional and productive lifestyles.

I am often called upon to provide expert testimony in State and Federal courts on vocational and rehabilitation issues in workers' compensation, medical malpractice, divorce, personal injury, wrongful death and Social Security disability determination cases. I testify on cases litigated under the Longshoreman Act, the Jones Act, Title 7 (EEO) and the American with Disabilities Act (ADA). In 1994, I participated in the Social Security Administration's (SSA) "Project Network," an initiative to assist beneficiaries of Social Security Disability Income (SSDI) to return to gainful activity. Additionally, because current Florida workers' compensation law defers to Social Security guidelines regarding disability determinations, many of the individuals I work with through the worker's compensation system have sought and are receiving SSDI benefits.

I am not an academician. I come before you with firsthand experiences and not theory. I am out there in the trenches. I actually go into the homes of those I assist in returning to work. I sit down with them, identify the barriers they face, work with them to develop strategies to overcome those barriers, provide placement assistance, interview and job retention skills counseling and actually transport them to interviews I have set up with an employer. It is this perspective that I bring before you today.

Regardless of their disability status, nature of impairment, or vocational attributes, one of the most common and substantial barriers against returning to work that I encounter is concern by the individual that he or she will lose access to affordable health care. When conducting a vocational evaluation and/or providing vocational rehabilitation services to individuals receiving Social Security disability benefits, whenever vocational alternatives are discussed, among the most common questions I have been asked, are:

- Are medical benefits provided with this job?
- If medical benefits are provided, how much will it cost me?
- Will I be accepted for medical benefits with my pre-existing medical condition?
- If I am accepted for medical benefits, will my pre-existing medical condition be covered?

Surprisingly, the above questions are commonly asked before inquiries regarding wages or the nature of the work to be performed. However, it does underscore the significance of medical benefits to Social Security beneficiaries with disabilities. Fear of losing these benefits represents one of the biggest disincentives against returning to work encountered in the field of vocational rehabilitation; and not just

for the individuals receiving Social Security disability benefits. It is a universal concern.

Concern regarding continuity of medical benefits is an extremely difficult barrier to overcome. Upon return to the workforce, the majority of the individuals receiving Social Security disability benefits are not, at least initially, likely to command high wages, and they are well aware of this fact. The majority of them either have ongoing medical concerns or fear that they may need future medical services.

When an individual is earning entry level wages, the cost of the very medications or treatments which may enable them to return to work can be financially devastating. Even when medical benefits are available through an employer, the cost to the worker is frequently prohibitive. For many individuals, returning to work may actually result in less net income than they received through Social Security disability benefits. From the perspective of the Social Security beneficiary with a disability, it often appears they have much to lose and little to gain by returning to work.

The specific impact of the loss of health care coverage became very apparent to me when I participated in "Project Network." This project was a pilot program that attempted to address, at least temporarily, the barriers that Social Security beneficiaries face by allowing them to work with vocational rehabilitation professionals in the private sector. I do not know the final statistics of the program, but I can tell you that most of the individuals I assisted through the project were eager to return to work, and I attribute much of their positive attitude to the fact that they felt secure that their medical benefits would remain intact for a protracted period, while they were re-establishing themselves in the workforce.

There is an old rehabilitation joke, that goes: How many rehabilitation providers does it take to change a light bulb. Only one, but first the light bulb must really want to change. There is a kernel of truth to this joke. Most of the individuals with disabilities that I see are motivated to return to work, however, their lights grow dimmer with each barrier that they must face. My experience leads me to believe that the concern regarding the loss of medical benefits all but puts out that light.

On behalf of NARPPS, all of my peers who are out there in the trenches and myself, thank you for the opportunity to appear before you today to provide this testimony. I would be happy to answer any questions at the appropriate time.

Mr. BILIRAKIS. Thank you, Mr. Cooley. Thank you very much.

You may not have heard the bells, I don't know, but we had the first bells and now the second bell, which means we have less than 10 minutes to get to the floor. There are four votes, and the first one will be 15 minutes, and then the other three will be 5-minute votes. So I am not sure really what that does to us, but it probably takes us to about 5. Mr. Auerbach and Mr. Gray, I apologize, but will you wait a little while, if you don't mind?

Mr. BROWN. You might find it curious that 15 plus 5 plus 5 adds up to 45.

Mr. BILIRAKIS. Well, I don't know. If we get back by 4:45, fine; otherwise, it will be about 5. Thank you.

[Brief recess.]

Mr. BILIRAKIS. Let's go ahead and get started. I apologize on behalf of all of us for the interruption, but also the fact that members haven't returned. I mean this is a pretty hectic place, I think some of you know that, but it is certainly not a reflection on the issue itself and on this panel.

Mr. Auerbach, why don't we just go ahead and go over to you now, sir, and your written testimony is a part of the record. You can complement it as you wish. Please proceed.

STATEMENT OF ROGER AUERBACH

Mr. AUERBACH. Thank you so much, Mr. Chairman. I appreciate the opportunity to appear before you today to give a State perspective on the health-related concepts embodied in the Work Incentives Improvement Act of 1999.

First of all, I commend you highly on focusing on this much-needed piece of legislation. You have heard testimony from a lot of people about the numbers of people with disabilities who are unemployed and who want the opportunity to go to work.

The major barrier to employment for disabled individuals, but not the only barrier, is the fear of losing essential health and personal assistance benefits. The current work incentive programs of the Social Security Administration do not sufficiently address these fears.

Oregon has implemented an employed persons with disabilities program, pursuant to section 4733 of the Balance Budget Act of 1997. Our program allows persons with disabilities to go to work, and to work to their fullest capacity, without fear of losing health and personal assistance benefits.

While we impose a cost share on unearned income over \$500 a month and have a sliding fee scale premium payment for income over 200 percent of the Federal poverty level, we pretty much are guaranteeing a healthcare safety net for disabled workers who cannot afford to risk this needed coverage. We are enabling people to make a dramatic impact on their lives, and we thank you very much for passing this legislation and giving our State the opportunity to help the working disabled.

With this comprehensive bill before you, I know we will be able to do much more for this deserving population to expand opportunities for independence, increased income, and self-esteem, to expand opportunities for more disabled persons to become taxpayers, to expand the labor pool needed in most areas of the country, and to expand the hopes and dreams of millions of people who want their chance to make more meaningful, societal contributions.

If this bill is passed, Oregon would seriously look at expanding income eligibility above 250 percent of the Federal poverty level, which we have already done, and expanding coverage to disabled workers whose conditions have improved, but still have an impairment.

From the standpoint of humanity and fiscal common sense, we should enable people to work as long and as much as they can and not drive them onto higher levels of public assistance.

We would use the grant to States to establish infrastructures to expand our current efforts to counsel people on how to best use current work incentive programs along with these new opportunities to begin outreach to people to let them know they really can go to work and retain essential health benefits.

Oregon might also use the infrastructure money to address other barriers to employment, affordable and accessible housing, transportation, job readiness skills, and needed support for job retention.

In the interest of time, and my hope to engage in a little dialog, let me just state that we are very encouraged in the legislation by the continuation of Medicare coverage for SSDI-eligible individuals. We are very enthusiastic about the proposed demonstrations. We are very supportive of the crucial provisions allowing expedited reinstatement if employment is lost, and employment not triggering continuing disability reviews. These provisions send the positive message that we want you to join the workforce and we will sup-

port your independence by continuing your essential health and personal assistance benefits.

I believe many States are interested in providing these new options for working disabled individuals. However, I do want to point out two big issues for States. First, most States are nervous about potential costs to their budgets. Although the bill defines a working person with a disability in Section 101(a)(2)(b) and 104(b)(1), it does not make that same definition on 101(a)(1). State officials are nervous that could allow people who work occasionally or really only enough to qualify for benefit to be able to qualify for this program.

We believe that States should be allowed to have a less restrictive definition of working, but at least be allowed to define working at 40 hours a month at the Federal minimum wage. We also believe that the age definition contained in the other subsections, 16 to 64, should apply unless the State wants a less restrictive definition.

Second, we believe the State should have the option to phase in the program and not be required to implement a program statewide from the first day they start it. As you have acknowledged in this bill, and we appreciate that acknowledgment, most States need to build infrastructures to support the program and need time to develop them. States ought not to have to ask for a waiver from HCFA in order to launch a planned phase-in program.

Again, I thank you for this opportunity to bring a State perspective to this bill, which has a potential to help so many people in all parts of this country. We believe in what this bill can do. We applaud you for investing energy in this proposal, and we in Oregon stand ready to answer your questions about both the philosophy and the operations of our existing program. Thank you.

[The prepared statement of Roger Auerbach follows:]

PREPARED STATEMENT OF ROGER AUERBACH, ADMINISTRATOR, OREGON DEPARTMENT OF HUMAN RESOURCES, SENIOR AND DISABLED SERVICES DIVISION

I am Roger Auerbach, Administrator of the State of Oregon, Senior and Disabled Services Division. The division arranges and pays for services for low-income Oregonians who need assistance with activities of daily living; determines eligibility for Medicaid acute and long term care services, food stamps and other cash assistance and health programs; licenses, monitors and provides technical assistance to all long term care service providers; investigates and acts on incidents of abuse involving the elderly and disabled; administers the federal Older Americans Act programs; assists disabled workers to obtain and retain employment.

I very much appreciate this opportunity to testify on the Work Incentives Improvement Act of 1999. As members of this committee, you are to be commended for focusing on this much-needed legislation. This is extraordinarily important legislation for a number of reasons. First, it benefits people with disabilities, increasing their opportunities for independence, increased income, and self-esteem. Second, it benefits federal and state treasuries by allowing people with disabilities to earn additional taxable income. Third, at a time when employers are seeking talented workers, this population has many to offer. Finally, serious consideration of legislation such as this delivers new encouragement to millions of people with disabilities who want their chance to make meaningful societal contributions.

You have asked me to present a state's opinion of the legislation. Besides having worked in Oregon's state government for eight years, I am a member of the executive committee of the National Association of State Medicaid Directors, an affiliate of the American Public Human Services Association. I also serve on the Board of Directors of the National Association on State Units on Aging. I understand not only what we are doing in Oregon, but also the aspirations—and fears—of many other states.

Oregon's work on helping people with disabilities go to work without losing Medicaid benefits began in the Summer of 1996. Then, the director of Oregon's human resources department, Gary K. Weeks, called for a stepped-up effort to help people with disabilities obtain and retain employment. Director Weeks called together not only my division, Senior and Disabled Services, but also the Vocational Rehabilitation Division, the Adult and Family Services Division, and the Oregon Employment Department. Subsequently, our Office of Alcohol and Drug Abuse Programs and the Mental Health and Developmental Disability Services Division became actively involved, as well. He reminded us of some bleak statistics, most recently reported last year by the National Organization on Disability. It reported a Harris Poll showing that 29 percent of people with disabilities ages 18 to 64 are employed compared with 79 percent of the non-disabled population. Moreover, 70 percent of unemployed people with disabilities say they want to work.

In planning for this new initiative, we spoke with many consumers and advocates about why more disabled individuals weren't working. We encountered a recurring theme: people were not working for fear of losing health-care benefits; specifically, personal care attendant and mental health drugs, which are costly and not ordinarily covered by private insurance plans.

We began working with consumers and advocates to craft a plan that would assist people with disabilities to retain essential Medicaid benefits after they went to work. Our initial intent was to seek a waiver from the U.S. Health Care Financing Administration (HCFA). However, when Congress approved Section 4733 of the Balanced Budget Act of 1997, State Option to Permit Workers with Disabilities to Buy-in to Medicaid, we elected instead to seek an amendment to Oregon's state Medicaid plan. (See appendices for explanation of Oregon's program). From the perspective of a state administrator who regularly works with talented people with disabilities who cannot risk the loss of Medicaid benefits, this legislation was a breakthrough of breathtaking proportion.

I also cannot say enough about the high level of cooperation Oregon received from HCFA. People from HCFA's regional and central office worked with us every step of the way, so much so that we consider them as partners in this effort. Not only that, but the people at HCFA approved our state plan amendment in what must have been record time, just a few weeks after submission.

Although there is a great deal to address in this bill, I want to focus on the concepts relating to continuation of health benefits. Again, we hear over and over again from consumers and advocates that the loss of health-care coverage is the No. 1 barrier to employment. We enthusiastically support the concepts in this bill as it gives states new, voluntary options to provide coverage for the working disabled. I believe that many states will be interested in these options and welcome the increased federal focus on this issue.

State Medicaid Options

The bill would allow states to cover people whose income exceeds 250 percent of the federal poverty level and have resources exceeding \$2000. We believe this is an excellent provision. Our current employed persons with disabilities program takes advantage of the flexibility afforded by Section 4733 of the Balanced Budget Act of 1997 to cover people up to 250% of the federal poverty level. If this bill passed, we would seriously consider raising the maximum income eligibility level. We also used existing law to allow people with disabilities to retain coverage and own greater assets. This bill also permits greater assets, which people with disabilities, like the rest of us, should be able to accumulate for children's college education or retirement or other quality-of-life purposes.

We also support the bill's provision to permit states to provide coverage for individuals aged 16 to 64 who cease to be eligible for Medicaid owing to improvement of their condition, but who still have an impairment and are employed. From the standpoint of humanity, and fiscal common sense, it is only reasonable to enable people to work as long as they can and not to drive them onto higher levels of public assistance.

Continuation of Medicare Coverage

We are encouraged that the bill would continue Medicare coverage for people with disabilities who are eligible for Social Security Disability Insurance. These are typically people who have an established work history and, therefore, are often the best candidates for employment. This clearly sends the positive message that we care about all people with disabilities, regardless of when their disability occurred.

Grants to Develop and Establish State Infrastructures

We very much appreciate that this bill offers grants to states to establish infrastructures to support people with disabilities. This would allow states to do a better

job of implementing policies for people with disabilities, and then to evaluate what works best. It is also important to note that this legislation will send a very positive, but different, message to people with disabilities: we encourage you to join the workforce and are going to support your independence by continuing your health and personal assistance benefits; we will not cut off your benefits and assume you are no longer disabled if you go to work. It will take resources and varied communication efforts to get this new message across. In addition, Social Security disability cash benefits and existing “work incentive” programs will still exist and people with disabilities need to know how this new law affects those existing programs.

I also ask that you remember that discontinuation of health benefits for people with disabilities is not their only barrier to going to work. Other barriers include affordable and accessible transportation, housing, and the need for job readiness training. Grants to states will help people closest to those with disabilities assess what is needed to help this often-overlooked population go to work, achieve greater independence, and pay taxes.

Additionally, as important as it is to help people with disabilities go to work, we also recognize that our job shouldn’t end with getting people ready for a job; grant funds could be used to develop job-retention services which are critical to the success of these programs. When people get jobs—all people—there can be problems, whether they be conflict at the worksite, transportation arrangements falling through, or interrupted child care. Any of these can lead to a person losing a job. Disabled workers, who often don’t have recent work experiences, face these problems and more.

Medicaid Demonstration Projects for Workers with Potentially Severe Disabilities

We are also very enthusiastic about the bill’s proposed demonstration projects to provide medical assistance for workers ages 16-64 who have potential disabilities. These are people who, if they didn’t receive Medicaid benefits, would see their health deteriorate and soon be too disabled to work. We are very interested in helping this population of working disabled individuals.

Elimination of Work Disincentives

For a large and growing population of Americans, this bill has been a long time in coming. These people will tell you not only that the loss of health and personal assistance benefits is the biggest barrier to going to work, but that they live in fear that, should they go to work, they will trigger what is called a “continuing disability review,” which means the government will question whether they are truly disabled. The Work Incentives Improvement Act says that although the Social Security Administration will continue to perform such reviews, these reviews will not be triggered by employment. This provision is very important to the success of this program.

In Oregon, we have struggled with the question of what happens if a person with a disability has gone to work only to find that his or her job is lost to an economic downturn or to a worsening of the disability. As you know, obtaining renewed eligibility for Social Security disability can take months or years. In contrast, this bill would entitle the person with the courage to go to work to expedited reinstatement if employment is lost. This is a welcome safety net that will show people with disabilities that they can work without totally risking loss of benefits.

Work Incentives Planning, Assistance and Outreach; Demonstration Projects

This bill is also helpful because it would direct the Social Security Administration to set up community-based programs to distribute work-incentives information to people with disabilities. The bill also provides for helpful grants to state advocacy programs that would give advice to those seeking information and assistance, such as the Oregon Advocacy Center in my state. Further, we support the provision allowing the Social Security Administration to conduct demonstration projects under the SSDI program. The bill mandates SSDI demonstration projects so that instead of a \$500 earnings “cliff,” people would realize a \$1-for-\$2 benefit reduction on earnings over a specified level, similar to the SSI disability program. This specific demonstration deserves support.

State Concerns

As stated previously, I believe many states are highly interested in providing these new options for working disabled individuals. However, as much as we support these concepts, I do want to point out two big issues for the states.

First, most states are nervous about the potential cost to their budgets. Although the bill defines a working person with a disability in Sections 101(a)(2)(B) and Section 104(b)(1), it does not have any definition of working in 101(a)(1). State officials are nervous that this could allow people who work occasionally, or only enough to

receive a benefit, to be able to qualify. We believe that states should be allowed to have a less restrictive definition of working, but at least be allowed to define working at 40 hours a month at the federal minimum wage. We also believe that the age definition (16-64) contained in the other subsections, should apply unless a state opts for a less restrictive definition.

Second, we believe states should have the option to phase in the program and not be required to implement a program statewide from the first day that they start it. As you have acknowledged in this bill, most states need to build infrastructures to support this program and need time to develop them. States ought not to have to ask for a waiver from HCFA in order to launch a planned, phased-in program.

Again, I thank you for this opportunity to bring a state perspective to this bill, which has potential to help so many people in every part of this country. We believe in what this bill can do, we applaud you for investing energy in this proposal, and we in Oregon stand ready to answer your questions about both the philosophy and operations of our existing program for the working disabled.

Mr. BILIRAKIS. Thank you, sir, and Mr. Auerbach, on behalf of all of us, thanks to the State of Oregon for using the resource of that BBA 1997 provided. Possibly later on we can get some of the details as to why you think some States are not going into it.

Mr. Gray, please proceed, sir.

Mr. AUERBACH. Thank you.

STATEMENT OF CRAIG E. GRAY

Mr. GRAY. Thank you. Good afternoon, Mr. Chairman, members of the committee. My name is Craig Gray. I am the Director of Program Management for the Services for Independent Living Division of UNUM Life Insurance Company of America, based in Portland, Maine. I also sit on the Employers Subcommittee of the President's Committee on Employment of People with Disabilities.

I have been asked to comment today on behalf of the Health Insurance Association of America, of which UNUM is one of 269 member companies who provide disability income, long-term care, supplemental and health coverage to 150 million people.

I am a person with a disability that has made a successful return to the workforce. Unfortunately, I am an example of the exception, not the norm.

In my professional capacity and personal life I regularly communicate in great depth with other people with disabilities and employers, and while I cannot, nor would ever, profess to speak for all people with disabilities, I would like to share a few observations that I believe are generally true.

People are beginning to understand now, much more than even just 5 years ago, that acquiring a disability doesn't mean that one's life has come to an end; rather, it has entered a new phase—a phase that many people find equally productive, exciting, and fulfilling. In some cases they have an even higher quality of life than they had before.

The general public is seeing people living successfully with disabilities in many aspects of society. Advances in assistive technologies enable people to participate in the workplace. Advances in recreational programs have people with disabilities recreating and competing in sports activities right alongside their able-bodied friends.

They see people like Marilee Maitlin, Thomas Quasthoff, Michael J. Fox, and Steven Hawking making valuable contributions to society. They watch the Paralympic Games in Atlanta. You can even

see people with disabilities in TV commercials and soap operas now.

With the advance in assistive technologies and medical treatments, it is becoming more evident that disability is a socially defined concept, that is, once traumatic injuries or disabling conditions have been stabilized, the issues of quality of life and productivity are determined by societal norms and values.

The ADA has done a lot to remove many of the physical barriers associated with disabilities. It is not the attitudinal barriers and institutional barriers that we need to address.

Attitudinal barriers are slowly beginning to change and have come a long way in the 20 years I have been disabled, but this will continue to be a long, slow process. Many attitudinal barriers are the result of institutional barriers that tend to perpetuate disability stereotypes and actually limit one's ability to re-enter main stream society. One of the major institutional barriers is the very real fear of losing your health insurance when you return to work.

This is real for me. In 1984 I was working as a computer programmer for an insurance company in Boston. I was recruited by another insurer here in Washington, DC. I took the job and the company actually moved me to an apartment in Annandale. I reported to work, and on my second day I met with the company's benefit manager who informed me that they would not be able to provide me with health insurance.

It had not occurred to me to ask about health insurance in the interview process. It had not been an issue or source of concern with my previous employer, and I incorrectly assumed that I would be covered the same as any of their other employees.

You can imagine my frustration. I had no coverage, and my new employer was not going to pay to move me back Boston. Had I not been willing and able to take a huge risk and rely on my own resources for a short period of time, I would have been forced to return to the ranks of Social Security. I found another job just as soon as possible and made sure that health insurance was part of that package.

Now you have to understand that I am luckier than many people who need personal assistance services and prescription drug services to be able to work. Had this been a requirement for me, I would probably still be out of work.

The Work Incentives Improvement Act of 1999 addresses several areas that are significant barriers for people with disabilities to return to work. It will eliminate several of the disincentives to return to work and will also move us a step closer to removing the attitudinal barriers that prevent people with disabilities from making greater contributions to society.

Of course, there are a number of practical issues that must be dealt with. We suggest that the following factors be considered in evaluating any return-to-work proposal: The proposal should make it easier for employers to hire people with disabilities and ease the cost and concerns of ADA compliance. The proposal should be structured so it does not harm the Social Security safety net provided to seniors. Similarly, the proposal shouldn't place any additional burden on the Medicare supplement market that would make coverage more expensive or less available to seniors. Finally,

expanded definitions of disability and other changes in the Federal programs should not be applied to private disability programs where they may not be appropriate.

In general, we believe this proposal does a good job of addressing the needs and concerns of people with disabilities. We strongly encourage you to give additional thought to ways in which employers can be encouraged and supported in their efforts to hire people with disabilities.

I would like to note that my written testimony contains detailed technical comments addressing this and other similar issues. Thank you very much.

[The prepared statement of Craig E. Gray follows:]

PREPARED STATEMENT OF CRAIG E. GRAY, DIRECTOR, SERVICES FOR INDEPENDENT LIVING, UNUM LIFE INSURANCE COMPANY OF AMERICA

Good morning, Mr. Chairman and Members of the Subcommittee. I am Craig Gray, Director of Program Management for the Services for Independent Living division of UNUM Life Insurance Company of America, based in Portland, Maine. While at Unum I have held various positions including disability consultant in product development, customer service, marketing, and communications. I currently serve on the Employer Subcommittee of the President's Committee on Employment of People with Disabilities. I have been asked to comment today on behalf of the Health Insurance Association of America (HIAA), of which UNUM is a member. The HIAA is the nation's most prominent trade association representing the nation's private health care system. Its 269 members provide health, disability, long-term care, and supplemental coverage to more than 115 million Americans. UNUM is the nation's leading provider of disability income insurance.

I am a person with a disability that has made a successful return to the workforce. Unfortunately, I am an example of the exception, rather than the norm.

In my professional capacity and personal life, I regularly communicate in great depth with other people with disabilities and with employers. And while I can not, nor would never profess to speak for all people with disabilities, I would like to share a few observations that I believe are generally true.

People are beginning to understand now, much more than even just 5 years ago that acquiring a disability does not mean that one's life has come to an end. Rather, it has entered a new phase—a phase that many people find equally productive, exciting and fulfilling. In some cases, they have an even higher quality of life than they had prior to acquiring a disability.

They see people living successfully with disabilities in many aspects of society. Advances in assistive technologies enable people to participate in the workplace. Advances in recreational programs have people with disabilities recreating and competing in sports activities right along side their able-bodied friends. They see people like Marilee Maitlin, Thomas Quasthoff, Michael J. Fox, and Stephen Hawking making valuable contributions to society. They watch the Paralympic games in Atlanta. People with disabilities are even seen on television commercials and soap operas.

Advances in assistive technologies and medical treatments are helping to demonstrate that "disability" is a socially defined concept. That is, once traumatic injuries or disabling conditions have been stabilized, the issues of quality of life and productivity are determined by societal norms and values. The Americans with Disabilities Act (ADA) has helped to remove many of the physical barriers associated with disabilities. It is now the attitudinal barriers and institutional barriers that our society must address.

Attitudinal barriers are slowly beginning to change. In fact, they have changed a great deal in the 20 years I have been disabled. But, this change continues to be a long, slow process. Many attitudinal barriers are the result of institutional barriers that tend to perpetuate disability stereotypes and actually limit one's ability to re-enter mainstream society. One of the major institutional barriers is the very real fear of losing your health insurance when you return to work.

This is real for me. In 1984, I was working as a computer programmer for an insurance company in Boston. I was recruited by another insurer here in Washington DC. I took the job and the company actually moved me to an apartment in Annandale. I reported to work and on my second day, I met with the company's benefits manager who informed me that they would not be able to provide me with health

insurance. It had not occurred to me to ask about health insurance in the interview process. It had not ever been an issue or source of concern with my previous employer and I incorrectly assumed that I would be covered on the same basis as their other employees.

You can imagine my frustration. I had no coverage and my new employer was not going to pay to move me back to Boston. Had I not been willing and able to take a huge risk and rely on my own resources for a short period of time, I would have been forced to return to the ranks of Social Security. I found another job just as soon as possible and made sure that health insurance was part of the package.

Now you have to understand that I am luckier than many people who need personal assistant services and prescription drug coverage to be able to work. Had this been a requirement for me, I would probably still be out of work. While the Health Insurance Portability and Accountability Act of 1996 (HIPAA) helps increase access to coverage in some specific situations, it is not a complete solution for all individuals with disabilities.

Efforts to help workers with disabilities return to the labor force have the potential to improve the lives of beneficiaries and strengthen the financial position of the Social Security Disability Income (SSDI) program. We fully support the goal of helping these individuals return to full participation in the workplace. At the same time, we believe that legislation designed to enable individuals with disabilities to return to the labor force, while maintaining their access to important federal health care benefits, should be carefully crafted to avoid unintended adverse consequences. We would suggest that the following general guidelines be considered in evaluating the impact of any specific return-to-work legislation:

- The legislation should seek to support employers that hire workers with disabilities and ease the cost of Americans with Disabilities Act (ADA) compliance.
- The legislation should be structured and funded so as to avoid adversely affecting the financing of the Medicare and Medicaid programs.
- The legislation should not place requirements on the private Medicare-supplement market that would increase the cost of coverage to seniors.
- Expanded definitions of disability should not be inadvertently applied outside the scope of the specific programs under consideration.

With respect to the "Work Incentives Improvement Act of 1999," H.R. 1180, we have two specific questions regarding its interactions with other public and private insurance programs. We believe that an understanding of the issues involved is important to evaluating the real world impact of such legislation.

- If an SSDI beneficiary returns to work while continuing Medicare coverage, what is the role of the employer's health plan? Does the aforementioned role change if their earnings are below the level defined for "substantial gainful employment?" Can Medicare be made primary to any employer-sponsored coverage for these individuals?
- If an SSDI beneficiary returns to work on a trial basis through the Ticket to Work program, would they be covered by the employer's short-term or long-term disability plan? If the beneficiary then proves unable to perform the duties of the job, does the employer become responsible for disability income benefits as a result of assisting the individual in returning to the labor force?

We believe the sponsors should clarify their intent regarding these issues as the legislation moves forward. We also have several specific technical comments that we hope you will consider.

- We would strongly encourage adding a provision amending the Medicare Secondary Payer rules (42 USC Section 1395y) to make employer-sponsored coverage secondary to Medicare and Medicaid coverage for those SSDI beneficiaries who return to the labor force. This would directly support the goals of the ADA and the Ticket to Work program by encouraging employers to actively seek out workers with disabilities. This would not represent a significant expansion of the Medicare program, because these individuals, in the absence of a return to work, already would be receiving Medicare benefits. It would also be consistent with the current treatment of individuals with end stage renal disease.
- The possibility of Medicare Supplement policies being allowed to suspend premiums and benefits during periods of time in which the policyholder is covered by an employer-sponsored program should be considered. This would reduce premium costs for beneficiaries while allowing them to keep their policies in force. It would also prevent multiple sources of coverage resulting in payments to providers that exceed their billed charges, and would be consistent with the current treatment of Medicaid coverage (42 U.S.C. Section 1395ss(q)).
- Title II, Subtitle B, Section 211 amends section 221 of the Social Security Act (42 USC 421) by adding a new subparagraphs (m). (B) and (C) of the new para-

graph (m)(1) should be clarified to indicate that they refer only to disability benefit determinations under sections 202 and 223 of the Social Security Act, and not to benefit determinations made under private disability programs.

In addition, we would suggest that the following enhancements be added to the legislation:

- The period of time during which expedited eligibility determinations are made available to applicants who have previously received SSDI benefits and attempted to return to the labor force through participation in the Ticket to Work and Self-Sufficiency Program should parallel the time during which continued Medicare eligibility is available.
- An extended trial work period should be established for participants in the Ticket to Work and Self-Sufficiency program, during which a return to the SSDI rolls does not trigger a second qualification period during which benefits are not available. This should parallel the extension created for Medicare eligibility.
- Beneficiaries who return to the SSDI rolls during the extended trial work period should have their earnings histories protected. In other words, their SSDI benefits should not be reduced due to lower earnings during their return to the workforce.

Again, I appreciate the opportunity to comment on this proposed legislation on behalf of UNUM and HIAA. We support the concept that the structure of the SSDI, Medicare and Medicaid programs should encourage disabled beneficiaries to return to an active role in the work force. The Work Incentives Improvement Act of 1999 addresses several areas that are significant barriers for people with disabilities to return to work. It would eliminate several of the disincentives to return to work and would also move us a step closer to removing the attitudinal barriers that prevent people with disabilities from making greater contributions to society. We would strongly encourage you to give additional thought to ways in which employers can be encouraged and supported in their efforts to hire people with disabilities.

This Subcommittee's consideration of efforts to help workers with disabilities return to the labor force have the potential to improve the lives of beneficiaries and strengthen the financial position of the SSDI program is an important step towards fully integrating Americans with disabilities into the mainstream of our society, and strengthening our social insurance safety net for all of our citizens.

Thank you Mr. Chairman and Members of the Subcommittee. We look forward to working with you to ensure that the best possible legislation becomes law.

Mr. BILIRAKIS. Thank you very much, Mr. Craig. We are going to go through rather than a second round or anything of that nature, apparently, there's only three of us, so maybe a 10-minute questioning session here.

Mr. Bangsberg, I understand, has to leave at 5:30. So I would ask my colleagues, if you have any questions of Mr. Bangsberg, you might want to—I will yield to you now. Do you have anything of Jeff?

Jeff, thanks for your testimony. Getting to your personal situation, let me ask you, do you have private health insurance?

Mr. BANGSBERG. Yes, sir, I do. I do have private insurance through my wife, and believe it or not, it does pick up most of the expenses that I do have, including much of my supplies and equipment that I have as well. However, it does not pick up personal care assistance services, and I privately pay 2 days out of the week for that service, and then, fortunately, my wife cares for me and provides all of the other cares that I need that a normal personal care assistant would do 7 days a week, both morning and night, and to assist me with food preparation as well.

So to answer your question, the insurance that I receive is for much of my supplies and equipment, and any acute and primary care costs that I incur, but as far as personal assistance services, no, they will not pick up for those kinds of costs.

Mr. BILIRAKIS. Well, now we heard Mr. Gray share with us a couple of his personal experiences. I wonder what types of barriers

have you faced regarding your health care. Is there anything you might want to share with us?

Mr. BANGSBERG. Sure. I guess that the barrier that we see in Minnesota is primarily the prescription drugs that we cannot get for many people, and I think another magnitude is supplies and equipment for most people who are trying to get prescription drugs.

One thing that is very important to note, as I stated earlier in my testimony, is that many of the people who are disabled like myself are going to be on Medicaid or Medicare regardless. In fact, the survey that I alluded to that is in your packets indicates that 77 percent of those people that were surveyed are on medical assistance and Medicare, and so those individuals would not add an additional expense to this program. In fact, we find that they would probably save additional dollars to this particular program.

Mr. BILIRAKIS. Well, there would be additional revenue coming into the treasury as a result of their working.

Mr. BANGSBERG. Precisely. I think there is a few ways to look at it. One is in the area of secondary disabilities, where you find a person with a disability who is not working, and with not being active, they become more sick, if you will, much quicker, and they are not staying as healthy because they are not living an active lifestyle and, in addition, depression and chemical dependency becomes a secondary disability to those individuals.

In addition to their primary care health insurance that would be allotted to those individuals, that is another expense that would be incurred by the medical assistance and the Medicare system, these people would become sicker and use the healthcare dollars much more frequently.

Mr. BILIRAKIS. Thanks, Jeff. Why don't we just go ahead and excuse you. That way you can leave at your leisure. Thanks so very much.

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

Mr. BILIRAKIS. I know you were not planning to stay here for this hearing. You were here last week for the press conference, and I know you had planned to return.

Mr. BANGSBERG. It was my pleasure and I was more than happy to stick on and stay around. I don't get this chance very often and I am very thankful.

Mr. BILIRAKIS. You have honored us. Good luck to you.

Mr. BANGSBERG. Thank you very much.

Mr. BILIRAKIS. Thank you, Mr. Bangsberg.

Mr. Gray, you brought up this point of making it easier for employers to hire individuals with disabilities, and, of course, you brought up the point of the Disabilities Act. Basically, what we are saying is that the Disabilities Act would require certain improvements on the part of the employer, which would be costly, and so might deter their thought about even hiring someone with disabilities; is that right? That is your point?

Mr. GRAY. That is correct.

Mr. BILIRAKIS. Yes, that is something that maybe we don't think about. But can you imagine the problem we would run into with some of the disabled community if we choose to make exceptions in some cases? I don't know. I guess it is something to think about.

Mr. Cooley, do you believe that the State of Florida is likely to pursue the Medicaid optional expansions authorized under this bill?

Mr. COOLEY. I certainly hope that they do. I don't have any personal insight, as I sit here today, that they will, but it would certainly be my position to encourage them to do so.

Mr. BILIRAKIS. All right, you were aware of the provisions of BBA 1997 I would imagine; right?

Mr. COOLEY. Somewhat, yes.

Mr. BILIRAKIS. And did you inquire of the State why they were not doing what Oregon is doing in terms of taking advantage of it?

Mr. COOLEY. Mr. Chairman, I actually have not had that communication with them, as I sit here today. I assure you that when I return back to Florida that will be one of my very first initiatives this week.

Mr. BILIRAKIS. So, in terms of current initiatives at the State level, what are they basically, and how would they be enhanced with this legislation being enacted?

Mr. COOLEY. I think one of the serious conflicts that exists in Florida today is that the State Workers Compensation system uses a Social Security Disability criteria for determinations of permanent total disability, and for the injured workers in the State everything is either all or nothing. I believe that if we can get this legislation through, passed, people won't be encouraged to seek total disability, and with the benefits that will be continuing, we will be able to get many, many more of the disabled population in our State back to work.

Everybody I see, as I earlier testified, their major barriers are whether or not they are going to have medical coverage. I think if we can get the State to buy into this, participate, it will certainly help us in Florida.

Mr. BILIRAKIS. Mr. Auerbach, you spoke of certain problems with the BBA 1997 language that you feel probably has deterred some States, and, apparently, did not deter Oregon, but you were able to surmount them. Do you think that this bill would take care of all of those problems?

Mr. AUERBACH. Mr. Chairman, I don't think it will take care of all of the problems. I wanted to highlight just two points in my testimony. One was, again, the definition of working and the fear of State budgets and actually biting off a bigger chunk than they thought they would.

People want to work with this program. I have talked with States from around the country. One of the things that happens when you are one of the first out of the chute, people call you. So we have spent a lot of time answering phone calls from around the country.

States were asking, how did you make an estimate about how much it is going to cost us? We have our State budget office saying that this is going to be a lot more expensive than you say it is going to be.

So that really the definition of who actually is qualified and the definition of who actually is a working disabled individual is a big question for States, and the other one, as I said, is the ability to phase in the program, to be able to build the infrastructure. I know

my colleagues in Wisconsin, I think, wouldn't be reluctant to have me say that has been their concern; that they think that they are going to have a program up and ready to go in certain areas of the State, but they would like to be able to phase the program in across the State.

Mr. BILIRAKIS. All right; so those two particular areas—

Mr. AUERBACH. Those are the two biggest areas.

Mr. BILIRAKIS. [continuing] you have repeated those areas?

Mr. AUERBACH. Yes, sir.

Mr. BILIRAKIS. I am glad you did. Those would not be taken care of necessarily by this legislation.

Mr. AUERBACH. On this bill, that's correct. That's correct. Let me just say—

Mr. BILIRAKIS. You would suggest maybe be a change in the language of the legislation or changing the BBA language, right?

Mr. AUERBACH. Mr. Chairman, members of the committee, I certainly would like to see some changes in the language of this bill. I think this bill is much more comprehensive than the Balanced Budget Act section was and really, again, affords States more opportunities, more options. We are appreciative, and let me speak on behalf of the other States, we are appreciative of the fact that this is an optional program, that it is going to be a partnership with the Federal Government, but I think, again, that there is some hesitation about going in without knowing exactly what all the ramifications are going to be, and those are two issues where you can help us with budget concerns.

Mr. BILIRAKIS. Well, Mr. Lazio is here and he hears you, and I think that speaks well for what you said.

Mr. Brown.

Mr. BROWN. Thank you, Mr. Chairman.

Mr. Bergman and Ms. Gennaro, your statements I thought—and your written testimony—were particularly poignant I thought. Let me cite a couple of things and ask you a question together, if you would.

Ms. Gennaro, in your statement you wrote that people with severe disabilities may have difficulties accessing coverage services because the insurer uses a narrow definition of medical necessity, limiting services to those which restore health and not covering services which maintain function and/or prevent deterioration or loss of function.

Mr. Bergman, you wrote that normally, quote “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 you underline none offer personal assistance services, and the healthcare package is constrained by rigid definition of medical necessity which is limited to services to restore health, rather than to maintain function or prevent deterioration or loss of function, which is critical to persons with disabilities accessing the benefit package.”

Talk about this rigid definition of medical necessity preventing people with disabilities from accessing many healthcare benefits, since obviously people with disabilities almost always have conditions that cannot be restored, if you would both elaborate on that.

Ms. GENNARO. Well, for instance, someone may need physical therapy that just maintains the functionality at which they have been able to progress, and it is important to maintain that, to maintain their mobility or whatever abilities they have been able to attain. The therapy may not be making them improved, but it is maintaining motor functions that they have, and losing certain functions can have a great impact on the different abilities that they have in other areas of their lives.

But it is not the way typically that insurers would look at that in terms of maintaining the abilities that you have and the necessity of that, and it is not just physical therapy; it is also work in rehabilitating people and helping them learn skills and tasks and helping them just maintain safe living in their communities, and so forth.

Mr. BROWN. And in most cases insurance would not cover that?

Ms. GENNARO. Well, you would have to—

Mr. BROWN. Would not consider that a medical necessity?

Ms. GENNARO. Well, you often have to, I think, argue with them over what is and isn't medically necessary. I think this comes up often with managed care and trying to get covered what needs to be covered.

Mr. BROWN. Mr. Bergman.

Mr. BERGMAN. Yes, let me take another shot at it and make it concrete, if I may. I think traditional health insurance comes from an accident and health indemnity model, and that is what most commercial insurance still is framed on, which looks at restoration.

So, for example, if one of us who is temporarily abled-bodied breaks an arm or breaks a leg, and you get it casted or you get it put in a sling or they put a pin in, whatever the medical end of it is, usually what is going to happen is you are going to get a prescription for physical therapy for restoration of function, whether it is your leg or your arm, and you are going to go see the PT. It is probably a capped benefit for 15 sessions, at which point you are probably restored pretty good and the therapist is going to say go home and squeeze the ball, do some stretching, but you got about 95 percent restoration, go have a nice day, end of benefit, end of coverage.

For somebody who has a neuromuscular disability, whether it is cerebral palsy, muscular dystrophy, spinal bifida—we go down a long list of things—residual from a traumatic brain injury, in that person's situation at the end of 15 sessions we are not talking about going home and taking care of it and everything is back to business, because what we are really worried about is preventing neuromuscular atrophy, and atrophy leads to function or loss of function, and that can be an independent living which then translates to higher costs and more personal assistance. It could also cause more problems in the workplace because the person isn't able to use their hands as well, their arms, their feet, depending on which limb is involved.

So what happens often with the employer-based insurance is the person with a long-term disability either is not able to access the benefit at all because of the definition of medical necessity or, even if they can access it, it's a capped benefit. There again, we would suggest that the Medicaid or Medicare needs to be available as a

wraparound, and I know that Congress is getting ready to address the limitations in Medicare that were put in in BBA to the \$1,500-a-year cap on therapies.

Mr. BROWN. So the wraparound works the wrong way?

Mr. BERGMAN. Well, the wraparound, at least as I think this bill would propose it, would work the right way, which is the commercial insurance would be primary and then the Medicaid and/or Medicare would be the secondary or in some cases the alternative payer.

Again, we talked about assistive technology and durable medical equipment. Jeff pointed out he has very good coverage there. An awful lot of commercial employer-based insurance either has a capped coverage, no coverage, one lifetime coverage—for example, power wheelchairs such as his, you get one forever. Well, if that is basically his mode of transportation, we know that is not going to last him forever. It breaks down just like our cars do. So every often you might get the one-time-only wheelchair for \$12,000 or \$15,000, but repairs are not covered and then the replacement chair 6, 7 years out isn't going to be covered, and then where does the next \$12,000, \$15,000, \$18,000 come from?

Mr. BROWN. Let me shift to Mr. Gray. You are representing the Health Insurance Association of America. That is the private for-profit insurance companies; is that correct?

Mr. GRAY. That's correct.

Mr. BROWN. In your testimony you mentioned the Health Insurance Portability and Accountability Act of 3 years ago, of 1996, and state that it helps increase access to coverage in some specific situations, but it is not a complete solution for all individuals with disabilities. If reversal of the status quo of Medicare as secondary payer were allowed, would HIAA lower the premiums charged to employers to reflect the fact that private insurance is paying only for things that Medicare doesn't cover?

Mr. GRAY. If I understand the question correctly, you are asking me if the HIAA position is that Medicare should be the secondary?

Mr. BROWN. If you were the secondary, if HIAA were second or if the health insurance were secondary, would you then lower your premiums?

Mr. GRAY. I would have to take that question back for more technical consideration by some of the actuaries. I am not sure. I don't want—I am not sure that I can answer that question correctly on behalf of HIAA.

Mr. BROWN. If it is true that disabled individuals today who have access to Medicare coverage aren't able to purchase Medigap insurance to help assist them with their extra costs, which I understand is true in almost every case, don't you think that this would improve the situation for the disabled, and would HIAA support such legislation?

Mr. GRAY. The HIAA perspective on this is that it should be—in some situations there should be no need for Medigap insurance any more, because we will have a full spectrum of coverage from what Medicare provides coverage for and then what the commercial insurer provides coverage for.

Mr. BROWN. But in those cases where it is not, would HIAA support availability of Medigap for Medicare beneficiaries?

Mr. GRAY. Yes.

Mr. BROWN. Thank you.

Mr. BILIRAKIS. Mr. Lazio.

Mr. LAZIO. Thank you very much, Mr. Chairman. Let me thank the panel for all of your efforts, and if I can, I want to start off with some questions of the Deeley partnership at the end. I just want to get back to two of the experiences that you have had, which I think in a very concrete, but simple way, make the case for H.R. 1180. Mr. Deeley, you were talking about Tom and the fact that he has been such an outstanding employee that he was offered a bonus and he couldn't take it?

Mr. HAROLD DEELEY. That is correct. We think we finessed it.

Mr. LAZIO. I am happy to hear that.

Mr. HAROLD DEELEY. We changed it from the \$200 award, which was a standard thing for his achievement, to a \$200 gift certificate, and that may be declarable as income, but we think it got around the type of income that raised his salary or his income over \$500 per month.

Mr. LAZIO. And Tom, you would like to work full time and it appears as though you have the opportunity to work full time and this is a company that would like to see you work full time.

Mr. HAROLD DEELEY. Yes, that is exactly correct. Tom was working full time at the start. He was evaluated and his performance was good enough to give him a substantial hourly raise. Once that came into being, we began to tread on thin ice. Then a second raise was in prospect and we got around that by reducing the number of hours, and it went from 5 days a week down to what are now 2 days a week. Tom would love to be a 5-day-a-week worker.

Mr. LAZIO. He says yes.

Mr. HAROLD DEELEY. Show that the plaintiff nods.

His boss would love to have him. I have been told by his current boss and the previous one that he is by far the best worker they have down there at the Defense Logistic Agency, and this is janitorial work, but he does a good job and he is eager. In fact, he carries it home and he pricks my conscience that my desk is such a mess. He is a neatnik.

Yes, he would very definitely like to go back to full time. He enjoys a very good relationship with his co-workers as well as his boss, and there is at least one or two of them who are reduced, but not to the degree Tom has been, down to the 2-day-a-week thing.

Mr. LAZIO. So this certainly is a perverse disincentive.

If I can just turn, if I can, to Mr. Gray. You had suggested earlier that there are attitudinal consequences to providing some opportunity for folks to feel secure about their healthcare coverage and the opportunity to go back to work. Could you expand upon attitudinal institutional barriers to employment?

Mr. GRAY. Thank you, yes.

Mr. LAZIO. Because I think that flows well from the testimony we just heard.

Mr. GRAY. I think that there are two areas that I would like to address. First is the existence of a continued attitudinal barrier that people with disabilities are less abled, rather than differently abled, and an extension of that kind of thinking is that people with disabilities are always going to require the maximum degree of

support, and help, and cost associated with what we think of in a worse-case scenario.

Now that is absolutely not true. There is more diversity in the ability of people with disabilities than there would be in the rest of the general population.

The second area I would like to address is what I consider an institutional barrier that we don't often talk about, which is amazing because it has to do with communication, and it is that we have a lack of an effective dissemination of information regarding existing programs and services that will enable people with disabilities to lead a higher quality of life and be more productive and independent.

That is why we feel that the community outreach portion of this legislation is so critically important. People need to know how to weave their way through the complex maze of laws and details, and quite honestly, most people are not prepared or have the desire to deal with things at that level of detail. We need to make sure that the most effective ways of disseminating information are in fact funded, and that may be through private means as well as public means.

Mr. LAZIO. But let me ask Mr. Auerbach this, if I can. There are some critics to the approach that we have taken who suggest that maybe a 1-year extension to the 4 that we currently have for Medicare coverage or 2 years would be enough. Why isn't 6 years enough? Why do we need, if you will agree that we need the 10-year timeframe, why is that important that is in this bill?

Mr. AUERBACH. Mr. Chairman, Representative Lazio, I think this is a major philosophical shift for the Federal Government saying to people with disabilities that we are going to support your independence and the continuity, and I don't know if there is a magic number. Candidly, I don't know if there is a magic number, but the longer that people know that they can have that support and go to work, your SSDI beneficiaries are much more likely, we think, to be able to make that transition to employment. Most of them already have work histories of some sort or another, and they are the most likely, we think, to be able to go back to work. They have a great chance of being successful. So I think it is the messaging, candidly.

Mr. LAZIO. So does that help us get the information out, get the word out? Mr. Gray was talking about it, and so many things, marketing it so that people understand clearly what their risk is, or how risk is alleviated, and whether this is a realistic choice for people to dream about it, think about.

Mr. AUERBACH. We spend a lot of time—right now we have—we started our program in February of this year and we have, at last report, 22 people on the program. It is not, you know, a situation where people bust down the doors. But this is just pent-up demand at this point. We haven't gone out and started marketing, but yet my staff in field offices throughout the State are saying, when are you going to send us more staff to be able to handle all the questions? Because there is a complex set right now, and you heard it from other people testifying, of work incentives, and to be able to explain to somebody how they go through and what they are allowed to do, and what they are not allowed to do, and how poten-

tially these new opportunities are going to fit in with the existing ones is going to take a lot of time. The marketing is very important, and the messaging is very important.

We have told people with disabilities that they had to prove to us that they are disabled in order to have cash benefits. For us now to say to them we have changed, we need to have as many real things to show them that there, in fact, is going to be a change for them.

Mr. LAZIO. So it is attitudinal in that sense as well that people feel as though this is a realistic opportunity, that this may even be an expectation for folks to actually pursue or explore opportunities to the extent that they can.

Mr. AUERBACH. This is absolutely what we would like to be able to do. We would like to be able to, as we sign someone up for benefits, say as you are signing up for benefits, we want to help you get your life stabilized so that we can talk with you about going to work.

So, in fact, we would like to be able to have that message from the time that people actually come in our doors and have an expectation that we are going to help them be as independent as possible, and for most people, as you can tell from the statistics, most people want that opportunity to work.

Mr. LAZIO. It is overwhelming. I know Mr. Bergman is shaking his head. One of the problems that some folks face is maybe an episodic disability. Some people go through stages in which they have problems functioning to full capacity, because they may be in remission for a while; they may be able to go back, for example.

How does this bill—does it address that problem?

Mr. AUERBACH. That is a very good question, Congressman Lazio. I think it does, but can I put a parenthetical on the last one, because it is very important. I think there is such concern about this bill from some parties opening up the woodwork effect and the floodgates, and, gosh, we should be so lucky.

I think there is so much history around the return-to-work mythology, and bad starts, and false starts, and failures, if you will, that I think the marketing piece that Roger talked about needs to really happen. And even with that, to build confidence and trust is going to take a long time within the collective disability community before we get any of the kind of numbers some of us hope we are going to see on this initiative. It is not going to happen quickly.

On the episodic issue, I think what the bill does is make it more comfortable for the person to take some risk to go to work by knowing that disability determination is not going to be another 2-year process, and if you will, there is re-entry back to, if you will, the safety net, some sense of security. You get through that next period of your situation, and then you go back to work, and obviously, that is going to take some flexibility with employers and people may end up changing jobs, but what it does is begin to give confidence to the person with the intermittent or episodic disability to be able to say, "Okay, I'm in remission now; I am feeling good. Life is good right now. Let's go." And whether that is something like MS and a physical disability or somebody with a psychiatric disability or a traumatic brain injury, that individual has some sense of security they can go forward, their health insurance will have some continu-

ity, and they go and feel good, and they make a contribution, and they pay some taxes, and get a real paycheck, and 6-8 months later they are back and they have to stop work for a while.

But, yes, this bill at least begins to put some underpinnings in there that says, just because you go to work, you haven't been cured, if you will, to go back to the healthcare model. You still are a person with a disability, and that is what we are trying to do here, is change the paradigm. As I said in my testimony, the old paradigm was disability was a synonym for incapable of work by definition of SGA, because if you reach SGA, you are not disabled. And there is a case going to the Supreme Court that is actually going to test that out for us very soon. This bill begins to say, no, disability doesn't have anything to do with employability and the Federal Government wants to create some real incentives.

Mr. LAZIO. Well, that is a great way to end up. I want to thank you, Mr. Chairman.

Mr. BILIRAKIS. Thank you, Rick.

Gentlemen and Mary, Mr. Lazio asked the question about some problem—maybe some people feel that we should really extend for another 6 years, and maybe another 2 years or something of that nature is adequate. I would suggest to you—and he already knows this—that that could be a very critical point with the progress of this bill, particularly with Ways and Means, and whatnot.

So, I am not going to take up any more time here. There will be a number of questions that will be afforded you in writing by the staff and that is one of them, and I would suggest, please, if you want to really help us here, give more thought to it.

Mr. Auerbach responded to it, but, you know, I think that you can do better, quite frankly. We would like to hear from all of you in that regard, how critical you think maybe the 6-year extension is versus anything less than that.

So are you all willing to respond to any written questions?

Okay, that being the case, the Chair yields to Mr. Brown for his statement.

Mr. BROWN. Mr. Chairman, I want to just thank you and thank Mr. Lazio and Mr. Waxman for bringing this bill here today, and thank the majority staff for working with us in a bipartisan fashion to invite appropriate witnesses. I think the hearing was excellent; the witnesses were terrific.

There were a couple of issues that minority members are concerned about that are procedural issues. One is that to find out an hour before the hearing that a new witness has been added is a bit problematic, and we were not told of the decision to combine the panels until we showed up today. I don't certainly blame Mr. Bilirakis personally, because he has always worked in good faith, but these issues are important to the minority, just so we can continue to fashion legislation bipartisanly, as we have today, that we can work as full partners. I would hope that your staff, the majority staff, would work a little more closely, and a little more directly, with the minority staff so we can work bipartisan and continue that effort. Thank you.

Mr. BILIRAKIS. Well, I would like to think that they are already doing that, but apparently they are not. I will tell you that we found out an hour before the hearing that the mayor was going to

be testifying. That's what they tell me. I don't know any of the background as to why he decided to testify, but I think that we all agree that he was a very valuable witness.

As far as combining, that is something that I always prefer, maybe less than—rather than 4 or 5 panels I like to see——

Mr. BROWN. Mr. Chairman, I can't quite see that far, way over on the left.

Mr. BILIRAKIS. But it worked. It worked.

Mr. BROWN. It did work. We don't object to the combining, but just that we are notified of combining a little bit earlier than when we show up because it does affect—sometimes, not today, because this was not a contentious hearing and all, not a partisan hearing or any of that, but sometimes it affects the way that we might prepare questions.

Mr. BILIRAKIS. Well, I agree, and I certainly ask the staff for better cooperation with the minority staff. But I do think that it is important that we don't get hung up with the size of the table or the shape of the table here; we have more important things to be concerned with.

Thank you very much. You were of tremendous assistance to what we are trying to accomplish here. Stay with us, and again, please feed any additional information you can think of that might be helpful to what we are trying to accomplish. Thank you. God bless you.

The hearing is adjourned.

[Whereupon, at 5:52 p.m. the subcommittee was adjourned.]